

e - BREAKTHROUGH

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

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Dates for your diary:

- **1 October–31 January 2016:** Abstract submission for EULAR Congress 2016, London
- **12 October:** World Arthritis Day
- **29 October:** World Psoriasis Day
- **3 December:** International Day of Persons with Disabilities
- **31 December:** Deadline for Knowledge Transfer Programme applications
- **31 December:** Deadline for Stene Prize 2016 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.gluensing@eular.org

Today is World Arthritis Day!



This is my first editorial as Chair of the Standing Committee of PARE. My first months showed me what an exceptional, demanding and interesting task I have assumed. My special thanks to Di Skingle, Marios Kouloumas, the EULAR Secretariat and the Board members for their great support.

Rheumatic and musculoskeletal diseases (RMDs) affect more than 120 million people in the European Union. They not only have a great impact on the individual but also mean enormous health care costs and a burden for the whole economy. World Arthritis Day on 12 October gives us a great opportunity to emphasize these implications and to raise awareness of RMDs. Our EULAR Conference in Brussels on 13 October entitled **"Towards more integrated healthcare in Europe"** will hopefully make decision-makers aware of what it means for patients to have an RMD, and what is needed to relieve this burden. Do join the World Arthritis Day action by taking part in our High 5 campaign: visit www.worldarthritisday.org

Enjoy reading e-Breakthrough!

Dieter Wiek, Chair
EULAR Standing Committee of PARE

IT'S IN YOUR HANDS
TAKE ACTION

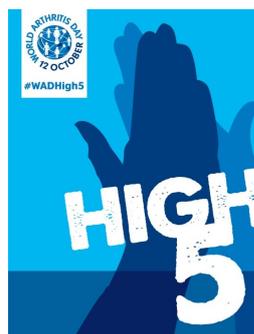
High 5 by EULAR President Prof Gerd R. Burmester and Past President Prof Maurizio Cutolo

Today is World Arthritis Day! Thank you for your continued support and great work for our 'High 5 for World Arthritis Day' campaign. People from across the world have engaged in this year's campaign, sharing their High 5s and helping to raise awareness of rheumatic and musculoskeletal diseases (RMDs).

We've seen celebrities, children and young people, healthcare professionals, people with RMDs, and the wider public all High 5ing and rallying behind the cause. If you haven't yet taken part – there is still time! Visit our website www.worldarthritisday.org

and share your High 5 alongside the hundreds of other people who are uniting to raise awareness.

Together we can take action for all those affected by RMDs, and make the impact of the diseases on people's lives more visible and well understood!



The PARE Board meeting in Zurich



The PARE Board and members of the EULAR Secretariat outside the EULAR House in Zurich

The PARE Board, led by Chair Dieter Wiek, held its annual meeting on 5/6 September 2015 in Zurich, Switzerland. The Board currently has 9 members: Nele Caeyers (Belgium), Jolanta Grygielska (Poland), Marios Kouloumas (EULAR Vice President, representing PARE), Elsa Matues (Portugal), Diana Skingle (Past Chair PARE), and three new members (see below).

The PARE Board had a full agenda, starting with a review of the PARE Board’s role and working mode. The current role of the PARE Board as a ‘Think Tank’ and a body to monitor and oversee PARE-related projects and activities was reconfirmed. A new working mode was agreed to make the work of PARE more efficient and to ensure greater involvement of all the Board members. “PARE has a very broad and dynamic programme and it is important that each PARE Board member is actively engaged in at least one of these projects or activities” said Dieter Wiek. He went on to say that “Training our future leaders is of utmost importance and PARE will look further into organising and offering support. The EULAR School of Rheumatology, which is currently being developed, will certainly offer many opportunities for PARE.” The PARE Board also monitored all projects and took strategic decisions where requested.

The Board also decided that implementation of the user-led principle, which is now explicitly referred to in the new EULAR By-Laws, will be a key focus in the coming months. The discussion around the topic of biosimilars will also gain more momentum in 2016 when the ‘NOR-SWITCH’ study will end and its results are published. PARE will continue to engage actively in this important field.

Welcome to the new PARE Board members



Petra Bednarova, Slovakia
Petra is a Board member in the Slovak League Against Rheumatism, and Chair of the Young PARE working group.



