Together we are strong!

Dear PARE friends,

We are already looking at the last bit of 2018. One year has already passed since I started as chair of PARE. And what an exciting year it has been. I am really impressed and happy to see so many volunteers working hard every day to make projects, working groups and various tasks a success. Together we are strong!

Of course, the work is never done. The campaign ‘Don’t Delay, Connect Today’ has been, and still is, a huge success in many countries. Organisations of people with rheumatic and musculoskeletal diseases (RMDs), health professionals and doctors are working together to spread the message of the importance of early diagnosis. Also, for next year, the campaign will be an important part of the strategy of EULAR. You can read all the details further on in this newsletter. Please join us in our efforts to reach out to all people in Europe.

However, it is not only the campaign that is creating awareness around RMDs. On 12 October all spotlights will be on World Arthritis Day! It is wonderful to see how many national organisations take action to give attention to RMDs. Don’t forget to spread our WAD video. You can translate it into your national language and use it to let the world know about our RMD health conditions.

Also in this newsletter: the collaboration of EULAR Young PARE, ENCA and PReS, all focusing on the needs of children and adolescents with RMDs; news about the latest developments in the fight against lupus, and the successful Swedish campaign ‘Doesn’t show, doesn’t exist?’, showing us how to counter the invisibility of RMDs.

I hope you’ll enjoy reading this issue and I wish you already a happy end of 2018.

Nele Caeyers
Chair, Standing Committee of PARE

---

Prague to host EULAR Annual Conference of PARE in 2019 …. and beyond

The ‘Golden City’ will host the next Annual Conference of PARE from 5-7 April 2019. The Czech League Against Rheumatism is excited to welcome around 120 patient representatives, mainly from Europe but also from Canada and the United States. The Conference Task Force, led by Nele Caeyers, Chair of the EULAR Standing Committee of PARE, is working hard to put together another exciting programme: “For the next two years the conference programme will continue to focus on the EULAR ‘Don’t Delay, Connect Today’ campaign but in 2019 will highlight its newly launched focus on the topic of ‘work’.” A variety of workshops will engage employers, trade unions and important EU institutions such as the European Agency for Health and Safety at Work (EU OSHA). Young PARE will again be organizing their dedicated workshops and activities.

Prague will not only be the host country for 2019 but also for the next few years. “Changing the venue on an annual basis has been, of course, a great opportunity for our national member organisations to showcase their activities and to benefit from EULAR’s presence and related activities in the host country. We now see considerable advantage in holding the Conference in the same venue each year, but the Task Force will discuss ways of how a national focus might still be kept in the future set-up” says Nele Caeyers.
PARE Board meeting

In July, all members of the PARE Board attended its annual meeting in Berlin to discuss important issues concerning EULAR PARE. Importantly, a strategic review of all PARE projects and activities was carried out during the meeting. After a vigorous examination of resources available (human and financial), and taking into account the views of all stakeholders, it was agreed that most of the existing projects should to be kept and developed. However, the Board decided that the printed version of Breakthrough would be discontinued due to financial reasons and because there is less interest in print media (see below).

One of the main priorities of the PARE Board from 2018 onwards is to implement the new EULAR strategy. Marios Kouloumas, EULAR Vice President representing PARE 2013 - 2017, has been co-opted to the PARE Board as strategic adviser to initiate this process in the coming 6 months. "We are delighted that Marios will be advising the PARE Board in this important period. With his overarching expertise and very recent experience of EULAR’s activities he will be able to ensure that the work and priorities of all the EULAR Standing Committees are strongly linked to deliver the strategy successfully." comments Dieter Wiek, EULAR Vice President, representing PARE.

The PARE Board consists of all working group leaders and the officially elected EULAR representatives. All working group leaders should now have two years experience before they can become PARE Board members. A new call for volunteers for vacancies in the working groups will be launched at the end of 2018. More details will be announced soon. We are again looking forward to receiving many applications.

