Dear friends,

Time flies when you’re having fun! I certainly agree. It seems like only yesterday I was taking over from Dieter Wiek as chair of the Standing Committee of People with Arthritis/Rheumatism in Europe (PARE), and today Elsa Mateus is ready to take my place! I have had a wonderful time within the PARE community and look back proudly on what we have accomplished together.

One of the most successful achievements over the past two years has certainly been the ‘Don’t Delay, Connect Today’ campaign. It has been wonderful to see such collaboration and energy all over Europe, spreading the same message in all countries. Many of our PARE members have taken the lead at national level, and I am very proud to see the successful projects that have made a difference in the lives of so many people with rheumatic and musculoskeletal diseases (RMDs) all over Europe, and even beyond. Please continue the good work! I want to thank all the people who in some way have contributed to the success of this huge campaign. The 2019 EULAR campaign theme ‘Don’t Delay Connect Today: Time2Work’ will offer plenty of opportunities in the coming year to again reach out to wider communities.

Within PARE, two years ago, we started a new way of working with volunteers. Although not optimal yet, since we are still in a transition phase, this way of letting volunteers grow within the PARE network before giving them responsible roles, is certainly a better approach than what we had in the past. PARE work is voluntary work, but even then we need people who are committed to the job and are willing to spend some time for our cause. Here, we also see the results of a well-established youth group. The first ‘leaders’ of Young PARE are now handing over to their successors, and we welcome them with pleasure to the PARE network.

Working together at international level demands a certain dedication and requires time to get things done. But when we see the results, we can only be happy and proud. Would you be willing to work as a volunteer in the wonderful PARE family? Every year in autumn, PARE launches a new call for volunteers. Please contact your national organisation to learn more.

Of course we have been involved in many more things. The EULAR School is expanding its activities, with PARE initiatives currently being developed. In line with the EULAR strategy, we are following with great interest the set-up of a virtual research centre. PARE is also involved regularly in public affairs meetings in Brussels. We continue to deliver quality programmes at both the PARE Conference and the PARE sessions at the EULAR Congress, offering valuable learning opportunities for our members.

Of course this is not the work of one person! I have had the privilege to work with a whole team of enthusiastic, wonderful people. It feels like a true family. And although my work as chair is nearing its end, I will not disappear! You have all gained a piece of my heart forever!

Thank you all!

Nele Caeyers, Chair, Standing Committee of PARE
New volunteers join the PARE Working Groups

by Polina Pchelnikova, PARE Board member

We are happy to announce that we have new volunteers joining the PARE Working Groups (WG). Nine applications were received and, in February, the PARE Board filled vacancies in the following WGs: Annual European Conference of PARE, Knowledge Transfer Programme, Patient Research Partners and the Editorial Board. Welcome to all the newcomers!

One of our new volunteers, Simon Stones, who will join the Patient Research Partners WG, shares his thoughts (below) on why he applied and how he hopes to contribute. Simon, 25, from the UK, is already an experienced and active rheumatic and musculoskeletal disease (RMD) volunteer both nationally and internationally. He is currently a member of the Arthritis and Musculoskeletal Alliance (ARMA) and is a trustee of Fibromyalgia Action UK, and has a strong research focus.

If you too have relevant experience and skills, why not think of applying next time?

Why did you decide to apply?

I am passionate about ensuring people with lived experiences are involved in designing and delivering research, and I have thoroughly enjoyed being a part of the EULAR Patient Research Partners network over the last four years. Therefore, when this opportunity arose, I had to apply! This coincided with me stepping away from the Young PARE WG after four exciting years, and so it felt a natural evolution in my work at European level with EULAR. Most importantly, I see this as an incredible opportunity to reach a wider group of people, to help them shape RMD research.

What do you expect from volunteering for this PARE WG?

I am really looking forward to thinking of new and exciting ways of engaging and involving more people with lived experiences of RMDs in research – including voices which are often not heard as loudly, such as young people. I’m expecting to navigate lots of challenges along the way as we work to ensure the meaningful involvement of patients and carers in research, building on the fantastic work of the EULAR Patient Research Partners network to date.

