Dear Colleagues

I am delighted to share this 4th edition of e-Breakthrough with you. It is my first editorial as Chair of the Standing Committee of PARE and therefore a special issue for me.

It is also special because it is one year ago that we started to use this new tool to update you more regularly about what is happening within EULAR and the PARE community. So it is time for some evaluation! Please let us have your opinion and views and help us to make e-Breakthrough as interesting and valuable as possible. You can fill in our short questionnaire if you follow the link: www.surveymonkey.com/s/e-breakthrough2

Thank you so much in advance!

This issue will give you some insights into the latest PARE Board meeting that was held in Dublin in July. Read more about the activities of Arthritis Ireland and country news from France and Romania. There are updates on World Arthritis Day, the Autumn Conference, our EU activities in Brussels and information about the Euro Team research project. So it is an issue packed full of inspiration and interesting ideas. I hope that you enjoy it.

The PARE Board and I look forward to an exciting Autumn and wish you a successful and happy World Arthritis Day.

Your views are important by David Magnusson,
Chairperson of the EULAR Standing Committee of PARE

World Arthritis Day 2013 Competition

The Vision 2043 competition is part of the World Arthritis Day (WAD) 2013 – 2014 ‘Living Better, Aging Well’ campaign and offers everyone over 18 years of age the opportunity to create an original artwork that shows their ideas and innovations for making a better world for people with rheumatic and musculoskeletal diseases (RMDs) now and over the next 30 years. With your ideas and inspirations we can change the future.

Details of the competition can be found on the WAD website: www.worldarthritisday.org - check it out and be creative! The competition runs until April 2014. The overall winner will be the person with the most online votes and runners up will be selected by a judging panel.

Other new information and resources on the WAD website include ‘Get Active’, which offers a guide to physical activity and exercise with expert advice and factsheets detailing seven types of activity suitable for people with rheumatic and musculoskeletal diseases.

The first of our ‘Living Better, Ageing Well’ features was launched in June with five aspects of Healthy Living – Physical Activity, Self Management and Motivation, Emotional Wellbeing (October), Healthy Eating (December) and Lifestyle Choices (January 2014).

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 31 December 2013.

Dates for your diary:
• 1 October – 31 January 2014: Abstract submission for EULAR Congress 2014 in Paris
• 12 October: World Arthritis Day
• 16 October: World Spine Day
• 20 October: World Osteoporosis Day
• 15-17 November: Autumn Conference for PARE, Reykjavik, Iceland
• 31 December: Deadline for Knowledge Transfer Programme applications
• 31 December: Deadline for Stene Prize 2014 essays to national EULAR member organisations of PARE

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The first of our ‘Living Better, Ageing Well’ features was launched in June with five aspects of Healthy Living – Physical Activity, Self Management and Motivation, Emotional Wellbeing (October), Healthy Eating (December) and Lifestyle Choices (January 2014).
What an excellent opportunity! The start of the new EULAR Strategy for 2013-2017 “Vision 2020” gave fresh impetus to the meeting of the PARE Board that was held on 5-6 July in Dublin. The Board mainly focused on reviewing all the projects and activities of PARE and the level of human resources, paid and volunteers, that will be needed to continue to deliver exciting and relevant programmes. We considered how our resources can be used and coordinated effectively for the best results, and we identified where gaps might occur in the future.

All the projects and activities of PARE were evaluated to ensure that they serve the purpose and targets of the new strategic objectives of “Vision 2020”, in particular the three strategic objectives that have been prioritised by PARE, namely: Education, Advocacy and National Relations. Also, through our discussions, lots of suggestions were tabled for updating and improving the projects. For example, to hold the EULAR Autumn Conference of PARE in the Spring rather than in the busy end-of-year period. All the suggestions will be openly communicated to the leaders and task force members requesting that the objectives for each project be revised and updated, made measurable, and promote the wider objectives of EULAR’s strategic plan.

