

e - BREAKTHROUGH

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

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Dates for your diary:

- **1 October to 31 January 2015:** Abstract submission for EULAR Congress 2015 in Rome
- **29 October:** World Psoriasis Day
- **7-9 November:** Annual European Conference of PARE, Zagreb, Croatia
- **3 December:** International Day of Persons with Disabilities
- **31 December:** Deadline for Knowledge Transfer Programme applications
- **31 December:** Deadline for Stene Prize 2015 essays to national EULAR member organisations of PARE

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

Inspiring others

by Diana Skingle,
Chairperson of the EULAR Standing Committee of PARE



Dear Colleagues

I can hardly believe that it is two years since the first issue of e-Breakthrough. It is now such an important part of how PARE communicates with you in the national organisations that I cannot imagine how we managed without it.

However, this is not a one-way communication tool. We rely on you to send us contributions so that others can hear about all your campaigns and projects. Don't be shy! We want to hear from you and give you the opportunity to share your best practice achievements, and inspire others by your successes.

It seems only a moment since the EULAR Congress in Paris and yet we are already planning the next Congress in Rome. Thank you to everyone who has sent ideas for another exciting PARE programme next year.

Recent PARE highlights include the World Arthritis Day competition and participation in the EULAR Brussels Conference. You can read about them in this edition of e-Breakthrough, together with information about EULAR Study Groups, and stories from Norway, Slovenia and Lupus Europe.

I am also delighted to introduce to you the new PARE Board members who will be working hard to plan, develop and deliver a varied programme of PARE activities and projects that we hope you will enjoy and find useful in developing the skills of your volunteers and the capacity of your organisations.

I look forward to seeing many of you at the Annual European Conference of PARE in Zagreb in November.



The World Arthritis Day competition "Vision 2043" invited people to share ideas that could help to improve the lives of people with rheumatic and musculoskeletal diseases (RMDs) by the year 2043. Entries poured in from across Europe and around the world. Ideas ranged from small practical interventions that would change day-to-day living for individuals to inspirational suggestions for fundamental reforms in healthcare delivery and treatment. Choosing winners was no easy task! The winners of the online voting were:

The European (EULAR country) winner: **Roula Stara (Greece)**

The Global winner: **Pavlina Pejkovska (Former Yugoslav Republic of Macedonia - FYROM)**

A full list of winners, runners-up and those commended by our jury can be seen, together with their winning entries, on the World Arthritis Day website: www.worldarthritisday.org/vision2043

Congratulations to all our winners!

Introducing the 2014/15 PARE Board



Diana Skingle (United Kingdom) Chairperson of the Standing Committee of PARE

Diana developed rheumatoid arthritis in 2005. She is a Trustee/Director of the UK National Rheumatoid Arthritis Society and a patient research partner in the EURO Team project.



Marios Kouloumas (Cyprus) EULAR Vice President representing PARE

Marios has rheumatoid arthritis. He is President of the Cyprus League against Rheumatism and of the Cyprus Federation of Organizations of People with Chronic Diseases. He is also member of the Administrative Board of the Cyprus Confederation of Organisations of people with Disabilities, and of the National Committee of rheumatic and musculoskeletal diseases (RMDs).



Dieter Wiek (Germany) Chair-elect

Dieter says "After working as a volunteer for Deutsche Rheuma-Liga for 30 years in different positions it is an honour for me to contribute to the work of EULAR and PARE. Our key goal has to be that all patients get the optimal standard of care - no matter where they live and what socio-economic status they have."



Jolanta Grygielska (Poland) Board member

Jolanta is a health economist especially interested in socio-economic aspects of rheumatic diseases. She is president of the Polish Rheuma Federation (REF) user-led umbrella organization and president of the Polish Association of People with Rheumatism and their Friends.



Nele Caeyers (Belgium) Board member

Nele was diagnosed with SLE (systemic lupus erythematosus) in 1997 and has been a volunteer since 1999 at national and international levels. She is the spokeswoman for ReumaNet, the Flemish league for patient organisations for rheumatism. She strongly believes patients can contribute on different levels to make overall care for people with RMDs better.



Gonzalo Aldenueva (Spain) Board member

Gonzalo is the current Chairman of the Management Board of the Spanish Behçet's Disease Association, and a Board member of LIRE (Spanish League Against Rheumatism). He believes in teamwork and one of his favourite quotes is "Together we are stronger".



