Don’t forget to #ConnectToday!

Dear friends of PARE,

As I am writing these few lines, I can still feel the positive vibrations from the Annual European Conference of PARE that took place in Brussels on 16 - 18 February. What an enthusiastic group of people! Three days of interesting workshops, never ending networking and sharing best practices passed by too quickly. A big thank you to all who made this event once again a big success. Did you miss it? You can still see the live stream on the EULAR website!

But no time to waste, we are already looking forward to the next meeting. This year, the city of Amsterdam will host the EULAR Annual European Congress of Rheumatology on 13-16 June 2018. It will offer limitless opportunities to learn, liaise and share during the numerous sessions with high profile speakers.

Oral and poster presentations will update you on the various activities of our national member organisations and those of our international colleagues. These will show the immense efforts that are being made all over the world to enhance the quality of life for people with rheumatic and musculoskeletal diseases.

Don’t forget to visit the EULAR village with the PARE booth in the exhibition hall, a great place for networking with old friends and meeting new people. See you soon in Amsterdam!

And last but not least, don’t forget to #ConnectToday! The EULAR campaign ‘Don’t Delay, Connect Today’ is being used in numerous countries to raise awareness of early diagnosis and access to care in the field of rheumatology. Join us in our efforts to spread the word!

Nele Caeyers
Chair, Standing Committee of PARE
Inside the EULAR Secretariat

The activities of EULAR, and hence the Secretariat, have increased significantly in recent years. Today the Secretariat fulfills many functions including the two growing flagships - the EULAR Congress and the EULAR School of Rheumatology. It was time to bring new people on board.

"I am really delighted that in Genevieve and Isabella we were so lucky to find two highly skilled and motivated staff members to support us. They have been welcomed very warmly by the team and beyond and they, as well as the whole team, do a wonderful job" says Julia Rautenstrauch, EULAR’s Executive Director.

Please meet Genevieve and Isabella below:

My name is Genevieve Schaerer-Lim, and I am currently working as Education Programme & Strategic co-ordinator, dealing with education related matters under the EULAR School of Rheumatology and, since May 2017, strategic related administration. I am an upbeat, self-motivated and enthusiastic team player who enjoys meeting new people and finding ways to help them to achieve their aims. In my work with the School of Rheumatology, I work closely with Dieter Wiek and Florian Klett in coordinating and supporting new educational activities that are currently in development. I am happy to hear all your wonderful ideas and project proposals and I look very much forward to helping you to implement them.

Hi, my name is Isabella Cottone and I am 32 years old and I live in Zurich, Switzerland. I started last September at EULAR as Congress Assistant. I support the Congress Manager in all administrative and organisational activities and I update the EULAR Congress website. I am also involved in the EULAR Secretariat’s projects for Health Professionals in Rheumatology (HPR). It is an exciting position because I can see behind the scenes of the Congress and be involved in the detail of various HPR projects. EULAR is an impressive organisation!

New volunteers to join PARE Working Groups

The first call for nominating volunteers to several of the PARE Working Groups was launched in December 2017. "We were really excited to see how the call would be received at national level and if there would be any candidates interested in joining and supporting our work” said Nele Caeyers, Chair of the Standing Committee of PARE.

The PARE Board was very positively surprised as there were numerous applications offering a great range of skills by highly qualified individuals. The PARE Board assessed all applications very carefully and took final decisions during the last PARE Board meeting on 18 February in Brussels. Many more applications were received than could be actively accommodated at the moment and it was not easy to take the final decisions. "It is fantastic to see that there is so much enthusiasm and knowledge out there, ready to engage with PARE – this is really encouraging and we look forward to benefitting from new expertise and input into our projects” commented Dieter Wiek, Vice President EULAR, representing PARE.

The PARE Board would warmly like to thank everyone who applied – there will be more opportunities in the future!
‘Don’t Delay, Connect Today’ 2018

In 2018, the EULAR Campaign ‘Don’t Delay, Connect Today’ will be brought to life in eleven countries across Europe with financial support from EULAR: twelve awards of €5000 were made available to national patients organisations in eleven countries (two awards to UK) to implement the campaign in their countries.

The first campaign event of the year was the Belgian national launch, which was co-hosted by EULAR national member organisation, ReumaNet, in the Belgian Federal Parliament, Brussels on 15 February. A further ten countries (Cyprus, Finland, Malta, Netherlands, Poland, Romania, Serbia, Slovenia, Sweden, United Kingdom) will hold dedicated campaign events in 2018. There will be exhibitions, media campaigns, and special events aimed at engaging policy makers and mobilising the public to recognise the importance of understanding, and taking urgent action to lessen, the impact that rheumatic and musculoskeletal diseases (RMDs) have on individuals and on society.

There will be many opportunities for people with RMDs to add their voices to this important campaign across Europe. We already know of exciting campaign activities in Italy, France and Spain; there will be many more. Be sure that your voice is heard. Make 2018 the year when there is a real step-change in early diagnosis and access to treatment for people with RMDs throughout Europe!