Boryana Boteva, Bulgaria,
Boryana is Vice-President of The Bulgarian Organisation for People with Rheumatic Diseases (BOPRD)



Theodora Papastavrou, Greece
Dora is Treasurer on the Board of Directors of the Hellenic League Against Rheumatism (ELEANA)

Edgar Stene Prize Essay Competition 2016

What are the top tips of people with a rheumatic or musculoskeletal disease (RMD) for living as independently as possible, for achieving important personal goals, and taking active control of their life? The Edgar Stene Prize Essay Competition for 2016 has been launched with the theme **“Living with a rheumatic or musculoskeletal disease (RMD): How I take action to enjoy life to the full.”** The Jury looks forward to hearing many inspirational stories.

For more information please visit www.eular.org or contact your national EULAR member organisation.



Charlotte Secher Jensen from Denmark, winner of the 2015 Edgar Stene Essay Competition, receiving her prize from the then EULAR President Prof Maurizio Cutolo at the EULAR Congress in Rome

Planning for the future

by Professor Gerd R. Burmester,* President of EULAR



Following on from the article in Breakthrough Issue 10 in June 2015, where he shared his presidency priorities, the new EULAR President Professor Gerd R. Burmester now shares his views on what are the most notable achievements so far of EULAR's Vision 2020, based on the 7 EULAR objectives 2017.

Objective 1 – Research

By 2017, EULAR will be a central platform to facilitate and stimulate innovative basic and clinical research projects in rheumatic and musculoskeletal diseases (RMDs).

Here, the close interaction of EULAR with FOREUM, the Foundation for Research in Rheumatology, will greatly facilitate the identification of research needs and will work on translational issues including new treatments and new diagnostic tools. EULAR itself will focus on evidence based recommendations and classifications that are necessary for the best possible treatment regimens and the identification of the appropriate disease groups.

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.

As mentioned above, EULAR already is a pre-eminent provider of high quality educational offerings. This will be further enlarged by founding the **EULAR School of Rheumatology** (explained in more detail in Prof Burmester's article in the June 2015 edition of Breakthrough).

Objective 3 – Congress

By 2017, the annual EULAR Congress will be the top congress for rheumatic and musculoskeletal diseases and will have broadened its offerings and reach.

The EULAR annual Congress already is a major event for rheumatologists, and health professionals, and also people with RMDs throughout the world. Again, here the strength of the three pillars of EULAR is evident combining research results provided by scientists, health professionals and people with RMDs. The annual Congress is a major part of the annual educational package provided by EULAR that includes participation at the meetings, the subscription of the major rheumatological journal **Annals of the Rheumatic Diseases** and online access to basically all Congress material.

Objective 4 – Advocacy

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

EULAR has already had a significant influence on the EU level, especially since RMDs are now recognised here as major diseases. Nevertheless, constant efforts are necessary to maintain the awareness of the importance of these disorders and especially to receive the appropriate financial support for research in these areas. The public affairs group has been founded to oversee the European situation constantly and to work closely with politicians and administrators to optimize the allocation of funds to rheumatology.

Objective 5 – Standards of care

By 2017, EULAR will have raised standards of care by elaborating and actively promoting, disseminating and implementing EULAR recommendations and criteria for the most common rheumatic and musculoskeletal diseases.

Here, there are tremendous efforts by EULAR to constantly generate new recommendations and criteria as well as to update those that are already in place. Also translations into lay language will be provided. EULAR is setting a prime example here for other societies to work on products that are of immediate help in daily clinical practice.

Objective 6 – Profile

By 2017, EULAR will have raised its profile and visibility to patients and health care providers.

EULAR is now recognized everywhere as a highly professional and important organisation in rheumatology. However, this needs constant reinforcement, and here the help of people with RMDs is especially important.

Objective 7 – National relations

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

Luckily, due to the internet and new media it is much easier now to work with national societies, and EULAR is striving to involve these as much as possible. Here, the work of the General Secretary will be of prime importance.