Elsa Mateus (Portugal) Board member

Elsa was diagnosed with Juvenile Idiopathic Arthritis (JIA) in 1977. "Winning the national Edgar Stene Prize competition in 2007 not only changed the way I cope with my JIA, but also made me realise the importance of being involved with RMD patients associations. Since 2011 I've been representing the Portuguese League against Rheumatic Diseases as a PARE delegate. I believe that patients can and must have an active voice, as experts, as consumers and as citizens."



Jean Noël Dachicourt (France) Board member

Jean Noël is the General Manager of the Association Française de Lutte Anti-Rheumatismale (AFLAR). He has been actively involved in EULAR PARE events since 2011 and is a member of the PARE youth group. His ambition is to improve the understanding, prevention and management of RMDs around Europe.

A special thank you to those leaving the Board



Maria Batziou (Greece)

Maria is now a member of the EULAR Secretariat staff



Ingrid Pöldemaa (Estonia)



Codruta Zabalan (Romania)

PARE Board meeting in Zurich



The new board (with the exception of Jean Noël Dachicourt who was unable to attend this time) and the EULAR Secretariat team came together for their annual PARE Board Meeting in the EULAR House in Zurich on 6-7 September 2014. The agenda was packed and featured strategic discussions as well as updates on the many projects and activities PARE is running. It was a busy 1 ½ days and a challenge for the new Board members to digest a lot of new information. Gonzalo Aldenueva, who was not involved with EULAR or PARE activities before being elected to the PARE Board, said afterwards: "It was a great experience for me to meet my new colleagues face-to-face. I really enjoyed it and I can't believe it was only my first meeting! I would like to thank all involved for making it so easy and welcoming for new members like me. I really look forward to contributing actively and supporting PARE activities."

What do you know about the EULAR Study Groups? They are established networks in their respective fields and play an active part in the research and treatment of rheumatic and musculoskeletal diseases (RMDs). In this article we hear from Dr Danielle M. Gerlag (Amsterdam Medical Centre, the Netherlands) and Professor Karim Raza (University of Birmingham, United Kingdom) about the EULAR Study Group for Risk Factors for Rheumatoid Arthritis (SGRFRA). Codruta Zabalan (Romania) writes about being a Patient Research Partner in the EULAR Psychology Study Group.

EULAR Study Group for Risk Factors for Rheumatoid Arthritis (SGRFRA)

The Study Group for risk factors for rheumatoid arthritis (RA) was established in 2010 under the auspices of the EULAR Standing Committee of Investigative Rheumatology and is chaired by Dr Danielle M. Gerlag (Amsterdam Medical Centre, the Netherlands) and Professor Karim Raza (University of Birmingham, United Kingdom).



*Dr Danielle M. Gerlag
(Amsterdam Medical Centre, the Netherlands)*

This study group focuses on the very earliest phases of RA and aims to facilitate research to:

1. Understand how and why people develop RA – with a particular interest in how genetic factors interact with environmental factors such as smoking and infections.
2. Develop ways of identifying which individuals without RA are at the highest risk of developing the disease in the future – with a particular interest in developing tests that can be widely used in clinic to test individuals in different at risk stages (for example relatives of patients with RA through to patients with early joint symptoms who haven't yet developed full-blown RA).
3. Develop treatments to reduce the risk of RA developing in the future.



*Professor Karim Raza
(University of Birmingham, United Kingdom)*

The Study Group brings together expertise from leading clinical research institutes within Europe. In addition, Patient Research Partners play a key role and have been instrumental in shaping some of the recommendations from the Study Group and informing discussions at study group meetings. By working with Patient Research Partners, the Study Group ensures that its activities are informed by those with a lived experience of RA, allowing tests and treatments to be developed and implemented in an ethical manner that is acceptable to patients. The Study Group meets twice a year at international rheumatology meetings (EULAR and the European Workshop for Rheumatology Research) to discuss progress and the research agenda.

EULAR Psychology Study Group



Codruta Zabalan is a Patient Research Partner in the EULAR Psychology Study Group and in the EULAR Study Group for Risk Factors for Rheumatoid Arthritis (SGRFRA)

The EULAR Psychology Study Group has 31 members (including two patient representatives) from seven countries, and is chaired by Dr Erik Taal (the Netherlands). It aims to provide a platform for researchers, health professionals and patients to promote psychological understanding of rheumatic and musculoskeletal diseases (RMDs), and to initiate, stimulate and discuss psychological research and psychological healthcare implementation in multidisciplinary healthcare for patients with RMDs.

