

e - BREAKTHROUGH

News from the Standing Committee of People with Arthritis/Rheumatism in Europe

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Dates for your diary:

- 10 May:** World Lupus Day
- 20 May:** World Autoimmune Arthritis Day
- 12-15 June:** EULAR Annual European Congress of Rheumatology, Madrid
- 29 June:** World Scleroderma Day
- 11-13 July:** Bone & Joint Decade 2013 World Network Conference, Rio De Janeiro
- 12 October:** World Arthritis Day
- 15-17 November:** Autumn Conference for PARE, Reykjavik
- 31 December:** Deadline for Knowledge Transfer Programme applications

Would you like to read about your national organisation's activities in the next issue? Please send your article (300 words max and photographs) to birte.gluesing@eular.org by 1 July 2013

An exciting agenda ahead

by Maria Batziou,
Chair of the EULAR Standing Committee of PARE



Dear Colleagues

I am pleased to present to you the second edition of our e-newsletter for 2013. I hope you welcome it as warmly as you did the previous issues.

We are greatly looking forward to the EULAR Congress 2013 where once again PARE will have an important role together with health professionals and clinicians. The PARE booth will provide a place for you to have informal discussions and where you can meet other people with rheumatic and musculoskeletal diseases (RMDs) in a relaxing atmosphere. It will also be where you can find out more about EULAR activities and projects.

In this issue of e-Breakthrough you will find articles on EULAR's 2017 Strategy,

how Sweden and Estonia used PARE's Knowledge Transfer Programme, the latest CEO meeting, plans for World Arthritis Day 2013, and we introduce you to the new Youth Research Project.

We have an exciting agenda ahead but people with RMDs continue to face many challenges and we should not forget to try to make them more visible to the public and to policy-makers. It is not an easy journey but "we'd rather attempt to do something great and fail than to attempt to do nothing and succeed" as Robert H Schuller, a wise clergyman, said some decades ago.

I do hope that you enjoy reading this issue.



Count-down to the annual EULAR Congress in Madrid

by EULAR Secretariat

From 12-15 June 2013 Madrid will become the world centre for rheumatology as the city welcomes more than 15,000 delegates for the annual EULAR Congress. We are delighted to share with you some of the forthcoming PARE highlights.

For newcomers and experienced attendees alike, we will start off with an overview of the Congress Centre and introduce you to the PARE programme. Then you are invited to join us in giving a warm welcome to the BaRIE cyclists (Biking against Rheumatism in Europe) who annually demonstrate partnership and teamwork between health professionals and patients by cycling together to the EULAR Congress.

Our packed programme includes sessions on: political campaigning; 'Healthy

Ageing'; tips on re-branding rheumatic and musculoskeletal diseases (RMDs); patients' rights; self-management; gender differences in care and treatment; family planning and parenthood; EUMUSC.Net; the latest findings around degenerative conditions; and advances in biological treatment. There will also be an abstract session show-casing an inspirational variety of activities and projects, and a session on patient empowerment through social media that we expect to be extremely popular. You are sure to find lots of things that interest you.

So we have some really exciting days ahead. We look forward to fruitful discussions with you and to exchanging experiences!

Hasta pronto!

Vision 2020 - EULAR Strategic Objectives by EULAR Secretariat

Issue 2 (January 2013) of e-Breakthrough introduced the new EULAR Strategy 'Vision 2020' and gave an overview of the 7 Strategic Objectives that will be the centre of EULAR's attention for the coming 5 years.

In common with all EULAR Standing Committees, the Standing Committee of PARE has chosen to have a particular focus on 3 out of these 7 Objectives. They are: **Education, Advocacy** and **National Relations**.

Neil Betteridge, Vice President, EULAR, representing PARE says "Of course we will continue with our current activities, with which the PARE community are already familiar, and there will be no ad hoc changes to the PARE project portfolio. Generally, all PARE current activities fit with the new Strategy and will continue to contribute to EULAR's overall success. But the Strategy offers an excellent opportunity to review what we are doing and to see if there is any room for improvements." He adds "We also very much welcome innovative project proposals and ideas from the PARE community to use the fresh opportunities presented by the new Strategy."

So which of the projects and activities currently organised by the PARE Standing Committee support the new EULAR Strategy?

Strategic Objective 2 – Education

By 2017, EULAR will be a pre-eminent provider and facilitator of high-quality educational offerings for physicians, health professionals in rheumatology, and people with rheumatic and musculoskeletal diseases (RMDs).

Education has always been at the heart of PARE's activities: the EULAR Autumn Conference has been a dedicated conference for people with RMDs since 1997; World Arthritis Day has shared various educational materials since 2003; the Patient Research Partners project has given people with RMDs vital skills to participate in research programmes; and the PARE programme at the EULAR Congress and the Knowledge Transfer Programme have provided a wide variety of learning opportunities for the organisations of PARE. EULAR has therefore invested, and will invest further, in educational activities of key importance to the patient community.

