Great events ahead by Dieter Wiek, Chairperson of the EULAR Standing Committee of PARE

Dear PARE community and friends

Another year has passed, time flies too fast, I feel. PARE’s “It's in your hands, take action” campaign around World Arthritis Day (WAD) was very impressive. People shared their personal stories and uploaded pictures or short videos. The stories and striking images of people underline the diversity of rheumatic and musculoskeletal diseases (RMDs) and people's very positive coping strategies, in spite of being seriously affected. If you have not yet done so, go to our WAD website to watch the innovative video that was launched at the EULAR Brussels Conference on 12 October. Reports of the Conference appear on pages 2 and 3.

We are looking forward to two great events for our PARE community in the first half of 2017. The EULAR PARE Annual Conference in Lisbon in February will focus on interactive workshops dealing with early prevention, diagnosis and access to care for people with RMDs. Again, like last year, organisations will be able to showcase their activities and inspire other organisations in the ‘Best Practice Fair’.

At the EULAR Congress in Madrid in June 2017, PARE’s sessions will showcase interesting topics, high profile speakers and, as always, the patient perspective will be central.

Finally, I’d like to thank you for supporting PARE. My special thanks goes to the PARE Board members for their engagement, to Marios and Nele for their help, and to PARE’s fantastic staff members Birte, Maria and Florian for their hard work and great commitment.

I am looking forward to meeting you at one of our PARE events.

The best possible health - not only for 2017!

Portuguese League Against Rheumatism prepares to host 20th EULAR PARE Annual Conference

The PARE community is getting ready to gather in Lisbon, Portugal from 24-26 February 2017 for the 20th anniversary of the EULAR PARE Annual Conference. The overarching focus of the conference will be ‘early diagnosis and access to care’, a topic high on the agenda of many organisations. “This is also a hot topic in Portugal” says Elsa Mateus, President of the Portuguese League Against Rheumatism. “We have organised a Round Table discussion at the Portuguese Parliament in connection with the conference. We are grateful for the support and participation of EULAR’s President, Prof. Gerd R. Burmester, of EULAR’s Vice President representing Health Professionals in Rheumatology, Prof. Christina Opava, and of the EULAR PARE team. We very much hope that this high level delegation will ensure that our voice will be stronger and heard by the decision makers.”

For the first time the conference has invited delegates from outside Europe and from non-EULAR member organisations to join the event at their own cost. “This development is very exciting and we look forward to working at international level and receiving fresh input and ideas from new perspectives.” comments Marios Kouloumas, EULAR Vice President representing PARE.
Improving the workplace for people with RMDs

by Dieter Wiek, Chair of the Standing Committee of PARE

At the EULAR Brussels Conference on World Arthritis Day 12 October (see Conference report on page 3), EULAR PARE was invited to speak about “Preventing rheumatic and musculoskeletal diseases (RMDs) and improving the workplace for people with RMDs. The experience and views of the RMD community.” In order to broaden the perspective EULAR PARE decided to explore the views of our member organisations by conducting a survey. Thanks to all of you who participated in this survey, added very useful comments and made this presentation possible.

An excerpt of PARE’s survey results

14 out of 19 organisations (74%) taking part in this survey said that they are involved in activities aimed at preventing the onset or progression of RMDs in the workplace in some form. These activities are addressed in different ways (e.g. by work coaches or psychological and physical support for people with RMDs), but organisations also try to encourage employers to integrate people with RMDs (e.g. by an online information portal). Over two-thirds of respondents (68%) felt that policy-makers were not aware of the need to reduce the burden of RMDs in the workplace. The number is still more worrying for employers: 79% of organisations said that employers were not aware of the need to reduce the burden of RMDs.

Workplace layout and working conditions

If your health status is seriously affected by your RMD, the workplace layout and the working conditions are vital. There seems to be a lack of employers’ support for people with RMDs in adapting the workplace and meeting people’s needs, with 74% of respondents saying that employers were not supporting employees well. However, across Europe this issue seems to depend on the individual company and whether the company sees employee health as an important issue and worth investing in. Smaller enterprises are less able to support employees. Organisations reported that employees often do not inform their employers about their need as they are worried about losing their job. And if they do, some say that legal interventions are necessary to make the employer act and initiate work adaptations.