The Study Group's special characteristic is that it concentrates on patients' psychological/emotional well-being and the connection between our mind (subconscious) and body (the physical symptoms induced by RMDs). Reading a bit about "mechanisms in psychotherapy" one can learn that there are three different generations of psychotherapy: the first generation focused on changing behaviour, the second focused more on changing attitudes and beliefs and the third generation focuses on accepting things as they are and learning how to deal with them. Being one of the patient research partners in the group, I believe that psychotherapy is a useful and practical aid to learning to cope with a RMD, but also to trying to change attitudes and beliefs.

In conclusion, while eagerly waiting to see the future outcomes of the EULAR Psychology Study Group I encourage you to THINK POSITIVE because WE ARE OUR MIND AND SPIRIT, AND ATTITUDE IS EVERYTHING!

Edgar Stene Prize Essay Competition 2015

“Taking control of my life: working together with health professionals to achieve my personal goals”

We invite people with rheumatic and musculoskeletal diseases (RMDs) to write about their personal experiences and the role that health professionals have played in supporting them to live as independently as possible, to achieve important personal goals, and to take control of their lives. Has your organisation launched the Edgar Stene Prize Competition for 2015 yet? If not there is still time! All EULAR member organisations of PARE are invited to organise a national writing competition to identify the best national essay on the 2015 topic by mid - January 2015. This will then compete with all entries at European level to win Euros 2,000 and a trip to the EULAR Congress in Rome in 2015. For more information on deadlines and other details please check out the EULAR website www.eular.org or contact Birte Gluesing at the EULAR secretariat at birte.gluesing@eular.org



EULAR Congress 2015 Rome

Abstracts and Bursaries

Are you ready? From 1 October 2014 to 31 January 2015 the EULAR abstract system for the EULAR Congress 2015 in Rome is open and ready to receive your contributions! Your contributions are crucial in making the PARE programme relevant and interesting for your fellow delegates. We count on you to share your campaigns, projects and expertise! Remember too that poster presenters are now offered much deserved attention through our official PARE Poster Tours. If you would like also to apply for a bursary please note that this is a separate application process which needs to be completed at the same time as submitting your abstract. If you have any questions about abstracts or bursaries please contact Birte Gluesing at the EULAR Secretariat at birte.gluesing@eular.org

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Brussels Conference by EULAR EU Office Brussels



As every October, EULAR celebrated World Arthritis Day in Brussels. This year, we organised a Conference on **“Analysing how to reduce the access barriers to health care for people with chronic diseases. Challenges, good practices and policy options for people with rheumatic and musculoskeletal diseases (RMDs)”**.



Opening plenary session of the EULAR Brussels Conference at the European Parliament

The aim of the event was to bring together the RMD community, policy makers and key stakeholders to debate how to improve access to health care, a topic of major concern for people with RMDs and other chronic diseases. The conference (part of which was held in the European Parliament) was hosted by Takis Hadjigeorgiou (MEP from Cyprus), and was attended by more than 140 participants. High-level representatives of the EU institutions, national and regional authorities, stakeholder organisations, and experts in different fields, presented during the event.

One of the key goals of the conference was to discuss and develop policy recommendations for improving access to care in Europe. To this end, four workshops were organised, each focusing on a specific access barrier or issue:

- **Health systems responses to financial constraints;**
- **Patient empowerment, health literacy & information to patients;**
- **Health professionals: availability/composition, roles, training, mobility, accreditation; and**
- **Access to treatments and medicines: availability, pricing and reimbursement.**

Each of the workshops was co-organised with a well-known stakeholder organisation, which brought in their expertise and helped to coordinate the discussion with participants.

The results of the workshops were the main topic of a panel debate that followed, and that focused on the role of the EU, Member States/regions and stakeholders in improving access to health.

For more information on this event, please visit the EULAR website (www.eular.org) or contact the EULAR Brussels Office (Brussels@eular.eu)



While we wait for a breakthrough

by Tone Granaas, Secretary General of the Norwegian League Against Rheumatism



The Norwegian Rheumatism Association (NRF) is one of Norway's largest voluntary organisations, with nearly 36,000 members. NRF is an organisation for people with all types of rheumatism, and other musculoskeletal conditions. We work on many fronts to better the conditions and lives of our members – and by extension everyone who is afflicted by the disease in Norway.

