Don’t Delay, Connect Today

Dear PARE friends,

Wishing you all a healthy 2018! Time flies when you’re having fun! Being part of the exciting PARE family means you are never bored. 2017 brought us so many great events we can all be proud of. And 2018 already looks very promising.

The concept of World Arthritis Day is getting more and more popular. We were happy to see so many countries organising awareness campaigns on 12 October 2017. The ‘Don’t Delay Connect Today’ slogan was spread all over Europe and beyond. It is particularly good to see the three pillars - scientific associations, health professionals and organisations of people with rheumatic and musculoskeletal diseases (RMDs), working together to tackle RMDs. Thank you all for your efforts. Keep joining forces!

At EU level, we can look back on a very successful advocacy event on 17 October in Brussels where we focused on health research and innovation. Research, including at EU level, is crucial to reduce the overall impact of RMDs in the future.

I am definitely looking forward to welcoming you all to Brussels in February 2018 for the EULAR Annual European Conference of PARE. Our team is ready for two days of inspirational exchange around the ‘Don’t Delay, Connect Today’ topic. Don’t miss it, either at the event or via live streaming!

In June, the city of Amsterdam will be our host for this year’s EULAR Congress. Again, the PARE programme will be packed full with interesting lectures and chances for networking.

Thanks for all your support in 2017, and I wish you the very best for the new year!

Nele Caeyers
Chair, Standing Committee of PARE

21st EULAR Annual European Conference of PARE

The next EULAR Annual European Conference of PARE is going to be held in Brussels, Belgium, from 16-18 February 2018. The programme will have a particular focus on the European Union, offering a visit to the European Parliament, and two workshops explaining how decisions are taken in Brussels and their relevance for PARE organisations. Delegates will also have the opportunity to consider how their organisations can engage most successfully at EU level. “We are absolutely delighted that Marianne Thyssen, Commissioner for Employment, Social Affairs, Skills and Labour Mobility, has agreed to speak at the opening session of the conference. This is a great honour for EULAR PARE and, as the working of the EU sometimes appears abstract and opaque, her presence will lend a human face to the understanding of its procedures and practices.” says Nele Caeyers, Chair of the EULAR Standing Committee of PARE, and Communication Manager of ReumaNet, the 2018 conference host organisation.

The conference expects around 130 attendees from all over Europe, Canada and the USA. Not able to be there? Follow our live stream - https://www.eular.org/pare_annual_conference.cfm - and engage in the discussions via #pare2018
PARE Board Meeting, Zurich

The annual meeting of the PARE Board took place on 8-9 September 2017 in Zurich. The meeting focused on implementing the vision that will offer future PARE Board members more involvement and integration into PARE activities.

A new application and nomination procedure has been set up for volunteers to join the various PARE working groups. In addition, more responsibilities and leadership tasks will be handled directly by the working group leaders. From now on, the PARE Board will consist of the individual working group leaders together with the officially elected EULAR representatives: the EULAR Vice President (elect) representing PARE and the Chair (elect or past) of the Standing Committee.

“I think this new set up will help our successors to be much better prepared for their role as PARE Board members. It took me almost two years to get a basic understanding about EULAR PARE – there are not only the activities but also a lot of procedures to follow” says Elsa Mateus, PARE Board member from Portugal. She adds: “In the future all PARE Board members will have two years of experience in their respective working group before they can be elected as working group leader and hence become a PARE Board member”.

The first call for nominating volunteers to the working groups was launched in December with a deadline of 10 January 2018. “We look forward to working with new and enthusiastic volunteers and hope there will be many interested candidates to support our cause” commented Nele Caeyers, Chair of the Standing Committee of PARE. The PARE Board will assess all applications in the coming weeks and final decisions will be taken during the next PARE Board meeting on 18 February in Brussels.

The PARE Board meeting in Zurich in September 2017

News from EULAR Young PARE

by Petra Balážová

We are delighted to announce that, having gone through a competitive shortlisting and election process, we have two new members of the Working Group.

Lembe Kullamaa joins us from the Estonian Rheumatism Association. With her vast experience of European lobbying and advocacy groups, we look forward to working with Lembe over the next two years. Sara Badreh, a Board Member of the Swedish Rheumatic Association, has been living with Lupus half her life. Dedicating her life to assisting those living with rheumatic and musculoskeletal diseases (RMDs) is a key motivation for Sara and something she shares with everyone in Young PARE.

The next key date in the EULAR Young PARE calendar is the 21st EULAR Annual European Conference of PARE in Brussels, Belgium. This will be a momentous occasion for Young PARE as, for the first time, our biennial youth conference will be included as part of the PARE conference. This way, we hope to see more young people attend the conference in Brussels, as well as engaging more in the wider work of PARE.

As well as hosting a youth-only leadership and advocacy workshop on 15 February, the Young PARE Working Group will be hosting two further workshops for all delegates on 16 and 17 February. These workshops and networking events during the PARE Conference will provide plenty of opportunity for you to engage and share ideas to enable Young PARE to evolve.