Legislation

63% of respondents said that existing legislation and policies are not effective in preventing the onset or worsening of work-related RMDs, or that legislation and policies do not address this issue. Even in countries where legislation and policies were rated as effective, respondents indicated issues with implementation. 79% of respondents said that existing legislation and policies were either not effective in retaining people with RMDs in the workplace, or that there was no legislation or policy on this; only 21% said relevant legislation and policies were effective. Organisations also complained that often legislation does not allow people with RMDs the possibility of working flexible hours or switching to part-time work.

Only 21% of respondents felt that existing legislation and policies were effective in allowing people with RMDs to return to work after treatment, with almost half (48%) saying that existing measures were not effective; 21% said that there was no existing legislation or policy on this in their country.

What is it like for young people?

64% of respondents thought that the existing legislation and policies were either not effective or do not address the issue of enabling young people with RMDs to enter the labour market. In many cases there is a lack of advice and information about legislation that could be of help to young people.

Key recommendations aimed at policy makers and employers

Finally, our organisations were asked to formulate their recommendations for improvement. Here are some key recommendations:

• Provide financial incentives to employers that systematically support employees’ well-being.
• Adopt legislation that requires employers to accommodate flexible/adjusted working hours for people with RMDs (similar to parental part-time rules).
• Adapt working environment and working hours to individual needs.
• Change perception and attitudes, and consider employee health as an investment.
• Focus on coordination between policies (employment, health care and public health, social affairs).
• Foster and strengthen primary, secondary and tertiary prevention, and reinforce legislation against exposure to risk factors.
This year, EULAR’s annual Brussels Conference took place on World Arthritis Day itself, 12 October, and was entitled “How to reduce the burden of chronic diseases in the workplace. New policies for better working conditions and the retention of ill people at work”.

The aim was to develop policy recommendations to EU and national policymakers on this topic. All 3 EULAR pillars – PARE, health professionals and clinicians were equally involved in the planning and delivery of what proved to be a highly successful event. Thanks go to the EULAR Brussels office, with great support from Birte Glüsing (EULAR Secretariat) for much of the hard work involved.

The need to improve working conditions is a huge issue for PARE members. The impact of rheumatic and musculoskeletal diseases (RMDs) is the most important work-related health problem and the main cause of work loss, absenteeism and early retirement. Moreover, the European Commission is currently reviewing existing legislation on health and safety at work and is likely to propose new legislative and non-legislative measures shortly.

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The two main issues discussed at the conference were how to improve working conditions to better prevent work-related RMDs; and how to improve working conditions to facilitate the retention of people with RMDs at work, as well as the return to work after sick leave.

PARE’s work was vital to the success of the conference. For example, thanks to the responses of PARE members to a survey organised ahead of the conference, EULAR could present the experience, views and opinions of people with RMDs with regard to health and safety at work issues. The presentation summarising this feedback was delivered by EULAR Vice-President representing PARE, Marios Kouloumas. Marios addressed issues such as: member organisations’ involvement in advocacy issues around occupational health and safety at work (OSH); the views of people with RMDs on the effectiveness of OSH legislation; policies in their countries for the prevention of RMDs and retention at work after diagnosis; and their views on the role of employers. (See Dieter Wiek’s article on page 2 for more information about the results of the survey.)

PARE helped lead some of the workshops too, such as that on retention of people with RMDs in the workplace. This was co-organised with the European Agency for Safety and Health at Work (EU-OSHA). Ailsa Bosworth (National Rheumatoid Arthritis Society, UK) and Brenda O’Brien (EU-OSHA) were the co-chairs. Delegates highlighted the need for timely support for employees, especially employers and health professionals such as occupational therapists.

I am grateful to all PARE representatives who contributed to this event. EULAR will shortly develop and share policy recommendations based on the outputs of the conference recommendations. If you missed the conference, you can still watch the recorded sessions on the EULAR website. The conference report and related documents will also be made available in the Public Affairs section of the website.

I am delighted to report that since the conference, EULAR has secured a meeting with the Cabinet of the Commissioner for Employment, Social Affairs, Skills and Labour Mobility, where these issues will be discussed directly.