It is important to continue to push the science frontier forward, and never lose hope of the possibility that new breakthrough medicines will appear on the market in the future. But waiting does not equal inaction. Despite the complexity of the disease, NRF believes it is important to maintain a steadfast focus on the many proven types of interventions that already exist. We have an obligation to make sure that every inch of accumulated knowledge gathered over the past decades is communicated and reaches those most in need.

To this effect, NRF uses its extensive organisational structure to reach literally every island and mountaintop in our far flung country. One of NRF's goals is that everyone can pick the low hanging fruit -

and more importantly, that we as an organisation empower individuals to take charge of their own disease, using all the measures that we already know can help. More than 220 local branches and disease groups help us to extend our reach. Human interaction does not involve any costs, but the benefits are huge. Thus we create opportunities for our members to develop self-esteem and independence by way of offering a social network, personal services, support, self-help groups, remedial training and information, along with the possibility of influencing health and socio-political policy and decision-making.

NRF welcomes every new treatment regime and has people on its staff who work toward this end full time but, while we wait, we strive to give people the necessary tools to achieve small and incremental breakthroughs in their own lives - every day. Breakthrough is a matter of definition. For many of our members it is a breakthrough to be able to go for a walk in the evening, or to start a new training regime.

So, while we wait for the big breakthrough, let us celebrate all the small breakthroughs that take place every single day.



Do you have trouble with back pain?

by Petra Zajc, Expert Adviser, Slovenian Rheumatism Association



There are diseases in which sleeping causes pain, and resting becomes a struggle. They are a little-known group of inflammatory rheumatic diseases - spondyloarthritis (SpA) - that affect the spine and other joints. In Slovenia SpA affects around 38,000 people.

Some of the key challenges in dealing with spondyloarthritis are: the need to improve recognition of the first symptoms of the diseases; to shorten the time to correct diagnosis and appropriate treatment; and to speed up referral to a rheumatologist. General practitioners (GPs) often do not recognise that back pain is a possible first symptom of SpA among young people. In Slovenia it can take as long as 7 years to be correctly diagnosed. In the

interim, irreversible functional damage to the joints can occur.

In June 2014, the Slovenian Rheumatism Association launched a national campaign to raise awareness among patients, the general public and GPs about SpA. The campaign is now running in collaboration with rheumatologists



in health centres across Slovenia under the slogan **"Do you have trouble with back pain?"** and targets young people between 20 and 40 years old. Information appears on our website www.revmatiki.si/SpA and we have developed booklets and posters (see above).

We also conducted a survey among people with SpA. The aim was to identify: the average time from first symptoms to correct diagnosis; the physical, emotional, and social impact of the disease; the most important personal goals of those with SpA; how information about the disease is obtained and how reliable it is; the general understanding about the disease; and the coping strategies used by people with SpA.

Preliminary results of the campaign show our posters have reached 200,550 people; 5,278 brochures have been distributed; 7,583 unique visitors have accessed our website; 4,155 people have completed our survey; and 15 media reports – in total we assess that we have reached 1,076,001 people.

Introducing LUPUS EUROPE



25th LUPUS EUROPE Convention 2014

by Kirsten Lerstrøm, Chair of LUPUS EUROPE



“I want life to my years rather than years to my life” – this quote from an Irish patient advocate with Multiple Sclerosis (MS) resonated well with the audience at the recent 25th LUPUS EUROPE Convention in Helsinki in September 2014.

The quote came during our key note address on the Convention Theme “Access to a Better Life with Lupus” by Christoph Thalheim, Director External Affairs, European Multiple Sclerosis Platform. It gave meaning to the superb speech on the rôle of the future European patient by MEP Sirpa Pietikäinen.

We have to do better for people with lupus.

LUPUS EUROPE is the European umbrella for 24 European national lupus groups. When we meet each year it is to share ideas and experiences, but also to learn about new advancements in research, health care and social issues of importance to those living with lupus. Our network and close personal ties cross various fields of expertise from work relations to medical developments. Although lupus is a rare

disease in some countries, we have close ties with the national rheumatism associations.

A world without lupus is our humble vision for the future and is the core of our Strategic Plan 2013-2017. With this we want to involve people in their own disease and research, and inspire and bring enthusiasm to our member organisations and give LUPUS EUROPE a voice.

We are most grateful for being recognized as a co-opted member of the Standing Committee of PARE at EULAR 2014. We are looking forward to working with all PARE colleagues to continue to develop the patient’s role at EULAR!

Delegates at the 25th LUPUS EUROPE Convention in Helsinki in September 2014



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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EULAR supports the BJD: www.boneandjointdecade.org