**Professor Gerd R. Burmester is Professor of Medicine in the Department of Rheumatology and Clinical Immunology at the Charité University Hospital, Free University and Humboldt University of Berlin, Germany*

Personalized Medicine, Patient-Centred Care, Person-Centred Care – What’s the big deal?

by Christina H. Opava,*

EULAR Vice President representing Health Professionals in Rheumatology



A couple of years ago the Swedish Queen visited our hospital and the hospital director proudly presented our new slogan 'The patient in focus'. Queen Silvia gently raised her hand and politely asked 'So who was previously in focus?' I cannot remember the exact answer to her question, but a couple of alternatives come to my mind.

When I first heard the term **Personalized medicine** I thought it had to do with focusing on the patients' perspectives and needs in the planning of their care. Since then I have learnt that it is merely about use of biomarkers, genetic information and imaging for diagnostics and the tailoring of treatment to each person's biological, measurable and unique characteristics. This is a very exciting development of the biomedical field and might have been on the hospital director's mind when developing the new slogan for our hospital.

Another possible answer to the Queen's question would have been that: 'We previously focused on our patients merely as physiological systems for us to treat and hopefully cure. From now on we will respect their wishes and needs and provide the education and support they need to make decisions and take part in their own care'. This is a very good start and actually resembles the definition of **Patient-centred care**.

The answer I would have preferred to hear from the hospital director to the Queen would have been: 'From now on we will listen to our patients' stories to identify their resources and possibilities that

may form the basis for a jointly formulated health plan, a true partnership. The relation between health professionals and patients will be underpinned by central values such as respect and understanding of the patients' self-esteem and will'. This is what characterizes **Person-centred care** and what every person with a disease or injury that seeks care deserves.



Prof. Christina H. Opava at the EULAR Annual European Conference of PARE in Dublin in April 2015, with (left to right) Marios Kouloumas and Prof. Hans Bijlsma

To many this sounds like Utopia and there are indeed many barriers to overcome in order for it to be realized. One prerequisite would be that all health team members are capable, responsible and willing to develop a health care based on the equal value of each human being. Another would be the development of a mutual respect for each other's competencies and a less hierarchical health care organisation. However, it is hard to imagine that it would not be worth the efforts to incorporate the patient as a partner and that this would not in the end lead to a more cost-effective care.

A South-African colleague performed a scientific study among people with HIV in an ethnic group with a poor socio-economic situation. The aim

was to evaluate a pain-management programme. One group received a self-help book in their own language; another used the same book at group meetings, including exercise, led by physiotherapists. All study participants were assessed regularly by health professionals from their own ethnic group. At study end both groups were significantly improved to similar levels.

One possible explanation for the result was that all study participants, normally treated in a health care system described as 'hostile', were treated with respect and addressed in a culturally accurate manner by the research team.

Another is that the self-help book was highly valued by participants in both groups, carefully read and reflected on as it was often their only book. However, while the group meetings had a pre-defined format based on the researchers' understanding of the participants' needs, those receiving the book only could use it to tailor the intervention to their needs and even become a resource by educating family, friends and neighbours in self-management. Qualitative interviews validated that respectful encounters, raised self-esteem and empowerment was the main outcome for both groups.

To me this is a great example of **Person-centred care** as a means to improve peoples' quality of life and develop cost-effective health care.

**Professor Christina H. Opava is Professor of Physiotherapy at the Karolinska Institutet and the Karolinska University Hospital, Stockholm, Sweden*



Animal models in biomedical research

by Rik Lories,* Chair of the EULAR Standing Committee on Investigative Rheumatology

The use of animal models in biomedical research remains a controversial issue. Unfortunately media addressing the general public rarely present a balanced view as spectacular actions of animal rights groups or undercover video footage of certain situations attract more viewers and readers than an academic debate.

This often leaves researchers with a sense of frustration that the debate is not fuelled by arguments but rather by ideology leaving little or no room for balanced discussion. Even worse, in some countries researchers prefer to stay away from the public eye as they are concerned with their personal safety. This is a pity as the real stakeholders in society for biomedical research – the patients who need better treatment – risk being poorly informed about the benefits of animal research.

Despite great progress, alternative models such as cell cultures, stem cells and bioartificial organs cannot fully replace the use of animal models. Rodent models in particular are still required to understand how a molecule that could be a therapeutic target works in a living organism that is far more complex than cells in a laboratory setting.