PARE Board Training

by Tanita Wilhelmer, PARE Board member

In December 2018, the PARE Board gathered in London, United Kingdom, to attend a presentation skills workshop. At the offices of Ruder-Finn, Esmé Newton-Dunn arranged an excellent training programme for six of the PARE Board members. Everyone was asked to prepare a presentation beforehand. After some expert insight into the theory of presenting, each board member gave their presentation. They then received valuable feedback on how to improve their skills. Not only were slides and arguments given feedback, body language, manner of speech and eye contact were also examined and formed an integral part of the training. To better understand the feedback given, the presentations were recorded on video and analyzed together. Mrs Newton-Dunn set up some very lively scenarios and challenges in the workshop. Through different role-plays the board members had to face some unforeseen situations, adjust to the circumstances and still give their best performance possible.

Presenting oneself to others more confidently was another skill the group was eager to work on. After more role-plays on leading a group discussion or a teleconference, they all felt they would be more comfortable facing these tasks in their work for EULAR PARE in the future.

Altogether, these were two productive days in London and we thank Mrs. Newton-Dunn at Ruder-Finn for providing such a stimulating and comprehensive workshop for the participants.
All good things come in threes! For the third time, Madrid will be the host city of the Annual European Congress of Rheumatology 2019. From 12-15 June, the IFEMA - Feria de Madrid - will receive about 14,000 participants ready to exchange the latest scientific and clinical information about rheumatic and musculoskeletal diseases (RMDs). In 2019, EULAR is delighted to celebrate its close cooperation with paediatric colleagues by jointly organising this year’s congress with the Paediatric Rheumatology European Society (PReS).

An exciting and stimulating PARE programme has been prepared by Dieter Wiek, EULAR Vice President, representing PARE, and his team. Please see an overview of the variety of sessions below. We hope to see you at many of them!

Do come and visit PARE representatives at the EULAR booth in the EULAR Village. There you will find information about the EULAR campaign ‘Don’t Delay, Connect Today’ and its current ‘Time2Work’ focus. You will also be able to pick up a copy of the 2019 Stene Prize booklet and learn about other EULAR activities such as the EULAR School. Don’t forget the two PARE Poster Tours on Thursday and Friday - sign up on the day but be quick, places go fast. And remember, if you are not able to fit in all the sessions at the congress that you wish to attend, the PARE Highlight session on Saturday will give you a good summary of the latest news from many of the scientific and health professional congress sessions. Not to be missed!

We look forward to seeing many of you in Madrid!