Will you #ConnectToday?

For more information visit: www.eular.org
Twitter: @eular_org @ArthritisDay @worldarthritisday
Facebook and Instagram

HarmonicSS

by Elsa Mateus, EULAR PARE Co-ordinator for HarmonicSS

One year ago*, we announced EULAR PARE participation in the project HarmonicSS, “HARMONIzation and integrative analysis of regional, national and international Cohorts on primary Sjögren’s Syndrome (pSS) towards improved stratification, treatment and health policy making disease”.

The vision of HarmonicSS is to create an international network and alliance of partners and cohorts, entrusted with the mission of addressing the unmet needs in pSS and improving the databases and tools - a crucial step for the study and diagnosis of this syndrome.

HarmonicSS will produce a platform to enable secure storage, governance, analytics, access control and controlled sharing of information at multiple levels. This will bring together pSS patient cohorts, improve comparability and streamline treatments, improve research outcomes and define a shared health policy on pSS across Europe.

EULAR PARE and the US Sjögren’s Syndrome Foundation (SSF), monitor and provide input into all aspects of the projects from the patients’ perspective e.g. in plans on data management.

In 2017, following the first informal meeting during EULAR Congress in Madrid, the pSS Patients Advisory Group was established. Two patients’ representatives also joined the project’s Ethics Advisory Board.

In the first half of 2018, detailed input into planned surveys of pSS patients and clinicians will be completed. Also a series of dissemination events are planned around meetings such as the 14th International Sjogren’s Symposium, Washington, USA on 18-21 April 2018 and the EULAR Annual European Congress of Rheumatology in Amsterdam, Netherlands on 13-16 June 2018.

Please follow us on Twitter @HarmonicSS_Proj

This project has received funding from the EU 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.

* e-Breakthrough Issue 15 April 2017

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EULAR recommendations: lay summaries

Today, more and more patients are becoming actively involved in the management of their own disease and the healthcare decisions that have to be made. This is called shared decision making: decisions about potential treatments made on the basis of information given by the health professional and on the preferences of the patient. To make a well-informed decision, it is necessary for patients to be provided with understandable, accurate and up-to-date information about the treatment options for their diseases. This includes the benefits and risks of taking or rejecting a particular treatment.

Do you know that EULAR develops specific disease management recommendations?

These recommendations are primarily developed and published to inform practicing health professionals and to improve their daily treatment routines. However, in many countries, parallel information for patients is not available. Without proper information patients may not be able participate fully in shared decision making or understand the implications of their treatment options. EULAR, and in particular the EULAR Standing Committee of PARE, therefore considers it most important that these recommendations reach patients as well as health professionals.

Do you know that EULAR develops lay summaries of its recommendations?

The traditional, scientific wording of the EULAR recommendations, often difficult for lay people to understand, has been adapted to the language of the patient, and made available to all. High quality patient versions are needed to ensure that all people with rheumatic and musculoskeletal diseases in Europe are aware of the latest recommendations, and can understand them. The lay summaries are written in English.

Do you know that EULAR develops lay summaries of its scientific papers?

The Annals of Rheumatic Diseases (ARD) now also publishes short research summaries in lay language for patients and non-clinicians of selected key research papers published in the journal. These aim to explain clearly the results of the research studies as well as any implications for treatment of the specific condition. The summaries are written in plain language and checked for accuracy and readability by expert rheumatologists and people from the EULAR patient research partners network. They are not EULAR recommendations.

Do you know that national patient organisations can translate and disseminate these lay summaries, and that there are Guidelines to help you?

For non-English speaking countries, the English lay version should be translated into the national language, with the help of a local rheumatologist, and disseminated in the country-specific context, taking account of the information needs of patients locally. This is important to make the recommendations accessible to a wide audience. To assist you in this, the EULAR Standing Committee of PARE initiated the development of a practical guide to the dissemination and translation of recommendations to patients. It contains easy to understand guidelines, checklists, tools and tips. In many cases patient organisations and health professionals will wish to work together in the task of promoting patient education in their country.

Do you know that there are also lay summaries of selected scientific papers?

The Annals of Rheumatic Diseases (ARD) now also publishes short research summaries in lay language for patients and non-clinicians of selected key research papers published in the journal. These aim to explain clearly the results of the research studies as well as any implications for treatment of the specific condition. The summaries are written in plain language and checked for accuracy and readability by expert rheumatologists and people from the EULAR patient research partners network. They are not EULAR recommendations.

“We want to ensure all Flemish patients have access to the high quality EULAR recommendations. Translating the lay versions is not too difficult and results in a wide implementation of the recommendations.”

Mitchell Silva, ReumaNet vzw
EULAR activities

EULAR Public Affairs by Neil Betteridge, International Liaison Officer, Public Affairs, on behalf of the EULAR Public Affairs Group

EULAR’s strategic plan for 2013-17 is now ending. So it is a good time to review not only recent developments in our Public Affairs activities, but also progress towards longer term goals.