Strategic Objective 4 – Advocacy

By 2017, EULAR will have a significant influence on EU level, and assist actions on national level, towards improving research funding, social policy legislation, and quality of care.

EULAR's activities at EU level have shown significant impact in the Brussels arena. Through events like the Belgian EU Presidency Conference on Rheumatic and Musculoskeletal Diseases in 2010, the Brussels Declaration and campaigns around the next Research Framework Programme Horizon 2020, the EULAR community has been recognised as a reliable and serious partner by the EU key stakeholders, and RMDs have moved steadily up their agenda. The PARE community has been instrumental in achieving this success and EULAR will continue to strengthen and support these activities.

Strategic Objective 7 – National Relations

By 2017, EULAR will have actively engaged all national societies as well as related organisations in key EULAR activities.

PARE has always put the national member organisations at the heart of its activities. The EULAR Autumn Conference for PARE and the Networking Dinner during the EULAR Congress have facilitated face-to-face and best practice exchanges, and have built a strong and successful relationship with EULAR. Country visits, where a EULAR delegation of scientific and PARE representatives have supported national member organisations in arranging high level political events, have been very successful and have had positive impact and outcomes. Two staff members at the EULAR secretariat provide dedicated support for all PARE activities and are the first point of contact for the national member organisations of PARE. And this e-newsletter is now giving national organisations the tools to be able to give their members timely information about the activities of the Standing Committee of PARE.

PARE is therefore already well positioned to support the successful implementation of 'Vision 2020'. The Secretariat looks forward to continuing to work enthusiastically with PARE national organisations to support programmes and projects within the Strategy that will make a real difference to the lives of people with RMDs.

EULAR activities



Living better ageing Well

The topic for World Arthritis Day (WAD) in 2013 – 2014 is 'Living Better, Ageing Well' growing up and growing older with a rheumatic and musculoskeletal disease (RMD).

All sorts of exciting activities are planned for this year and next. The centrepiece of activities in 2013 will be an online competition which will invite people with or without RMDs to be creative – more will be revealed soon on www.worldarthritisday.org

'Living Better, Ageing Well' covers the physical and mental changes that occur throughout our life, as well as all the other factors that affect our ability to enjoy an optimal quality of life. These include access and technologies, medicines and treatments, societal attitudes, and our lifestyle choices. The WAD website will feature key topics aimed at improving the quality of life of people with RMDs starting with 'Healthy Living': physical activity; nutrition and weight management; self-management and motivation; and emotional well-being.



16th EULAR Autumn Conference for PARE
15-17 November 2013, Reykjavik, Iceland

Reykjavik calling!

The 16th Autumn Conference for PARE will be held on 15-17 November 2013 in Reykjavik, hosted by the Icelandic organisation Gigtarfélag.

The overarching topic of the Conference will be **Healthy Ageing** featuring the WAD motto 'Living Better, Ageing Well'. As usual, the Autumn Conference agenda will be full of exciting topics to get you thinking and talking about issues that affect people in Europe living with RMDs.

Einar S. Ingólfsson, President of Gigtarfélag says: "We are delighted to welcome our European colleagues to Iceland. Our members are excited to learn more about EULAR activities and look forward to exchanging experiences with the delegates. We very much hope that this Conference will also raise awareness about RMDs among Icelandic policy makers."



Knowledge Transfer Programme

by Enid Udras, Media Co-ordinator, Estonian Rheumatism Association



The Estonian Rheumatism Association made a three-day educational visit in October 2012 to the Swedish Rheumatism Association thanks to the EULAR Knowledge Transfer Programme. The educational visit was focused on patient organisation structure, members and membership fees, fundraising, collaboration with politicians, the role of social media, and early diagnosis and treatment.

The educational visit gave the Estonian Rheumatism Association and their member organisations and partners a great overview of good practice in Sweden. It also highlighted the importance for patient organisations to co-operate with external stakeholders and professionals from the health sector.

The visit helped the Estonian Rheumatism Association and their member organisations to understand better how their work should be organised in the future,



Estonian group introduction and warm welcome from Sweden

how the organisations could be strengthened and how to develop a better fundraising strategy. Useful tips were collected on how to work successfully in the political area and also ideas about how to collaborate with stakeholders in Estonia and in Sweden.

As a result of the visit, the Estonian Rheumatism Association and their member organisations hope to attract new members through better co-operation with rheumatologists, health professionals and through social media networks. Awareness about rheumatic and musculoskeletal diseases (RMDs) will be raised by inviting the Ministry, the Health Insurance Fund, Parliamentary

Representatives and Members of the European Parliament to take part in future projects. The overall ambition is to motivate people to work for the organisation and to develop closer co-operation between the Estonian and Swedish organisations. Finally, the Association will work hard to strengthen its organisation by sharing information more effectively between members, partners and staff.