We were delighted to have with us the former Vice President of EULAR representing PARE, Neil Betteridge, who will continue to contribute in his new role as Liaison Officer of EULAR EU Affairs. We were also happy to have with us, Anna Ageberg, a former member of the Board. The perspectives of these members were especially important and we would like to give them warm thanks for their participation. It was with great pleasure that we welcomed a new member of the Board, Dieter Wiek, to his first meeting and we would like to wish him a very successful term of office.

This Board meeting was especially timely and important, and the discussions were very productive. All the members worked extremely hard over two days and their contributions to the final result will define PARE activities going forward. We have many challenges ahead of us, at national level as well as at European level, but I am confident that we can face them together and so succeed in all our strategic goals.

Introducing new PARE Board member, Dieter Wiek

“Being diagnosed with a rheumatic illness as a teenager was a great shock to me. My sporting ambitions vanished. Without sports and with cortisone treatment, my outward appearance changed and so did my entire life. However, now aged 65 and looking back I must say I was very lucky. Despite my illness, I was able to finish my education. I also worked as a grammar school teacher for almost 40 years, which I did with great enthusiasm, until I retired last year.

The realisation that exercise is important, and that only an informed patient is able to self-manage his/her rheumatic and musculoskeletal disease (RMD), made me join Deutsche Rheuma-Liga. I volunteered locally and then extended this to state and national level.

Now that I am a member of the PARE Board, I hope that I can contribute a little to EULAR's successful work. Across Europe, patients should be diagnosed as early as possible and should experience comparable standards of treatment and care. We need research, so that one day rheumatic diseases will no longer be a life-long burden and, perhaps, our work will become superfluous. User-led organisations in Europe have to unite in order to lobby and co-operate in projects and activities enabling patients with RMDs to receive the best possible treatment and care.”
From 15-17 November 2013, Reykjavik will host more than 120 European delegates at this year’s 16th Autumn Conference for PARE. An exciting programme around the overarching topic of “Healthy Ageing – Living Better, Ageing Well”, and a warm welcome from the hosts Gigtarfélag, will make up for the long journey to reach the most westerly European capital.

The organising team is delighted that EULAR President Prof. Maurizio Cutolo will join the event for the first time and will give the Opening Speech on behalf of EULAR. There will be workshops on “Politics and Healthy Ageing in Europe”, “Healthy life-style”, “Working with volunteers”, “Self-management”, “Supporting older people with rheumatic and musculoskeletal diseases (RMDs)”, “Improving healthy ageing” and “Young people and RMDs”, plus lots more. A poster exhibition will give space to those organisations which would like to display their activities visually – there are prizes waiting for the winners!

“The Icelandic delegates are very excited to have the opportunity to exchange views and experiences with their European colleagues. As an organisation we aim to raise awareness for RMDs with our newly elected government and have invited some leading representatives to the opening of the event” says Dóra Ingvadóttir, President of Gigtarfélag.

Can art be an advocate for a better future?
by Codruta Zabalan, Romanian League Against Rheumatism

“I found I could say things with colour and shapes that I couldn’t say any other way - things I had no words for.” Painter Georgia O’Keefe’s statement inspired Romanian League Against Rheumatism’s (LRR) members and their partners to organise an experiential series of art workshops encouraging rheumatoid arthritis patients and their rheumatologists to work in partnership, sharing views and articulating personal perspectives.

The InspirART event took place in 2012 in two major cities in Romania. Rheumatologists and patients worked together to express their mutual feelings through art, with the help of renowned Romanian artists. Patients and rheumatologists learned that good communication requires:

- an acknowledgement that the rheumatologist is an expert in treating the disease, and that the patient is an expert in living and coping with the disease;
- a willingness to start an open dialogue in order to create a partnership in treating the disease.

