

Priorities of New EULAR President

More Recognition of the Burden of Musculoskeletal Diseases

Maxime Dougados is Chief of the Department of Rheumatology at the Cochin Hospital in Paris as well as a teacher of rheumatology at the René Descartes University, Medicine Faculty PARIS V. He has been President Elect of EULAR since 2009, EULAR-ACR liaison person since 2007 and Vice President of ASAS (ASsessment of Ankylosing Spondylitis) since 2003. Maxime will come into office as new President of EULAR at the EULAR London Congress.

EULAR is an old institution, founded many years ago. How would you say EULAR has grown since and how do you see its purpose today?

Concerning your comment related to the “old age” of EULAR, I would answer yes and no. Yes, you are right, EULAR has existed for more than 50 years and therefore can be considered as an “old” institution. No, because although EULAR has existed for this long, we have to recognise that the current structure and consequently dynamism of EULAR has dramatically improved during the past decade and, in particular, since the first scientific annual congress meeting in Nice in 2000.

What plans do you have for your term of office?

My priority is to try to maintain the excellent quality of the major EULAR initiatives in the fields of research, education and lobbying. Moreover, and at least as important, is to maintain the friendly atmosphere that exists within and between the different EULAR Steering, Standing and Scientific Committees. In addition, and if possible, I will try to improve the communication between EULAR committees and each national EULAR member society. In terms of educational tools, we are developing a EULAR slide library, in close collaboration with Hans Bijlsma, which will permit anyone to



Incoming EULAR President Maxime Dougados

download PowerPoint slides illustrating the diverse facets of the main musculoskeletal disorders. Finally, I would like also to try to improve the role of health professionals, and in particular nurses, in the management (education, monitoring) of chronic musculoskeletal disorders.

What is the major difference in the role of patients nowadays compared to 10 years ago?

It is amazing to see the recent importance of patients in the different ongoing EULAR initiatives. This has been facilitated by the fact that EULAR is not only a scientific society for rheumatologists but also an umbrella institution including doctors, patients

and health professionals. Currently, patients are invited to participate in studies/initiatives proposed by doctors and are also a part of the team in charge of such studies/initiatives from their elaboration to their implementation.

How do you plan to further foster the relationship between the three pillars within EULAR?

Again, the strength of EULAR in comparison to other scientific societies in rheumatology is based on the fact that doctors, health professionals and patients are full members of the EULAR Executive Committee. It is my opinion that transparency and application of simple procedures will further foster the relationship between these three pillars. For example, any planned initiative for any standing committee should be discussed **from the beginning** by these three groups. At the very least, any initiative should consider inviting a representative from these three pillars.

How do you envisage to follow up on the recent major achievements of EULAR in the political arena in Brussels?

One of the main objectives of EULAR is to improve the recognition of the burden of musculoskeletal disorders by the different national health care systems and, in particular, by the politicians working at European community level. In doing so, we aim to improve the daily life of rheumatic patients (e.g. support at work and access to public places etc) and also convince politicians to financially support basic, translational and clinical research in the field of rheumatology. For this purpose, we plan to continue, or even reinforce, all the initiatives which have started in this area. Personally, I am convinced that the expertise that we have now acquired in this domain will help us to reach our goals in the near future. ■

DEAR COLLEAGUES

by Marios Kouloumas



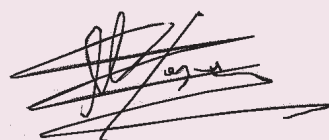
This issue of Breakthrough is a special one for me as this is my last editorial as Chair of the EULAR Standing Committee of PARE.

I am happy to hand over to Jacqueline Mäder from Switzerland, who will take my place after the EULAR congress in London. As Past Chair, I will continue working for PARE and providing Jacqueline with unlimited support, and would like to wish her every success.

One of the key achievements during my term of office was that we enhanced our partnership with clinicians and health professionals in rheumatology under the umbrella of EULAR. I am also delighted that EULAR succeeded in its work at an EU level. For the first time, an Interest Group on Rheumatic and Musculoskeletal Diseases has been established in the European

Parliament and is achieving remarkable results. Another great success was the Belgian EU Presidency Conference on Rheumatic and Musculoskeletal Diseases.