I am pleased to add also that the day after the conference, EULAR met the EU Commissioner for Health and Food Safety, Dr Vytenis Andriukaitis. This delegation comprised Prof. Gerd R. Burmester (EULAR President), Annette de Thurah (Chair of the Standing Committee of Health Professionals in Rheumatology), Prof. Hans Bijlsma (President Elect) Sören Haar (Head of the EULAR Brussels Office) and myself. The aims of the meeting were: to explore enhanced collaboration between the Commission and EULAR; to discuss on-going EU policies on public health; and to present EULAR’s views and recommendations. Specifically, we discussed the Commission’s work on chronic diseases; the possible contribution of EULAR to both the EU Health Policy Platform and other policy initiatives; and the need to promote actions on early intervention.

The meeting was fruitful and a number of follow-ups were agreed, which we will share with you as they take shape.
The “Change the Future” youth conference was part of EULAR Young PARE’s objective to establish an active European network of national youth groups representing young people with rheumatic and musculoskeletal diseases (RMDs). Thirty-nine individuals from 18 European countries travelled to Retie in Belgium on 21 October 2016 for a weekend of networking and collaborative learning. It was a wonderful experience to bring together such a diverse group of individuals, each with their own experiences of living with, or caring for someone with an RMD. By combining social activities, networking opportunities, and skills-development workshops, this conference was a productive and useful experience for all.

Across the weekend, three skills-based workshops were delivered around pitching ideas, organising and chairing meetings, and working with volunteers, where participants learnt practical skills that will help them to become better leaders, improve their (youth) organisations and start new youth projects to improve the quality of life of young people with RMDs. Six walk-in workshops were also held, enabling individuals to develop skills that would add value to their work. The topics of the workshops included: ‘Writing abstracts for the EULAR Congress’, ‘Taking action with the Knowledge Transfer Programme’, ‘Designing the perfect poster presentation and online graphics’, ‘Using social media to deliver effective and engaging interaction’, ‘Making the most of the Virtual Knowledge Centre’ and ‘Writing effective articles for your website and print media’. We also allocated time for digital poster presentations, where each individual presented a pitch about the work their organisation has been doing in their respective country for young people with RMDs. This gave the EULAR Young PARE working group insights into the existing youth projects in different countries and the needs of these organisations.

Alone, we can do so little. Together we can do so much!

A view from EMEUNET by Alessia Alunno

On 21-23 October 2016 the cosy city of Retie in Belgium hosted the 2nd EULAR Young PARE Meeting “Change the Future”. The Emerging EULAR Network (EMEUNET) was given the opportunity to have two representatives, Paul Studenic and myself, to provide the experience and perspective of young rheumatologists. The main purpose of the meeting was to empower young people with RMDs aiming at the establishment and, where already present, consolidation and growth of national young patient associations in EULAR countries.

We were directly involved in the preparation and facilitation of two workshops where presentations on theoretical aspects were followed by role plays and practice. Many brilliant ideas were put forward during the workshops and patients also shared their personal experience and commitment. Lively discussions in an informal environment allowed a dynamic exchange of different views and proposals for future collaborations. Each of us was enriched by this experience and we believe that it further strengthened the bond between EMEUNET and Young PARE. This exchange also allowed us to gain another view on patient care, which raises the question whether patient partner meetings should be included in clinical rheumatology training programmes in the future.

The meeting was a milestone in the path we all, health professionals, physicians and people with RMDs, walk together aiming to change the future and to improve the quality of life of young people with rheumatic and musculoskeletal diseases.
In early November 2016, PARE leaders Dieter Wiek, Chair of the EULAR Standing Committee of PARE, together with Marios Kouloumas, Vice President EULAR, representing PARE, and supported by Birte Glüsing, EULAR Secretariat, travelled to Norway to meet Prof. Tore K. Kvien, Head of the Department of Rheumatology at the Diakonhjemmet Hospital in Oslo. It was a great opportunity to learn first-hand about the results of the Nor-Switch Study.