Patients, relatives, physicians, national authorities, celebrities and media representatives were invited to learn about the project. Interviews were carried in the national and local press, and there was significant on-line and TV coverage. Twelve outstanding paintings created by the Romanian artists following the project have been displayed in several national and international exhibitions.

The other outcomes of the project: the Rheumatoid Arthritis (RA) Charter, the weekly symptom diary and the RA tips brochure can be downloaded from the dedicated websites: www.articulatera.com (English language) and www.inspirart.ro (Romanian language).

This project was about identifying appropriate ways of addressing RA, both medically and emotionally, to improve the quality of life for patients, and the message that it sends is:

“Art is the international language of emotions of any kind. These emotions make us human beings and people suffering from rheumatoid arthritis need a ‘human echo’ at national and international level. Along with the Charter for rheumatoid arthritis this will represent our trump card in relationships with our health professionals, with society and with governmental bodies.”

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The PARE Board Meeting in Ireland offered a wonderful opportunity for the Board to visit Arthritis Ireland (AI), the EULAR member organisation representing people with rheumatic and musculoskeletal diseases (RMDs) in Ireland, and to hear about its change agenda and innovative projects and programmes. John O’Flynn, Chairman of AI and John Church, CEO of AI together with several team members welcomed the PARE Board very warmly to their headquarters in Dublin.

AI was founded 32 years ago, set up by health professionals with a medical focus supporting mainly the research agenda. John Church, with a background in marketing in the commercial sector, joined AI in 2005. Over the next few years, the organisation introduced a new logo and underwent a full re-focusing of its strategies and activities. The work changed from being purely medical to being oriented to patient education and support, finding a cure for RMDs, and advocacy for improved services. New branding and a dedicated team of 11 full time staff have helped the organisation to change and to become today one of the most well-known and successful charities in Ireland.

Now, in 2013, John O’Flynn is the first elected non-medical Chairman of AI. This is another exciting development for the organisation. AI offers a great variety of printed and on-line information material, advice on exercise, self-management courses and seminars for those with RMDs, and many other services (e.g. telephone and e-mail helplines) to its members and the general public. There is also a dedicated programme of events and information for children with arthritis and their parents (see Laura Hickey's article on AI's juvenile arthritis programme below). Despite all this hard work and exciting progress, there is still a lot to do. The AI team is completely dedicated and committed to making a real difference to the lives of people with RMDs in Ireland. “The main problem for people with RMDs in Ireland today is to get diagnosed as there is a serious lack of rheumatologists. Therefore, one of AI’s projects is to work on getting GPs trained to be more aware of the early signs of RMDs” says John Church.

The Chair of the Standing Committee and the PARE Board would like to thank the whole AI team for their hospitality and for sharing their impressive success story.

For more information about AI please visit www.arthritisireland.ie or the AI Facebook page.

**Children with arthritis**

by Laura Hickey, Arthritis Ireland

Children with arthritis are some of the most amazing young people I have met. Children who live every day in excruciating pain and, despite this, continue to forge ahead and try their best at everything they do. Unfortunately, the public generally have a very low level of awareness about juvenile arthritis (JA) and that makes it a very lonely place to be for a child living with the condition. And that is why we are here in Arthritis Ireland.

We work closely with hundreds of families to provide a diverse range of activities, events and support services. From working with children with JA, their siblings and their parents, we know that JA is a condition that affects the whole family and our support services are tailored to suit all. They range from vital resources like the JA information service, the ‘Living Well with JA’ self management programme and the JA Helpline, to exciting events, such as the JA Family Day and the JA Road Trip for teenagers. The JA programme educates, empowers and facilitates peer support so that families living with JA do not feel alone. To find out more please visit www.juvenilearthritis.ie
In France, between 9 and 10 million people suffer from osteoarthritis (OA). This disease is the second cause of disability in France and can be responsible for a significant loss of quality of life.