The PARE Programme

<table>
<thead>
<tr>
<th>Day/Time</th>
<th>Session Title</th>
<th>Session type</th>
<th>Room number</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 June 13.00 - 14.00</td>
<td>Opening Plenary Session</td>
<td>PARE Session</td>
<td>Hall 6</td>
</tr>
<tr>
<td>12 June 14.15 - 15.45</td>
<td>What’s new: Latest news on biological treatment</td>
<td>PARE Session</td>
<td>N105/N106</td>
</tr>
<tr>
<td>12 June 16.15 - 17.45</td>
<td>Bringing digital healthcare solutions to patients</td>
<td>PARE Session</td>
<td>N105/N106</td>
</tr>
<tr>
<td>12 June 18.00 - 20.00</td>
<td>EULAR Standing Committee of PARE Business Meeting</td>
<td>By invitation only</td>
<td>S12/S14</td>
</tr>
<tr>
<td>12 June 20.00 - 22.00</td>
<td>Networking Platform</td>
<td></td>
<td>Avenida</td>
</tr>
<tr>
<td>13 June 10.15 - 11.45</td>
<td>From child to adult care - breaking down the barriers of transition</td>
<td>Joint Session</td>
<td>N115/N116</td>
</tr>
<tr>
<td>13 June 12.00 - 13.30</td>
<td>PARE Poster Tour I</td>
<td></td>
<td>PARE Poster Area</td>
</tr>
<tr>
<td>13 June 13.30 - 15.00</td>
<td>Treatment is more than drugs</td>
<td>Joint Session</td>
<td>N115/N116</td>
</tr>
<tr>
<td>13 June 15.30 - 17.00</td>
<td>Should we worry about anything else - young people also have multi-morbidities</td>
<td></td>
<td>N115/N116</td>
</tr>
<tr>
<td>14 June 10.15 - 11.45</td>
<td>From abstract to concrete - the variety of activities of PARE organisations</td>
<td>PARE Abstract Session</td>
<td>N115/N116</td>
</tr>
<tr>
<td>14 June 12.00 - 13.30</td>
<td>PARE Poster Tour II</td>
<td></td>
<td>PARE Poster Area</td>
</tr>
<tr>
<td>14 June 13.30 - 15.00</td>
<td>The benefits of involving patients in health technology assessment</td>
<td>PARE Session</td>
<td>N115/N116</td>
</tr>
<tr>
<td>14 June 15.30 - 17.00</td>
<td>Don’t panic - round table discussion on risk perception</td>
<td>PARE Session</td>
<td>N115/N116</td>
</tr>
<tr>
<td>15 June 09.00 - 10.30</td>
<td>Workshop: #ConnectToday and tomorrow: The campaigning continues</td>
<td>PARE Session</td>
<td>N115/N116</td>
</tr>
<tr>
<td>15 June 12.00 - 13.30</td>
<td>Restless lives: Managing fatigue, sleep and pain</td>
<td>PARE Session</td>
<td>N115/N116</td>
</tr>
<tr>
<td>15 June 13.45 - 14.45</td>
<td>Highlight session</td>
<td>PARE Session</td>
<td>N115/N116</td>
</tr>
</tbody>
</table>
‘Nothing about us, without us’ were the opening words of Prof. Johannes W.J Bijlsma, President of EULAR, at the start of the inspiring EULAR Annual European Conference of PARE in Prague on 4-8 April 2019. Giving the welcome address, Adam Vojtěch, Minister of Health, Czech Republic, went on to praise the important work done by patient organisations, in particular the Czech League Against Rheumatic Diseases.

The focus of this year’s conference was about the importance of work. The 2019 EULAR campaign, ‘Don’t Delay, Connect Today’, carries the theme ‘Time2Work’, raising awareness across Europe about the significance of enabling people with a rheumatic and musculoskeletal disease (RMD) to take part in the workforce, whether paid or as a volunteer. The aim of the conference was to inspire, educate and empower delegates and their national organisations to take action on the topic, and to ensure that the voice of people with RMDs is heard by, and has influence among, decision makers in Europe.

During various workshops and panel discussions we learned how to engage with employers, policy makers and trade unions, how organisations can support patients in work, and how to move from disability to ability. Francisco Carreira, 3rd prize winner of the 2019 Edgar Stene Prize, gave a great speech about what an ideal employer should be like, commenting that workplace adaptations are always a good investment. Keynote speaker, Sarah Copsey from the European Agency for Health and Safety at Work (EU-OSHA), spoke about the relevance of occupational rehabilitation in keeping people in work.

It was a powerful conference. It is very important that everybody is included in our society. Patients, policy makers and employers should speak with one voice, and see opportunities instead of problems. People often ask me: ‘Why are you so eager to participate? You are sick, you have a lot of pain.’ That’s true. We each have our own story, our own pain and our own RMD. But we are using our lived experience to try to improve the quality of life for the 120 million people in Europe who live with a RMD. Together we are working towards changing the world. Isn’t that great!

An engaging and inspiring conference "Give musculoskeletal health to school-children and young workers!" organised by the European Agency for Safety and Health at Work (EU-OSHA), in conjunction with the European Network Education and Training in Occupational Safety and Health (ENETOSH), took place on 20-21 March 2019 in Bilbao, Spain.