One such goal, for example, was seeking recognition of rheumatic and musculoskeletal diseases (RMDs) as one of the major chronic diseases. To realise this aim we have had several meetings with high-ranking policymakers to discuss EULAR’s views and recommendations. These include: the EU Health Commissioner, Dr Vytenis Andriukaitis; the re-establishment of the European Parliament Interest Group on RMDs; the organisation of annual conferences in collaboration with key stakeholder organisations; and the development of RheumaMap, our long term vision for research in rheumatology.

Several long-standing challenges still remain though, and others are expected to arise in the coming years. This is why EULAR is now developing a new 5 year public affairs strategy, which will once more be aligned with the new EULAR strategic plan, with PARE heavily involved.

Key topics likely to feature are the development and implementation of health and safety at work, and wider disability policies; the development of the next EU Research Framework Programme (FP9); and innovation in health care. One of the main activities addressing these issues will be this year’s World Arthritis Day (WAD) Conference. This will take place in Brussels in October 2018.

Professor Johannes W.J. Bijlsma addressing the EULAR World Arthritis Day Conference 2017 in Brussels

Last year’s conference, “The future of health research and innovation after Horizon 2020. Do we need a novel approach?”, was attended by more than 130 participants, including representatives of the main EU institutions, WHO and key stakeholder organisations, together with representatives of PARE and other EULAR members. As a result of the conference, policy recommendations have been developed which will support new advocacy activities.

Thank you PARE for your continued engagement with these activities!

European Patients’ Forum Youth Group by Lembe Kullamaa

The European Patients’ Forum (EPF) Youth Group unites young patient representatives between the ages of 15 and 29 who are passionate about change, integration and patient empowerment.

The EPF Youth Group represents all chronic conditions and young patients from around the European Union. The aim of the Youth Group is to become the reference group of the young patient community and its role is to communicate the needs and expectations of young patients to EPF and its members.

The goals of the Youth Group are: to strengthen the involvement and representation of young patients in patient organisations; promote young patients’ rights and recognition of their needs and expectations within and beyond the health policy area; promote better cooperation between young patient and adult patient advocates; and strengthen young patient representatives’ skills and self-confidence.

We want to inspire, motivate and find innovative ways to help young patients like ourselves to find their voice and speak out. To achieve that, we work together with the EPF board, secretariat and external stakeholders. In the near future, the Youth Group intends to focus its work on topics like discrimination and transition to adult care which are very sensitive topics for young patients, including people with rheumatic and musculoskeletal diseases. Other project goals include creating a toolkit for empowered young patients, capacity building and member recruitment.

This year, EPF is organising a ‘Summer Training Course for Young Patient Advocates’ for the second consecutive year. The programme is an exciting and unique opportunity offering tailored high-quality training to young (18-30) patient advocates or representatives of young patient advocates who have the motivation to learn more about advocacy and maximise their leadership potentials in real environment.

You can find more info on www.eu-patient.eu and on social media.

EPF Youth Group: Back row: Marlou Schenk (The Netherlands), Lembe Kullamaa (Germany), Nathalie Schwarz (France), Polis Stavrou (Cyprus), Andreas Christodoulou (President, Youth Group, Cyprus)
AGORA: (Platform for organisations of people with rheumatic and musculoskeletal diseases in Southern Europe) by Eva Kritza

For the past 12 years of my life, and after I was diagnosed with rheumatoid arthritis, I have been an active volunteer with the Arthritis Foundation of Crete (elected as a Board member twice). In September 2017, I was elected to the Board of AGORA as the Chairperson.

This new task has given me personal fulfilment as a volunteer, and a sense of added responsibility towards our members, healthcare partners and collaborators. It is within this healthcare community that AGORA has been enthusiastically active as a patient organisation since 2011.

Being a patient myself, with a life-long disease, I have always believed and supported the idea of patients being genuinely involved and engaged in promoting: their preference for equitable access to healthcare; their need for self-management and empowerment; and their eagerness for participation in decision making. The result of this commitment could never be other than better health for all, dedicated volunteer activities, and lower and safer cost of treatment for patients.

I believe that I am able to promote these ideas through my involvement in AGORA. With the help of our Board and our member associations, I will carry on sustaining our aims and goals, influencing policy changes at national and EU levels, embracing innovation and advocacy through our partners’ collaboration, and eventually establishing AGORA as a leading patient led organisation in the European health landscape.

Our Agenda for 2018 (based on the AGORA Strategic Plan) includes: a project which was started last year on axial spondyloarthritis (AxSpA), and which continues into 2018; our Annual Conference in September with the topic ‘Patients’ involvement in shaping health-care’; and projects involving patients that are still under discussion with our valuable allies and collaborators.

See more about AGORA and its activities: www.agora-platform.eu

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

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