The final outcome of this study was awaited with great anticipation worldwide and is expected to have an immense impact on national health systems. Although the results show that the tested biosimilar was not inferior to the originator biologic, it is only the first study; many more will follow. "Studies need to be done for each medication separately – our results cannot suggest that switching patients to biosimilars in general can be approved. But in this specific case it does show that it is worthwhile to investigate further so that, in the long term, access to treatment can be improved" commented Prof. Kvien. PARE is currently working on updating the EULAR PARE position paper on biosimilars and the discussions with Prof. Kvien and his team were extremely insightful and helpful.

The second highlight of the visit was meeting the team of the Norwegian Rheumatism Association (NRF) and their CEO Tone Granaas. “We are always very happy to liaise closer with EULAR. Over the last 4 years we have had to focus on the review and renewal of our internal set up and structures but now we feel excited and ready to engage at European level " said Tone. The World Arthritis Day activities in Norway were a great starting point and BURG, the Norwegian organisation for young people with rheumatic or musculoskeletal diseases, plans to engage more closely with Young PARE. “We are very impressed by the variety of high level activities and projects organized by the Norwegian association. There is a lot of best practice here. It is a highly engaged team and we look forward to our future exchanges” said Marios Kouloumas.

The Association of Rheumatic Diseases Patients of the Republic of Serbia (ORS), just as every year, observed the 2016 World Arthritis Day (WAD) on 12 October. The whole event was organised under the title “The Future is in Your Hands - Find Support”. This year’s celebration focused on spondyloarthritis. We wanted to draw the attention of the public and politicians to the burden of these diseases.

We organised a public event at the Belgrade Zoo! The accent was on ankylosing spondylitis (AS), and as people suffering from AS feel as if elephants are sitting on their backs, the whole event took place near the elephant’s enclosure. Three people carried dolls in the shape of elephants. People from all our ORS branches came to Belgrade in order to take part in the WAD event. We also invited representatives of the all main Serbian media. We screened the WAD montage video (which we had previously translated and subtitled) to an appreciative and interested audience. The next day we took the opportunity to present the video live on television.

The whole event was held in cooperation with the Rheumatology Association of Serbia and the Association of Parents and Children suffering from Rheumatic Diseases. In spite of the rainy weather, more than 120 people from around Serbia were present. Reports of the events and information about World Arthritis Day were published in 25 printed and electronic media. Our 95 minute appearance on television reached an estimated audience of 1.3 million. Additionally, the WAD montage video was shared and seen by even more people through the ORS Facebook page and ORS website. World Arthritis Day 2016 was therefore a fantastic success for our organisation!
Country activities

News from the Russian Federation
by Polina Pchelnikova, Head of the Moscow branch of ‘Nadezhda’

In 2016, our patient organization, the Russian Rheumatological Association “Nadezhda”, celebrated its 10th anniversary. Our organisation is one of the most active patient organisations in the country. Nadezhda is an umbrella organization with 55 regional branches and five thousand members. It deals with government officials at both regional and federal level, provides psychological and legal assistance for patients, and organises educational conferences for patients. Nadezhda is one of the founders of an annual event that takes place in Moscow – the Russian Patient Congress. Every year this Congress is attended by hundreds of non-governmental organisations that specialise in various diseases, and by many health professionals, government officials and ministers. Many journalists from various mass media report on the event.

The 2016 Congress took place from 9–11 October. The main aims of the Congress were to develop a dialogue between government institutions and the patient community, to empower patient organisations, to discuss legal initiatives in the healthcare sphere, and to establish a public control system in the healthcare sphere. One of the main topics was biosimilars. This topic is crucial not only for people with rheumatic and musculoskeletal diseases (RMDs) but also for many people with other diseases. Patients had an opportunity to get up-to-date information on biosimilars from top health professionals specializing in this issue, and to understand the current legal aspects of the regulation of registration and usage of biosimilars. They were also able to ask ministers directly face-to-face, in the presence of the mass media, questions on the existing problems with biosimilars in the country. There were also many workshops where patients learned how to manage their patient organisations during the economic crisis, how to establish dialogue with government officials, how to solve certain widespread legal issues, and how to promote patient organisations through social networks etc.

We hope that this event will make the work of patient organisations more productive and that eventually all patients in the country will have access to modern treatment.

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

EULAR supports the BJD: www.boneandjointdecade.org