Dear Colleagues,

I would like to thank everyone who contributed so enthusiastically to the PARE activities in 2012 and who supported our aims in many different ways. I hope that you will continue to work with us as we plan our projects and activities for the coming year.

The economic crisis has affected many aspects of life in Europe, and has put severe strain on our health and welfare systems. So issues like access to care, early diagnosis, appropriate rehabilitation and social support for people with rheumatic and musculoskeletal diseases (RMDs) will be highlighted through the new EULAR Strategy and some will also be reflected within the 2013/2014 campaign around Healthy Ageing.

I really hope that you enjoy reading the variety of articles in this issue of e-Breakthrough. I look forward to hearing your comments and suggestions for topics in future issues.

The PARE Board and I would like to send you and your loved ones our warmest wishes for a prosperous and healthy 2013.

Greetings for 2013 by Maria Batziou, Chair of the EULAR Standing Committee of PARE

Vision 2020: EULAR sets sail for the future by Heinz Marchesi, EULAR Executive Director

EULAR enters 2013 invigorated by a new strategy that encompasses seven strategic objectives underpinned with a number of more specific concrete goals. These will guide our programmes, activities and thinking in the next five years. The new strategy builds on all important aspects of EULAR that have formed our past success, while adding a nudge here or giving a new twist there. Under the leadership of President Maxime Dougados EULAR’s strategy development was designed as an embracing process, involving as many constituencies as possible.

Vision 2020 owes much to its predecessor, the first EULAR strategy running from 2007 to 2012. “Mobilizing the Planet”, as the strategy was labelled, was initiated and guided by the then President Ferdinand C. Breedveld. In retrospect, there is little doubt that much of what EULAR has achieved or launched in recent years has seen its origin in the strategy 2012. This was expressed by a survey we made towards the end of 2011 gathering responses from a large and diverse group of people: the “creators” of strategy 2012, 47 national member societies including PARE, and some 500 rheumatologists attending the EULAR Congress 2011. The survey also generated lots of ideas and opinions suggesting where EULAR should be heading in the coming years. And this feedback served as fertile soil where the new strategy was grown.
The new EULAR strategy offers many exciting opportunities for PARE to engage effectively in making a difference to the lives of people with RMDs in Europe in the coming years. Activities such as education, advocacy and national relations for example are all prominent in the strategy and these are, of course, embedded in many PARE activities.

The PARE Board is very grateful for the input of the Standing Committee of PARE in the consultation process which helped to shape the strategy. This will help to ensure support for our activities from EULAR as a whole going forward, and provide a strong foundation for existing and future projects.

There is still time to submit your abstract for the EULAR Congress 2013 in Madrid. The deadline is 31 January. We would like to encourage all national organisations, local groups and individual researchers to tell us about your work at national level as the EULAR Congress is the platform to share your experiences and to inspire other delegates. For the first time all PARE sessions will feature at least one abstract. Tell us about a successful campaign, collaboration, research or other project that has made a real difference for people with rheumatic and musculoskeletal diseases (RMDs) in your country!

The 2013 programme is expected to include sessions on 'Patient Rights', 'Political Campaigning', 'Healthy Ageing', 'Family Planning', 'Re-branding RMDs', 'Social Media', and there will be one abstract session showcasing a variety of PARE activities. All you have to do is go to the EULAR Congress web-page, via the Congress icon on the EULAR homepage: www.eular.org Then click on 'Abstract submission' on the right-hand menu bar and you will find everything you need to know about submitting an abstract e.g. how the abstract should be structured, its length, the categories (PARE is one category), creation of a user account, etc. Please read all the information carefully before starting the submission process. If you have any difficulties or questions please contact the EULAR secretariat at: Birte.Gluesing@eular.org

Once you have successfully submitted your abstract do not forget to apply for a travel bursary. The form and related information is under 'Travel bursaries' on the Congress web-page.

Good luck and we look forward to receiving your abstracts!
The 2012 15th Autumn Conference for PARE was held in Zurich, Switzerland, the home of the EULAR Secretariat, and was hosted by the Swiss League Against Rheumatism. It was attended by 145 delegates from 35 countries. The 2012 programme focused on EULAR’s core activities, on physical activity and rheumatic and musculoskeletal diseases (RMDs), and on fundraising.

The Friday programme saw the introduction of EULAR’s new strategy “Vision 2020” by Prof. Nemanja Damjanov, General Secretary of EULAR, and workshops featuring EUMUSC.NET, patients as research partners, World Arthritis Day, EULAR’s EU activities in Brussels and an introduction by the Swiss League Against Rheumatism into assistive technologies.