New members Lembe Kullamaa (above) and Sara Badreh (below)
The EULAR Campaign ‘Don’t delay, Connect Today’ has been a great success in 2017 and thanks to your efforts even more will be done in 2018! The campaign connects scientists, health professionals and people with rheumatic and musculoskeletal diseases (RMDs) to help highlight the importance of early diagnosis and timely access to evidence-based treatment for RMDs.

Combined efforts: Global impact
The World Arthritis Day website listed 104 campaign events in 40 countries, on 5 continents, in 2017. The impact on the public was particularly noticeable around 12 October when our community owned #ConnectToday across social media!

To help raise awareness, three personal stories were selected and included in the campaign video, which was launched on World Arthritis Day itself. By 9 November 2017, this video had been shared more than 625 times on Facebook alone, thereby reaching almost 1 million people worldwide. EULAR invited organisations to take part in educational webinars on the topic of early diagnosis and encouraged individuals and organisations to coordinate and engage in campaign activities.

Get involved in the 2018 plans!
In 2018, EULAR will again organise multi-disciplinary webinars to help you learn how to raise awareness about early diagnosis. We will also actively support national events; a call for applications was sent out in the second half of 2017. Around 10 successful events will be supported with up to Euros 5000 donated to each proposal. We warmly congratulate the successful applicants and thank everyone for the incredible amount of creative thinking that has gone into these project proposals. We look forward to seeing the results in 2018.

EULAR Patient Research Partners Network
In October 2017, 45 EULAR Patient Research Partners (PRPs) gathered for the bi-annual training and evaluation meeting in Amsterdam. An intensive weekend was filled with a mix of short plenary presentations, small group assignments and opportunities to share personal experiences. Prof. Johannes W.J. Bijlsma, the EULAR President, spoke about EULAR’s vision and ambition for the future direction of research and the involvement of patient research partners. He introduced the RheumaMap and asked the participants to provide further input. Prof. Loreto Carmona from Spain emphasized the relevance of Quality of Life instruments for patient research partners and gave much input to group work, sharing experience and practical recommendations.

Sunday morning was dedicated to communication skills training to optimise collaboration between PRPs and researchers. This workshop was led by Klaartje Spijkers, a EUPATI fellow with wide experience of patient advocacy. Evenings gave participants opportunities for informal networking. Participants represented a variety of rheumatic conditions and came from 17 European countries. The group of experienced EULAR PRPs was joined by specially selected patient representatives from national and international arthritis patient organisations with hands-on experience in EULAR projects or other types of participatory research.

The network of EULAR Patient Research Partners has now grown to 59. The network has established itself as a reliable resource of trained and dedicated research partners. The number of projects, both inside and outside of EULAR, in which PRPs actively participate has expanded dramatically. Thanks to everyone who dedicates their time and experience as a PRP!
EULAR Brussels Conference: Health research and innovation
by Neil Betteridge, International Liaison Officer, Public Affairs, on behalf of the EULAR Public Affairs Group

As every year around October's World Arthritis Day, EULAR organised a conference in Brussels to discuss relevant policy issues with EU and national decision-makers and stakeholders. The topic of the 2017 conference was “The future of health research and innovation after Horizon 2020. Do we need a novel approach?”

The issues under debate come at the time when the European Commission is evaluating the current Research Framework Programme, Horizon 2020. It has also started to discuss the development of the next Research Framework Programme, which will be launched in 2021.

Given the relevance of EU support to research in rheumatic and musculoskeletal diseases (RMDs) and other diseases, EULAR is actively engaged in collaborating with the development and implementation of EU policies in this area, and the patient input provided by PARE is a crucial part of this.

To this end, the aim of the conference was to discuss current and future challenges in health research and innovation (in particular in RMDs) as well as the role and contribution of EU and Member States in addressing these challenges. The programme included two key-note speeches which framed the overall discussion.

Prof. Timothy R.D.J. Radstake (Utrecht University) provided an insight into success stories of research and innovation in the past years, focusing on the aspects that will define the next decade of research for RMDs and other chronic diseases. In turn, Prof. Dr. Andreas Radbruch (German Rheumatism Research Centre Berlin, DRFZ) presented his perspective on the next decade’s challenges in health research and innovation, and the process of establishing research priorities.

High level representatives of the World Health Organisation (WHO), the European Commission, the upcoming Bulgarian EU Presidency, key stakeholder organisations, as well as Members of the European Parliament, presented their views, expectations and recommendations on how to further support research and innovation on major chronic conditions such as RMDs.

In turn, the views and recommendations of the EULAR community were well represented. EULAR President, and Chair of the conference, Prof. Johannes W.J. Bijlsma presented RheumaMap, the roadmap for research and innovation in RMDs, an initiative that EULAR launched earlier in 2017. Partly based on information provided by PARE member organisations, Nele Caeyers (Chair of the Standing Committee of PARE) stressed the important role of patients in research and innovation and analysed the challenges faced by people with RMDs in engaging in research and innovation activities.

In one of the key activities of the conference, participants joined in the discussion on policy recommendations to EU policy makers. Four workshops were organised, each of them focusing on a key policy issue:

- development of the next research framework programme
- engagement of patients in research and innovation
- Public Private Partnership in research and innovation
- challenges in the transfer of research and innovation results into clinical practice.