Evaluation of e-Breakthrough and Breakthrough 2018

In August 2018 EULAR PARE conducted a survey among the EULAR member organisations of PARE to assess the value of e-Breakthrough and Breakthrough to our readers. 26 organisations out of 36 responded.

The majority of the respondents were satisfied with the number of issues and overall appearance and length of the newsletter. Among the most popular topics were EULAR Annual European Conference of PARE, World Arthritis Day and sharing best practice. Coincidentally, ‘rheumatology news’, which we feature for the first time in this issue (page 5), was proposed as an interesting new theme. Other suggestions for possible new topics were: the School of Rheumatology, news from organisations such as the European Patients Forum, and the different problems faced by patients in each country.

65% of the respondents read the whole issue and 84% shared the information. Compared to the results of the previous survey made in 2013, in 2018 respondents had started to share more information from the newsletters with academics, government ministers or officials, and journalists (see figure i). 36% of respondents had translated some of the e-Breakthrough articles into their national language. Translation is a challenging issue for many organisations but currently there is no easy solution to the problem. 68% of respondents stated that their organisations had already contributed to the newsletter and 67% have plans to do so in future. As for the hard copy of Breakthrough, 64% of the respondents would now prefer it to be replaced by an e-newsletter. This is reflected in the recent decision by the EULAR PARE Board to stop printing Breakthrough with immediate effect because the popularity of print media is generally declining and it is very costly to produce.

We would like to thank our readers for taking part in the survey. We are always willing to receive more articles for publication. Please send your contribution to birte.gluesing@eular.org so that it can be considered by the Editorial Board for one of the future issues.

Abstracts for EULAR 2019 in Madrid!

The EULAR abstract submission system is now open! Here is your chance to share your organisation’s success with the worldwide RMD community. The Scientific Committee eagerly awaits your abstracts and hopes to receive an exciting range of best practice and latest information from the PARE community.

Don’t forget – the abstract submission system closes on 31 January 2019!
Paediatric Rheumatology European Society (PReS) by Berent Prakken*, President

For everyone involved in paediatric rheumatology these are exciting times. In Lisbon in September we celebrated the 25th PReS conference dedicated to children with rheumatic diseases. Many good things have happened over these 25 years; the introduction of biologics being an important one. But what makes these times even more exciting is the change in our approach to paediatric rheumatology. Let me explain.

Traditionally the paediatric rheumatology community has been good in working together. Paediatric rheumatic diseases are rare diseases and professionals simply need each other to further advance the field. What has changed now is that this collaboration is stretching across borders, across disciplines, across specialties, even across continents. Last but not least, we are moving towards real partnership between patients and professionals.

To begin with, PReS and EULAR have developed a close collaboration, acknowledging that we are all working for the same goal: better care for patients. Therefore, we acknowledge the importance of adult rheumatology for the field of paediatric rheumatology and vice versa. We can and must learn from each other. Thus, with great support of the EULAR and vice versa. We can and must learn from each other. Thus, with great support of the EULAR programme for the 2019 joint EULAR and PReS Madrid conference. The collaboration between EULAR and PReS starts with the generation of the future: young investigators. Young investigators from Emerge and Emeunet will organize a joint Young Investigators conference dedicated to children with rheumatic diseases.

We also realise that paediatric rheumatology is not just a problem in Europe. Hence, we work across the borders with paediatric rheumatology in North America (CARRA). The problems for patients are exponentially bigger in places in the world where patients and their parents have no access at all to any expert care. We need to support patients and health care givers in these areas also.

As part of the 25th PReS congress we launched a large strategic programme called PReS 2025 with a central role for patients and their parents. Together with parents, patients and young investigators from the Emerge network we started an international awareness campaign. The European Network for Children with Arthritis (ENCA), PARE and PReS will work together on this. No more walls, but all together with the same ambition: dedicated to advance the care and improve the health and well-being of children and young people with rheumatic conditions, all over the world.

For more information please see the PReS website.