Very many thanks to Anne Carlsson, Magdalena Olsson and the Swedish team.

Magdalena Olsson,
General Manager,
Swedish Rheumatism
Association



"It was a great experience for us to meet the Estonian representatives—they were so motivated and eager to learn and we were very impressed. We also learnt a lot. The exchange benefitted both organisations and we look forward to continuing this fruitful co-operation."



Young people with arthritis undertake their own research

by Ingrid Kihlsten and Maarten de Wit



What are the challenges of young people living with rheumatic and musculoskeletal diseases (RMDs) in Europe today?

This is the question that the PARE Youth Research Project is currently investigating. Representatives of the target group have identified the topics that are the most important from their perspective. On the basis of these topics a survey is being developed to explore how young people experience the impact of their disease. This electronic survey will be circulated in all European countries in the coming months. The results will be presented this year and hopefully will stimulate discussion about the needs of young people with RMDs, not only within the Standing Committee of PARE but also in the national organisations.



Empowering youth groups all over Europe is important to improve health care

for young people. "But unfortunately we know relatively little about this group of young patients" says Ingrid Põldemaa, for many years one of the leaders of the Estonian youth group and currently a member of the PARE Board. Together with Maarten de Wit she put together a task force bringing together young expert representatives from all over Europe to conduct a study that aims to collect solid data on the needs and preferences of young people living with RMDs between 18-35 years.



WORKSHOP IN TALLINN MARCH 2013

Participants: Angela Loré from Italy, Astrid Kuentzel from Germany, Epp Adler, Kristi Mustkivi and Ingrid Põldemaa from Estonia, Ingrid Kihlsten and Anna Ageberg from Sweden and Linda van Nieuwkoop and Maarten de Wit (Project Convenor) from the Netherlands.



Mapping youth groups in Europe and their activities

has been an

important part of this project. To identify to what extent EULAR member organisations of PARE have activities for and/or by the young patient group, Florian Klett, working at the EULAR Secretariat, found out that 24 countries out of 35 reported some form of youth activities. This inquiry is a first attempt to map out existing youth work in Europe systematically and has shown that the definition of "youth group", and the range of ages involved, varies considerably from country to country. Additional research is needed to complete the overview and to fill in the blank spots.

Qualitative research was conducted during the latter part of 2012 and was co-ordinated by Ingrid Kihlsten, Project Co-ordinator of the PARE Youth Research Project. During a 2-day workshop in Tallinn (Estonia) at the beginning of March 2013 she

presented the preliminary findings from 20 individual interviews and two focus group discussions. These were organised in Sweden, Estonia, The Netherlands, Germany and Cyprus by five national researchers. From the data she identified six main topics: *Me, Myself & I; Family & Intimacy; Social Life; Study and Work; Health Care and Disclosure*. The qualitative data was reviewed at the workshop by a mixed group of national researchers, task force members and guest representatives from the target group.



An extensive European survey was developed during the workshop. It aims to

reveal the variety of circumstances affecting the lives of young people with RMDs in Europe and to recognise the main priorities and needs of this rather invisible patient group. All youth groups and EULAR member organisations of PARE will be invited to help to distribute the survey by internet link, in their magazines, through social media and other opportunities.

Reflections from a Focus Group participant

"I have never talked about my disease like this before. Or actually, I never talk about it. This meeting (Focus Group session) has really made my head full of new thoughts. Good thoughts ... I am not alone, I feel lighter in a way."

For more information about the PARE Youth Research Project and the survey, please contact Project Co-ordinator Ingrid Kihlsten at ingkih@gmail.com



EULAR visit to Serbia by Marija Kosanovic, The Association of Rheumatic Diseases Patients of the Republic of Serbia



The high level EULAR visit to the Association of Rheumatic Diseases Patients of the Republic of Serbia (ORS) and the Rheumatology Association of Serbia (RAS) in February 2013 greatly assisted the two organisations in raising their visibility and progressing their work, and resulted in the informal signing of the Brussels Declaration.

The visit started with a tour of the Institute of Rheumatology in Belgrade. ORS, RAS and the Serbian Association of Health Professionals in Rheumatology (SAHPR) gave presentations on their structures, activities, funding and current challenges. This was followed by Prof Dr Maurizio Cutolo's lecture on 'New Possibilities in the Use of Corticosteroids'.