The scientific rationale underlying the use of animals in biomedical research including research on rheumatic and musculoskeletal disorders (RMDs) is that a living organism provides an interactive, dynamic system that can be observed and manipulated experimentally to investigate mechanisms of disease. As a result, a greater understanding of living systems can be attained and this can be generalized to other species including humans, facilitating the development of effective therapies.

The acceptability of using animals in research rests on the expectations that the research will be meaningful and that the suffering will be minimal. The view that human beings have the right to make this decision is based on various arguments. For research based on an animal model, the validity of science is dependent on the validity of the animal model, that is, it is dependent upon the extent to which experimental findings in the animal model can be generalized to humans.

Ethical justification converges with the scientific and in some respects depends on it. It is based upon the view that increasing knowledge makes it possible to develop therapies that mitigate pain and suffering caused by

illness, and thereby responds to the moral imperative to do good. It assumes that research can be carried out with no or minimal distress to the animals, and that any pain and suffering experienced is compensated for by the alleviation of human pain and suffering caused by disease.

Any experimental animal work bears consideration in terms of the principles of **Replacement, Reduction and Refinement**. These principles promote good scientific practice and the search for alternative approaches to reduce the number of animals used in research. Over the last decades – as a consequence of society's pressure on well-defined use of animal models – legislation and regulation of procedures have become much more complex and many mechanisms are in place to support these overall principles on animal research. This includes specific guidelines on housing conditions, animal well-being assessments, reporting and training of researchers. Like any systematic approach, this does not exclude the existence of poor situations but imposes a framework for daily practice. Controls by the competent authorities but also peer pressure from within the scientific community should reassure the public that concerns about animal research are adequately answered.

"The use of animals in biomedical research is an important topic for patients to understand. It is vital that such information is available in lay language and I am grateful to Prof. Lories for his contribution. PARE looks forward to further collaboration on this topic with EULAR colleagues."

Marios Kouloumas
EULAR Vice-President
representing PARE

The rheumatology research community also uses a number of models. One EULAR study group that operates under the umbrella of the EULAR Standing Committee on Investigative Rheumatology is specifically focused on animal models and has, among other activities, drafted guidelines for the use and evaluation of animal models of rheumatoid arthritis. Such efforts are important to optimize standardization, reproducibility and therefore the intrinsic value of the models to improve the health of patients. The investigative rheumatology community therefore wishes to keep PARE and patients informed about the use of animal models, advantages and concerns and values their input and opinion.

*Professor Rik Lories is Professor at the KU Leuven, Belgium

For more information about the EULAR Standing Committee on Investigative Rheumatology, please see the article by Professor Lories in Issue 8 of e-Breakthrough January 2015 that is available on the EULAR website: www.eular.org/myUploadData/files/e-Breakthrough%20issue%208%20Jan%202015.pdf

Country news



World Arthritis Day 2015 in Slovakia

by Petra Bednarova, Slovak League Against Rheumatism (SLAR)



World Arthritis Day (WAD) 2015 in Slovakia will be celebrated by many social, educational events and cultural activities in local branches and clubs.

The WAD 2015 activities will be launched on 10 October when patients with rheumatic and musculoskeletal diseases (RMDs) around Slovakia will gather in Piešťany, the beautiful spa town in western Slovakia.

What will the programme be like? We will not only celebrate World Arthritis Day but we will also celebrate the 25th anniversary of SLAR. We will announce the winners of our prestigious “KROK” journalist awards, selected by our members who voted for their favourite printed/radio/TV article about RMDs over the last six months. We will also have a concert by popular Slovak singer Katarína Koščová. Our overall aim is to have an exciting and motivational day together and to raise awareness of RMDs throughout Slovakia.



High 5 from the Slovak League Against Rheumatism

World Arthritis Day 2015 Slovakia Main events

- * Motivational and educational course for leaders of branches and clubs of the SLAR
- * National cultural event celebrating WAD 2015 in Piešťany
- * 7th anniversary of the “KROK” journalist award—members of all types of media will be present
- * Concerts
- * Workshops for children
- * Presentation of an anthology “25 Years of Slovak League Against Rheumatism”
- * Improvised rheumatologic office at the cultural event for all participants
- * Promotion of the Centre for Psychological and Social Support
- * And gifts and other surprises for the participants!

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



EULAR supports the BJD: www.boneandjointdecade.org