Edgar Stene Prize Essay Competition 2019

“How can an employer support people with RMDs? What measures, aids or attitudes by employers* would support people with rheumatic and musculoskeletal diseases (RMDs) and make work more accessible and manageable for them? The Edgar Stene Prize Essay Competition for 2019 has been launched with the theme: “My ideal employer – Work without barriers for people with RMDs”’. We want everyone to live their life as independently as possible and to the full, and work - inside or outside the home - is an essential part of our life. We want to hear your views, ideas and stories, and maybe even some best practice examples. The Jury looks forward to receiving many inspirational entries from all over Europe. For more information please visit www.eular.org or contact your national EULAR member organisation.

*for the purposes of the competition this can also be family or the society/institution/organisation for which you volunteer
‘Don’t Delay, Connect Today’: Celebrating a year of success and looking forward to 2019

For 2019, a new set of awards has been launched for EULAR member organisations on the implementation of the EULAR campaign at national level. The aim is to engage all remaining countries in the campaign.

Grassroots action across Europe
‘Don’t Delay, Connect Today’ is now active in over twenty five countries in Europe. Since its European launch at the 2017 EULAR Congress in Madrid, Spain, and at national events in Lisbon, Portugal and Zagreb, Croatia, the campaign has gained impact across all audiences. In the first half of 2018, Belgium launched its national campaign at the federal parliament in Brussels and, in April, politicians and members of parliament in Romania attended a dedicated, high-level event for the campaign launch in the country’s capital, Bucharest.

Many other countries have also launched dedicated activities. Germany once again has brought to life its ‘Rheuma truck’, a large vehicle that is set to tour three of the country’s regions to raise awareness. Finland, Poland, Serbia and Slovenia have all brought the campaign to life through social media, public relations activities or other events organised nationally.

Get social
To address a wide variety of audiences, events and activities have been run in national languages. Information about ‘Don’t Delay, Connect Today’ has been translated and tailored to fit specific cultural and linguistic needs. This has also helped to capture the attention of national media: “Based on stories in the media there is significant impact – almost all the way across Europe!” commented Marios Kouloumas, former EULAR Vice President representing PARE.

Having the campaign literature and logos translated into local languages, especially the hashtag #ConnectToday, has also seen the campaign successfully reaching out across borders via social media.

For more information, please see the EULAR and World Arthritis Day websites.

Further campaign launches have recently taken place across Europe: in May, Cyprus marked the start of the campaign with a series of events including meetings with policy-makers; and a sponsored cycle along the Hebridean Way in Scotland marked the campaign’s first steps on British soil.
Systemic Lupus Erythematosus: one disease or many diseases?
by Prof. Marta Mosca, University of Pisa, Italy

Systemic Lupus Erythematosus (SLE) is a systemic autoimmune disease predominantly affecting women of childbearing age. According to a recent study, the highest estimated incidence and prevalence of SLE is in North America (23.2/100 000 person-years and 241/100 000 people, respectively). The Lupus Foundation of America estimates that around five million people worldwide have a form of lupus.

One disease or many diseases? This phrase indicates the great variability of the SLE clinical picture, with symptoms that can not only vary from person to person but also over time in the same person. The most common lupus symptoms include skin rashes, joint pain, fever and fatigue, photo-sensitivity; the involvement of other important organs such as kidneys, neurological manifestations, and abnormalities in blood cell counts. The severity spectrum of the disease is also variable as it ranges from less severe to life threatening.

In addition to those which can be directly attributed to the activity of the disease, there are other clinical manifestations that are associated with drug side effects or with damage accrued over time, either due to drugs or to the consequences of the disease itself. In addition, lupus has an impact on the quality of life, causes fatigue, and is associated with fibromyalgia and poor sleep quality. All these are ‘ingredients’ contributing to the overall SLE clinical picture. This complexity explains why it is difficult to treat SLE, as different approaches (both pharmacological and non-pharmacological) are needed to improve patients’ health, outcomes and quality of life. For these reasons, many current research areas focus on defining lupus, proper monitoring protocols and clinical practice guidelines, understanding quality of life from the patients’ point of view, unmet needs, and the development of new drugs.