EULAR Visit to Serbia: Signing the Brussels Declaration by Dr Perisa Simonovic, Secretary General of the Ministry of Health

A round-table meeting gathered senior Serbian Government Officials, public figures, and a guest from the Macedonian Non-Governmental Organization for Rheumatism & Arthritis (NORA). Major challenges in disease treatment were identified and important offers of alliances and partnerships were discussed.

The subsequent signing of the Brussels Declaration received extensive media coverage, with the Secretary General of the Ministry of Health pledging support for the establishment of

early arthritis clinics, training for primary care doctors, establishment of a Commission for Rheumatology to promote a new National Strategy for RMDs, and a commitment to increase investment in biologics and infrastructure. The final review resulted in the development of a draft Serbian Strategy and National Action Plan to fight RMDs.

These events and the positive statements issued by the Ministry of Labour, Employment and Social Policy and the Ministry of Education, Science and Technological Development, and support indicated by the Union of Employers, all signal a new approach to RMDs in Serbia. We are grateful to EULAR for their dedication and guidance through this process, and their unwavering support for ORS and RAS.



Be The Cure (BTCure)

by Marios Kouloumas, President, Cyprus League Against Rheumatism and Florian Klett, EULAR Project Co-ordinator



Be The Cure (BTCure)* is an IMI funded research project which aims to develop new therapies against rheumatoid arthritis (RA). Marios Kouloumas and Florian Klett were invited to attend BTCure's first Annual Scientific Meeting in Prague in September 2012.

We were honoured to be invited to attend this BTCure meeting as representatives of patient organisations and, in the case of Marios, also as a patient research partner. Participants included principal scientific investigators, key opinion leaders in RA, researchers, industry experts, patient representatives and experts in the field of medical ethics.

It was interesting to see the different stakeholders in this consortium, all specialists in the field, in a very productive and collaborative atmosphere. Expert patients were integrated into the project right from the conceptualization stage. Knowing the challenges faced by patients taking part in scientific initiatives, we were delighted to learn that they and their representatives were being trained to ensure that

their input would be both productive and highly valued.

This public-private partnership consortium has completed its first year and has seen a lot of interaction between the different partners. Major challenges in data collection, sharing and protection, intellectual property rights and standardisation of data across many different stakeholders in Europe are now being tackled. This consolidation phase is common to all complex consortium projects in Europe and vital to the success in developing new methods in researching chronic diseases like RA.

Reports and information will be regularly disseminated over the whole 5-year project duration. We look forward to sharing the eventual outcomes of this important project with you.

For more information please visit <http://btcure.eu>

*BTCure is an IMI JU funded project, contract no 115142-2. The Innovative Medicines Initiative (IMI) is a public-private partnership and Joint Undertaking between the European Union and the pharmaceutical industry association, EFPIA.



News from the heart of EUROPE

Brussels hosts meeting of EULAR PARE Chief Executives

by EULAR Secretariat

The General Secretaries/Chief Executive Officers (CEOs) of the 11 largest EULAR member organisations of PARE came together for their latest meeting in Brussels on 19 March 2013.

The event, hosted by EULAR, gave participants a platform to exchange experiences and best practice around hot topics like fundraising and campaigning, and an opportunity to hear the latest news of EULAR's activities in the Brussels arena.

Across Europe, many organisations are feeling the impact of the challenging economic environment and have to find innovative ways to finance their activities. The discussions revealed that it was extremely difficult to compete for funding as rheumatic and musculoskeletal diseases (RMDs) often lost ground to other disease areas. However, Marios Kouloumas, CEO of CYPLAR, the Cyprus League Against Rheumatism, said "We have recently been very successful with community fundraising. These events organised by other parties helped us to raise awareness among circles to which CYPLAR usually has no access". Ailsa Bosworth, CEO of NRAS, the United Kingdom's National Rheumatoid Arthritis

Society, stimulated a lively discussion with her presentation on how to work with the pharmaceutical industry.

Political and awareness-raising campaigns continue to be an important part of the portfolio of all of the organisations represented. Ursula Faubel, CEO of the Deutsche Rheuma-Liga, presented their campaign "Day of Action for Volunteers 2013" and Mervi Ahlroth, CEO of Suomen Reumaliitto Ry, the Finnish Rheumatism Association, informed the meeting about their activities addressing policy makers.

Delegates also heard updates on the next Research Framework Programme Horizon 2020, the Chronic Diseases Reflection Process, Healthy Ageing, the implementation of the Patients Rights' Directive, and the UN Convention on the Rights of People with Disabilities.

At the end of the day, delegates agreed that it had again been a very inspiring event and that it was extremely useful to exchange experiences. The group intend to explore further ways to stay in touch on a more regular basis.

The European League Against Rheumatism (EULAR) is the organisation which represents people with 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



The Bone and Joint Decade
Promoting musculoskeletal health
Keep people moving

EULAR supports the BJD: www.boneandjointdecade.org