In 2002, a socio-economic study showed that, in the ten years prior to the study, the number of people suffering from OA increased by 54%, triggering a 156% increase in medical costs directly linked to OA. A more recent study established the cost of OA treatment at around 3 billion Euros per year. Paradoxically, the two public health objectives connected to OA – ‘reduction of functional limitations and incapacities’ and ‘improvement in the quality of life for people with arthritis’ – have been left without action or evaluation. Overall, as a public health and medical cost challenge, OA has been largely ignored in France.

To create a sense of urgency, AFLAR, the only patient organization in France dealing with this issue, decided to create “The National Alliance Against Osteoarthritis”. This Alliance, which includes patient organisations, medical associations, and healthcare professional boards, met in November 2011. The following objectives were agreed:

- To bring together all the professionals involved in OA care and to mobilise action on these neglected public health issues
- To stimulate collective thinking around the challenges of OA care
- To raise awareness and visibility of OA
- To disseminate prevention messages, especially regarding the role of physical activity
- To identify and promote the needs of people affected by OA
- To increase the involvement of local and national governing bodies.

Through the expertise and innovation of its members, the National Alliance Against Osteoarthritis aims to contribute significantly to the mobilization against OA in France by: disseminating educational messages; an on-line national survey; a web portal to gather all AFLAR OA-related activities; and a regional prevention project.

Preventing rheumatoid arthritis (RA)! Would you believe it’s possible? And when? 30 years from now, 20 years from now…….?

I daresay this decade we might see this dream come true or at least we might move closer to the concept of “prevention for RA”.

How do I know that? Because a world-class research team of 13 academic partners from 6 European countries (Austria, Germany, the Netherlands, Sweden, Switzerland and the United Kingdom), in collaboration with three companies with an interest in developing predictive kits, together with patient research partners, are working on it within a European Union funded project called “EuroTEAM”. The project started in November 2012 and its goal is to predict the onset of RA in people who do not yet have the disease. The ultimate goal is to develop treatments to prevent people from getting RA in the first place.

I was one of the patients invited to participate as a Patient Research Partner and I had a very rich experience attending the kick-off meeting earlier this year, a half day of which was exclusively patient-centred. The project is complex and technical, but the lay-language material sent in advance (many thanks here to Prof. Karim Raza, Deputy Coordinator of Euro-TEAM and academic lead for patient representation) was a very useful tool, helping patients to feel totally included and prepared. Not only did all the researchers make us very welcome in the team, but they were very interested in what we had to say, our input being regarded as high value.

Being a project that fits alongside other initiatives, like MASTERSWITCH and BeTheCure (see EULAR e-Breakthrough Issue 3 – April 2013), this 4-year research programme represents the very best in international efforts to try to reduce the impact of RA on individuals and society. It is also a fine example of excellence in terms of listening to the patient’s voice at all stages in the development of a research project. For more information please visit: www.team-arthritis.eu
A busy Autumn for EULAR in Brussels

by EULAR EU Office Brussels

The eumusc.net project (www.eumusc.net), one of the most important EU funded initiatives in the field of public health in recent years, has come to an end in 2013.

In order to present the results and recommendations of the project and discuss how the EU institutions, Member States and stakeholders can better contribute to reduce the enormous burden of rheumatic and musculoskeletal diseases (RMDs), EULAR is organising the conference “Chronic diseases and health care delivery 2020: The challenge of Rheumatic and Musculoskeletal Diseases. Findings, lessons and perspectives from the eumusc.net project”.

The event will take place in Brussels on 17 October 2013 and will be hosted by Paul Rübig (MEP from Austria). Health care and patient representatives, EU and national decision makers, and other key stakeholders from all across Europe will discuss and propose specific recommendations on how to implement the results of the eumusc.net project in EU countries.

The previous day, 16 October, the 12th meeting of the European Parliament Interest Group on RMDs (whose secretariat is run by EULAR) will focus on the impact of the upcoming new Data Protection Regulation on health research.

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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