With one in eight children and young people affected by rheumatic and musculoskeletal diseases (RMDs), prevention of these conditions, promotion of good musculoskeletal health and the exploration of how to bring occupational health and safety into mainstream education were timely and important discussion points. As a representative of EULAR Young PARE at this conference, I had a responsibility not only to represent all those children living with RMDs in Europe, and those who might develop RMDs, but also teachers, lecturers and educators.

We are all aware that young people living with RMDs face challenges in school, in further education and in transitioning to work. Children and their families need advice on, and access to, various reasonable adaptations and aids they can apply for and ask schools to provide. However, this EU-OSHA conference, with the input of a vast number of ergonomists, looked at this issue from a slightly different angle. They examined how appropriate furniture in schools might prevent or minimise RMD impact. For example, they looked at using technology for course material rather than students having to carry books.

However, the ergonomists also considered whether using tablets and smart phones might bring new risks and cause RMDs in the neck area, rather than the current risk to shoulders and knees caused by heavy school-bags.
OBJECTIVES
The NECESSITY project aims to overcome these challenges with three objectives to enhance the development of new medicines for pSS:

- To develop and assess sensitive clinical endpoints to evaluate the response to drug treatments in patients with pSS;
- To identify and evaluate discriminative biomarkers for stratification of pSS patients;
- To design and perform a multi-arm multi-stage clinical trial to validate the newly defined pSS endpoints and the identified biomarkers.

IMPACT
The NECESSITY project, by bringing the relevant stakeholders together including academia, pharmaceutical industry, health authorities, funders and patient groups, is expected to generate impactful novel tools and capabilities for the confirmation of new endpoints and design of new pSS clinical trials to ultimately facilitate new drug development for patients with pSS.

In the field of autoimmunity, given the frequency of pSS and the absence of any treatment available, finding an efficient treatment for patients is a key unmet medical need which will be more easily achieved by combining Horizon 2020 and private sector funds in a public-private partnership. The project methodology implemented in this project will be transferable to other autoimmune diseases.

KICK-OFF MEETING - PARIS
The kick-off meeting for the NECESSITY project took place in Paris on 16-17 January 2019. The project consortium was represented by twenty-one academic partners and four EFPIA (European Federation of Pharmaceutical Industries and Associations) member companies representing nine European countries: United Kingdom, France, Italy, Switzerland, Netherlands, Spain, Sweden, Greece and Norway.

The project is scheduled to run for 72 months at a total cost of €15.4 million.

* Prof. Xavier MARIETTE, INSERM, AP-HP, Université Paris-Sud
The Polish Rheuma Federation ‘REF’ was very impressed by the Finnish patient organisation, Reumaliitto, and their success in recruiting volunteers. Because Polish organisations have a lack of human resources, we decided to ask our Finnish partners to teach us how to be more successful in engaging with people. In 2017, we applied for support from the EULAR Knowledge Transfer Programme, which is designed to enable patient organisations to develop their skills through applying lessons learnt by others in the EULAR network. This enabled us to undertake exchange visits to deepen our knowledge in this area and to be inspired by Reumaliitto.

We had an opportunity to visit Reumaliitto’s office in Helsinki and learnt about their practical planning and funding system, and how the organisation builds its public image. It was important for us to understand how to reach people living with rheumatic and musculoskeletal diseases (RMDs) using different media, and how to work together with health professionals, both areas in which the Finnish organisation excels. We were amazed that Finnish organisations working with RMD patients have about 60 volunteers engaged in physical activity programmes. With the support of healthcare professionals, Reumaliitto maintains a knowledge and information platform for patients, and it offers IT training for older patients to enable them to engage with the on-line community. The role of volunteer support was highlighted in every aspect of Reumaliitto’s work.

We took the advice we received very seriously and we immediately started to change things. Better communication about the preferences of our stakeholders and better activity on social media, being our main goals. We started by looking for volunteers to organise activities and to attract people to participate. There is still much to do but the visit gave us new perspectives on many problems, and inspired us all. Thank you!