The EULAR Call to Action on Physical Activity for people with RMDs was introduced on Saturday by Kare Birger Hagen, EULAR Vice President for Health Professionals in Rheumatology. The document generated lively discussion and suggestions about implementation in the subsequent workshops. Marianne Krijgsman (project manager at Reumapatienenbond) and Hans Bloo (sports physiotherapist and human movement scientist) presented ‘Reumanetwerk’, a highly successful programme developed in the Netherlands to provide physical activities for people with RMDs and a stimulating example of what can be done with good collaboration. Neil Betteridge, EULAR Vice President representing PARE, and Sören Haar, from the EULAR Brussels office, demonstrated via role play how to carry out effective lobbying, and encouraged delegates to incorporate some of the strategies into their own campaign work.

On Sunday morning, delegates were inspired by Jenny Christensson’s personal story and by Nichola Mullen’s (Head of Fundraising and Development, Arthritis Ireland) presentation and the very practical tips that she shared on how to develop an imaginative and successful fundraising strategy.

Looking back: 15th EULAR Autumn Conference for PARE, ZURICH 2 - 4 November 2012
by EULAR Secretariat

What you said:

“For me it was a great experience. I learned a lot from the other representatives and I hope I can adapt their experience in our country as soon as possible.”

“All the subjects discussed were useful and interesting. It is difficult to say which were the highlights as our organisation needs so much information about everything ...... but the fundraising sessions were an asset for us and we are sure to adopt some of the tips.”

“High quality presentations, interesting topics, overall the conference has inspired and motivated the delegates to take action at national level.”

Comments by participants at the 2012 Autumn Conference for PARE in Zurich

Poster Competition

Delegates again had the opportunity to display a poster illustrating the activities of their organisations, and to introduce them to their colleagues during the “Poster Reception” on Saturday. Greece won the prize for ‘the most beautiful poster in 2012’, the Deutsche Rheuma-Liga was awarded the prize for ‘the most successful campaign’ category and the Former Yugoslav Republic of Macedonia was voted to have had ‘the most innovative campaign’.

Participants at the 15th EULAR Autumn Conference for PARE in Zurich

Greece: (left to right) Christina Psoma, Nadia Tsiliakou and Spyridoula Trivizaki in front of their winning poster
Thank you for making 2012 such a successful year for World Arthritis Day (WAD)!

Our campaign “Waving for World Arthritis Day”, launched under our theme “Move to Improve”, truly united people across the world to raise awareness of the importance of physical activity for people with rheumatic and musculoskeletal diseases (RMDs). More than 63,000 people from more than 80 countries participated!

Instrumental in reaching this phenomenal number of waves was a group of fantastic people - our WAD Ambassadors - committed and enthusiastic volunteers from all around the world who acted as key drivers of the campaign. They worked around the clock, every day of the week, using print and social media to encourage people to wave. A huge thank you to them for their great contribution in making the Waving for World Arthritis Day campaign such an enormous success!

You can still download the supersize mosaic image, made up of thousands of your waving photos. This and all other related materials such as press releases and templates for your own use* can be found at: www.worldarthritisday.org/resources/organisations

* World Arthritis Day items cannot be used with any commercial product promotion and are only intended to raise awareness about RMDs.

The EULAR visit was a landmark for INBAR. We are most grateful for the expertise that the delegates shared with us. It will give us the opportunity to enhance our activities for the benefit of all people with RMDs in Israel.

Thank you

Ram Blass, Chair INBAR
Miki Kapner, Treasurer
Ofra Balaban, Board Member

In October 2012 we were excited to host a EULAR delegation visit to INBAR. The EULAR delegates and INBAR representatives had an important meeting with the Director General of the Ministry of Health of Israel Prof Ronni Gamzu. We outlined INBAR’s efforts to increase rehabilitation treatments for patients with rheumatic and musculoskeletal diseases (RMDs) in Israel and stressed that additional treatments could prevent deterioration of the patient’s condition. Being able to present a European perspective this time helped to focus attention on our cause and we hope for positive developments. We were delighted that the Ministry acknowledged that the Anti-CCP (anti-cyclic citrullinated peptide antibody) examination should in future be included in the Israeli basket of health services.

At the Chaim Sheba Medical Center, we saw innovative assistive equipment developed by MILBAT (the Israel Center for Technology and Accessibility). We were honoured to be guests at the first Israel/Italy Meeting on Advances in Autoimmunity and Rheumatology in Haifa, co-hosted by Prof. Yehuda Shoenfeld of the Zabludowicz Center for Autoimmune Diseases. The delegates also visited the Dead Sea to experience its unique natural therapeutic properties that benefit conditions of the skin, joints etc.

The EULAR visit was a landmark for INBAR. We are most grateful for the expertise that the delegates shared with us. It will give us the opportunity to enhance our activities for the benefit of all people with RMDs in Israel.