The recommendations from these workshops will be further developed in the coming months. Once approved by the EULAR Executive Committee, these will be published on the EULAR website and will be used as a basis for discussion with policymakers and stakeholders as part of EULAR public affairs activities during 2018 and beyond.
The Goldilocks Philosophy:
CreakyJoints is ‘Just Right’ for Patients
by Seth Ginsberg, President and Co-Founder of CreakyJoints

CreakyJoints® (and CreakyJoints Australia), the go-to source for more than 100,000 arthritis patients and their families world-wide who are seeking education, support, advocacy and patient-centered research, aims to be ‘just right’ for all people with rheumatic and musculoskeletal diseases (RMDs).

We know it is overwhelming to be diagnosed with, and to have to manage, a lifelong chronic disease. Some of our members are simply seeking education and information. Beyond our extensive, online library and our #Arthritis365 daily Twitter fact, in 2017, we began publishing an educational series of free patient guidelines focused, respectively, on rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis and family planning with autoimmune diseases. The patient guidelines provide comprehensive, unbiased information about treatment options (traditional, alternative and complementary) and management strategies. They also explain how to work through insurance coverage (very complicated in the United States) and advocate for patient-centred health policy locally and nationally.

“*We know it is overwhelming to be diagnosed with, and to have to manage, a lifelong chronic disease*”

More active members also participate in our research (or 50-State Network advocacy) activities. Aligned with the publication of the family planning patient guidelines, in November 2017, CreakyJoints presented data at the 2017 ACR/AHRP Annual Meeting in San Diego, California, demonstrating that 59 percent of women with inflammatory arthritis surveyed (n=250), had fewer children than they desired because of fears related to being unable to care for a child (85%) and arthritis medications potentially harming a child (61%). Concerningly, 28 percent of women taking methotrexate were using ineffective contraception. This study, and data from six other presented abstracts, demonstrates CreakyJoints’ growth into a fully fledged research organisation.

By September 2017, our research registry, ArthritisPower, enrolled over 11,500 members who can participate in studies developed by CreakyJoints and our research partners, all using the free app as a disease tracker for shared decision-making with their rheumatologist or rheumatology nurse. ArthritisPower data was also presented at the Annual European Congress of Rheumatology (EULAR 2017) meeting in Madrid.

Fun with Fashion
In September 2017, CreakyJoints presented the Spring/Summer 2018 Tumbler and Tipsy collection by Michael Kuluva at New York Fashion Week (#NYFW). A member of CreakyJoints, the Los Angeles-based designer revealed last year, for the first time, his seven years of living with rheumatoid arthritis. This year’s collection played with patches and camouflage patterns, some up-cycled from retired military uniforms. CreakyJoints supports Michael because his message is inspirational. Despite managing an often painful and tiring chronic condition, he pursues his dreams and career by designing colourful, arthritis-friendly clothes.

Looking Ahead
CreakyJoints is an open community. We urge rheumatologists and our members to invite the newly diagnosed or others living with arthritis to learn about our organisation, which has always been free to join (and never asks for donations). Whether you want to get involved with advocacy, research or simply learn more about your disease, CreakyJoints can be a perfect fit.
The Canadian Arthritis Patient Alliance (CAPA) is a virtual, grass-roots, patient-driven, independent, national organisation with members across Canada, and supporters both in Canada and internationally.

CAPA facilitates links between Canadians with arthritis and their support systems through collaboration and partnerships with other organisations, researchers, representatives from all levels of government, and the arthritis community. CAPA believes in the need for Canadians with arthritis to increase their knowledge of their disease, patient involvement in arthritis research and planning agendas, and the levels of public and political awareness of arthritis. We communicate the latest news on research, technology, health policy and emerging issues relevant to members through our: website (www.arthritispatient.ca), quarterly newsletter, Facebook (https://www.facebook.com/CAPA.Aca/), and Twitter (@CAPA_Arthritis).

Since CAPA is a small, primarily volunteer-based organisation, we use our resources carefully - providing members with links to organisations that have general information about arthritis, medications, and programmes; and focusing our efforts on developing tools and resources in areas that we feel are lacking for our members. For example, we have recently developed an Arthritis Patient Charter (below) that outlines basic rights and responsibilities that we feel are important for people who live with arthritis, presented by Dawn Richards at the EULAR Congress in 2016, as well as a comprehensive resource about pregnancy and parenting with arthritis, presented by Laurie Proulx at EULAR in 2017.

We look forward to attending the EULAR Congress in June 2018 – most of our Steering Committee members will be in attendance so we can strengthen our ties with PARE members as well as create new relationships so we can all best leverage information and resources from our international counterparts.

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

EULAR Vice President representing PARE: Dieter Wiek
PARE Standing Committee Chair: Nele Caeyer
Newsletter Editor and Co-ordinator: Diana Skingle
Editorial Board: Boyana Boteva, Wendy Olsder, Polina Pchelnikova, Diana Skingle
Publisher: EULAR Standing Committee of People with Arthritis/Rheumatism in Europe

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