**JIGSAW-E: European collaboration between patients and health professionals to battle osteoarthritis joint pain**

In 2016, EIT Health Innovation** funded the JIGSAW-E (Joint Implementation of Guidelines for Osteoarthritis in Western Europe) project to improve the management of chronic joint pain from osteoarthritis (OA). Joint pain in adults 45 years and over is one of the largest causes of years lived with disability world-wide. In the EU, delivery of quality OA care is highly variable. By implementing a new model of supported self-management in general practices across six European countries, the quality of life of people with OA can be improved.

**Patient collaboration is key**

In JIGSAW-E, OA patient champions, patient organisations and health professionals already work closely together to improve adherence to OA quality standards in UK (England), Netherlands, Portugal, Denmark and Norway. The model consultation for OA in primary care is now planned for extension to France, Poland and UK (Scotland). The role of patient champions is key in translating the English OA patient guidebook into other languages and ensuring that the information is adjusted to the culture and health system of their own countries. According to John Murphy, one of the patient champions: “Patients are the most under-used resource in any health care system, but in JIGSAW-E there are no boundaries between us, we are just one body of people trying to make a difference to those with arthritis across Europe.”

**Training health professionals**

Patient education and training of general practitioners and other health professionals such as GP nurses and physiotherapists, is crucial. Currently, the JIGSAW-E approach is implemented across 70 practices with over 350 healthcare professionals trained and 600 patients directly benefitting internationally. The in-development online training courses will further increase outreach and accessibility among, for example, pharmacists. “Without EIT Health’s support, there would not be an integrated and systematic implementation of international guidelines for the primary care and management of osteoarthritis.” says professor Krysia Dziedzic, Chief Investigator JIGSAW-E.

If you would like to read more about this OA project, visit the JIGSAW-E website or contact health.iau@keele.ac.uk

* Maarten de Wit, PhD; Ambassador Participatory Research
** European Institute for Innovation & Technology
World Arthritis Day in Slovakia
by Jana Dobšovičová Černáková, Slovak League Against Rheumatism

The Slovak League Against Rheumatism (SLAR) held a rich programme of events in Piešťany to mark World Arthritis Day 2018 (WAD) under the banner “Do not miss the opportunity to join us!” (derived from the EULAR campaign ‘Don’t Delay, Connect Today’).

On 12 October, SLAR held a seminar “From Theory to Practice 2”, attended by health professionals and patients. The following day, there was a meeting bringing together Nordic Walking stick users, including those with rheumatic and musculoskeletal diseases (RMDs), from all over Slovakia - see below. An introductory lesson was given by the President of the Slovak Nordic Walking Association, Lucia Okoličanová, who explained that Nordic Walking can be preventive and enhance the physical condition of the walker, thus reducing the burden of illness on both the individual and society. The Association also drew attention to their new information leaflet "Don't be left alone with rheum!" highlighting further benefits of Nordic Walking.

Concluding the WAD events was a festive ceremonial evening honouring the journalists and editors who have contributed to STEP 2017, a bulletin of media articles that raise public awareness about RMDs and the importance of not neglecting first, possibly unobtrusive, symptoms. Three famous buildings in Piešťany - the statue of Barlolamač on the Colonnade Bridge, the nearby statue of the Lovers, and the Lido Bridge - were illuminated in honour of WAD 2018, the blue light representing symbolic support for people with RMDs - see below. The event, under the auspices of the President of the Slovak Republic, Andrej Kiska, was attended by the Mayor of Piešťany, and General Director of the NIRD, Dr Richard Imrich, and other eminent public figures. Entertainment was provided by the Sobotište folk group.

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 Secretariat
Seestrasse 240, 8802 Kilchberg, Switzerland

For any questions about e-Breakthrough or future contributions please contact Birte.Gluesing@eular.org

Publisher EULAR Standing Committee of People with Arthritis/Rheumatism in Europe

All pictures supplied by EULAR and contributors unless indicated otherwise.

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