Thank you

Ram Blass, Chair INBAR
Miki Kapner, Treasurer
Ofra Balaban, Board Member

David Magnusson, Chair-elect of the EULAR Standing Committee of PARE

“INBAR arranged an impressive programme for EULAR. It was a great opportunity to meet key Israeli stakeholders and I was delighted at the positive results. EULAR looks forward to continuing to support INBAR and its aims, and I extend my sincere thanks to all involved and wish you many further successes.”

Emmi Myöhänen, WAD Ambassador

“Being a WAD Ambassador was very rewarding. The number of waves and likes increased right in front of my eyes and it gave me motivation to continue. The whole community of ambassadors worked together, which made it so special and successful. I would definitely do it again!”

WORLD ARTHRITIS DAY 2013
“Living Better - Ageing Well”
The World Arthritis Day campaign in 2013 will feature different elements of living with RMDs at all stages of life. Positive case studies and tips on how to self-manage and maintain a positive attitude and lifestyle will be available from: www.worldarthritisday.org
On 16 October, EULAR organised two important events in Brussels:

- The Conference “Preventing chronic diseases for a healthier Europe: The case for rheumatic and musculoskeletal diseases”, and
- The Workshop “Tackling the burden of rheumatic and musculoskeletal diseases through research: Towards a European roadmap for research and innovation in musculoskeletal health for the next decade”

These events were co-organised with EFORT, the European Federation of National Associations of Orthopaedics and Traumatology, with whom EULAR has recently formed the European Musculoskeletal Health Alliance (see below).

The European Musculoskeletal Health Days also included the Fit for Work Summit organised by the Fit for Work Europe Coalition.

European Musculoskeletal Health Alliance (EMSA)

Last July, during the EULAR Congress in Berlin, EULAR and EFORT launched the European Musculoskeletal Health Alliance (EMSA). Its main objectives will be:

- Increased public awareness of the burden of RMDs;
- More political support for innovative solutions to address musculoskeletal health at European and national levels;
- Closer inter-professional co-operation to improve musculoskeletal health

The Conference and the Workshop, which were organised in the context of the European Musculoskeletal Health Days, were attended by about 130 and 60 participants respectively.

**Conference**

The aim of the Conference was to discuss the implementation of chronic disease prevention strategies at both the EU and national levels, paying special attention to the prevention of rheumatic and musculoskeletal diseases (RMDs).

To this end, high-level representatives of the European Commission, the European Parliament, the Cyprus EU Presidency and Member States, together with representatives of the RMD community, presented on different aspects of chronic disease prevention.

Topics discussed included: the individual, social and economic burden of these conditions; the EU and national efforts in preventing chronic conditions (particularly RMDs); the need to focus not only on primary but also on secondary and tertiary prevention; the role of patients in the design and implementation of prevention strategies; and the critical role of research and innovation in RMDs in the prevention of these conditions.

During the Conference, EULAR President Prof. Maxime Dougados launched the EULAR Call to Action on Physical Activities for People with Rheumatic and Musculoskeletal Diseases (see more details on page 6).

**Workshop**

The aim of the event was to prepare the ground for the development of a roadmap for research and innovation (R+I) in RMDs. Such a roadmap is expected to help address some of the main challenges affecting R+I in these diseases, such as: the insufficient consensus regarding research priorities; the lack of co-ordination of national research efforts; the insufficient collaboration between scientists, health professionals and the industry; and the lack of sufficient investment in research and innovation in RMDs.

Prominent scientists and researchers in the field, health professionals, representatives of patients, Members of the European Parliament, representatives of Member States, and representatives of the European Commission discussed the different aspects that should be taken into account in the development of the roadmap.

As one of the results of the event, the preliminary action plan for the development of the roadmap was presented.

The Conference and the Workshop, which were organised in the context of the European Musculoskeletal Health Days, were attended by about 130 and 60 participants respectively.
EULAR Call to Action on Physical Activity for People with Rheumatic and Musculoskeletal Diseases by EULAR Secretariat

People with rheumatic and musculoskeletal diseases (RMDs) call upon policymakers to:
- Provide timely access to physiotherapists and other qualified instructors for improving maintenance and rehabilitation treatments and programmes
- Remove financial hurdles to accessing these services
- Improve education regarding the necessity of physical activity and exercise for people with RMDs

At the conference
“Preventing chronic diseases for a healthier Europe: The case for rheumatic and musculoskeletal diseases” organised by the European Musculoskeletal Health Alliance on 16 October in Brussels (see page 5), EULAR President Prof. Maxime Dougados (pictured right) launched the “EULAR Call to Action on Physical Activity for people with RMDs”. The document addresses policy makers and calls for their support to remove the barriers preventing people with RMDs becoming more active. It is designed for use as a tool to engage key stakeholders and decision makers at national and European levels when discussing this important topic.

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

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 BJD: www.boneandjointdecade.org