The treat-to-target initiative has led to the development of recommendations to guide physicians in the treatment of lupus. These recommendations, for example, have highlighted the need to taper steroids and have also promoted the development of a consensus definition of remission in SLE, which is a target to adjust treatment. However, the clinical picture and management of the disease still requires a better understanding of patients’ quality of life and their needs and expectations. An important step forward in the treatment of the disease will occur when both the physician’s and patient’s needs are fully considered and the therapeutic decisions take into account all the different aspects of this multifaceted disease. Research in this field is now underway with the participation of Lupus Europe in a European Pilot Project (INTEGRATE), together with the University of Pisa, Italy, and the University of Düsseldorf, Germany.

There is no cure for lupus, but there are many drugs that have been successfully used over the decades to control the disease and that have improved the prognosis and survival of patients with SLE. Nevertheless, unmet needs are still faced by patients and physicians as some patients have persistent disease activity, requiring continuous use of glucocorticoids. Glucocorticoids are still the mainstay of treatment of SLE, particularly in severe disease, leading to important damage accrual in the first years of disease. Many traditional immunosuppressive drugs also carry side effects such as the risk of early menopause (cyclophosphamide) or infection, as an example.

Over the past decade new knowledge has become available on the mechanisms underlying SLE and, very interestingly, new potential therapeutic targets have been identified. This knowledge had led to the approval of belimumab, the first lupus treatment approved for 50 years, and to the development and the study of new promising drugs such as anifrolumab, baricitinib, blisibimod, rigerimod, atacicept, voclosporin which are performing phase II and III studies. We may therefore now begin to envisage future targeted and tailored treatments for the different and heterogeneous manifestations of SLE, taking into consideration the different aspects of the disease, patients’ expectations and needs, and leading to better outcomes and quality of life.

1 Rees F et al. Rheumatology 2017; 56: 1945-1961
3 Van Vollenhoven R et al. Ann Rheum Dis
Doesn’t show – doesn’t exist?
by Kim Nordlund, Secretary General of the Swedish National Organisation for Young Rheumatics

Being questioned and doubted as a young person with rheumatism is pretty standard. But it should be enough to have to live and deal with our swollen joints, with the pain and fatigue, and with the possible side effects from medication. We shouldn’t have to defend ourselves and convince people that rheumatism amongst young people actually exists.

To show that you can’t tell if someone has rheumatism or is in pain just by looking at them, we partnered up with AbbVie to create the campaign “Doesn’t show, doesn’t exist?”. Our focus was to spread awareness regarding public transport and the stigma surrounding young people using the priority seats.

We created a quiz for people to guess who out of two people on a bus they thought needed to sit. We also created a new symbol (right) to complete the already existing symbols for the priority seats, and sent it to every company providing public transport in Sweden, calling on them to include people with invisible disabilities in the priority seats.

The quiz and the symbol were released on 9 October, just before World Arthritis Day 2017. Our members put up stickers with the new symbol on buses, trams and trains all over Sweden. Members were also called on to share their own personal stories.

Ambassador members wrote opinion articles for local media and were interviewed by local newspapers, radio and television stations. On World Arthritis Day, we published an opinion article in Sweden’s biggest newspaper, titled “It doesn’t always show who needs to sit on the bus”. We also hosted an event in Stockholm where people could do the quiz, try on ‘arthritis simulation gloves’ and learn more about rheumatism amongst young people.

The campaign ended up being our most successful campaign so far, reaching more than 4.5 million people. The quiz, the personal stories and the articles were liked and shared more than any of our other posts on social media. People from all over Sweden could see the new symbol on public transport. We managed to create a powerful statement that raised both awareness and debate, and the conversation continues at #synsintefinnsinte.

Learn more about the Swedish National Organisation for Young Rheumatics and its activities at www.ungareumatiker.se

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

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

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