Finally, I would like to thank my colleagues, the members of the PARE board, the Standing Committee and the EULAR Secretariat for the great support they have given me during my term of office. It was a great pleasure for me to work with you all.



Marios Kouloumas is the Chair of the Standing Committee of PARE

The EULAR Standing Committee on Investigative Rheumatology (ESCIR)

EULAR Standing Committees are set up to manage and perform the various activities of EULAR on behalf of the Executive Committee. Currently, eight standing committees cover the major activity areas of EULAR. One of these, ESCIR, seeks to enhance knowl-

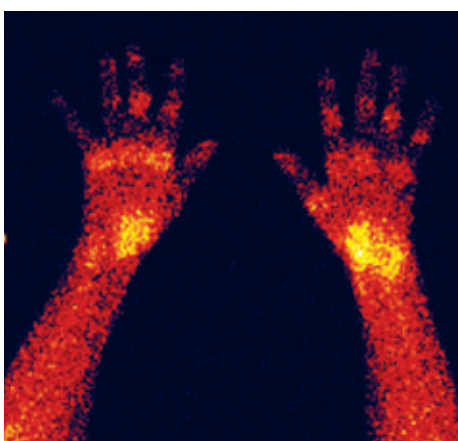


Professor Paul-Peter Tak is the Chairperson on Investigative Rheumatology

edge about the genetic, molecular and cellular basis of rheumatic diseases. Its goal is to develop better prevention, early detection and diagnosis as well as treatment for rheumatic diseases. ESCIR was established in 1991. The committee is led by Paul-Peter Tak (Chairman) and Steffen Gay (Past Chairman).

ESCIR and its study groups have built an international network of excellence by fostering European co-operation and scientific collaborations. In developing a database of the most active research centres in Europe information is provided about current research activities, training and funding possibilities. ESCIR is also informally involved in the organisation of the European Workshop for Rheumatology Research (EWRR), which was held in Amsterdam in March 2011 – www.ewrr.org

The Committee currently has five study groups that are focused on neuro-immunology, laboratory investigation in



Labelled monocytes in inflamed joints

rheumatology, gene and cell therapy, animal models for rheumatic diseases and synovial tissue analysis. In the near future, studies aimed at understanding the earliest phases of rheumatoid arthritis will be increasingly important.

Moreover, in 2007, a 4-year orphan disease programme was launched focusing on systemic sclerosis. This programme has two focus areas: pathophysiology and therapy. After peer review, projects were selected for funding by an independent grant advisory council, and research in this field is ongoing.

Finally, EULAR has been an active participant in Autocure, an EU funded research project. The objective of this successful project was to transform knowledge obtained from molecular research into a cure in an increasing number of patients suffering from inflammatory rheumatic diseases. ■

IN MEMORY OF MARJAN HUDOMALJ

It was with great sadness that the Standing Committee of PARE received the news that our longstanding friend and colleague, Mr Marjan Hudomalj, from Slovenia, had passed away in early December 2010 due to his severe illness. Marjan became a member of the Rheuma Association of Slovenia in 1983 and later on was its President for many years. He was a founding member of the PARE Manifesto and a member of the Standing Committee of PARE. It is a great loss for the PARE community as Marjan was a committed and active member and he will be greatly missed. He was a true fighter on behalf of all people with rheumatic and musculoskeletal diseases and he will always be remembered.



New PARE Standing Committee Chair takes over

Jacqueline Mäder was diagnosed with osteoarthritis in both knees at the age of 17. In 1996 she started a patient group for young people with osteoarthritis and thus got in contact with the Swiss League Against Rheumatism. From 1997 on she was elected as their international contact person. She was a member of the PARE board from 2005 until 2009. After the EULAR Congress in London, Jacqueline will succeed Marios Kouloumas as Chairperson of the EULAR Standing Committee of PARE.

What are your aims for your term of office and which subjects will you be focusing on?

The EULAR Standing Committee of PARE has an annual theme, which is exercise and rheumatic and musculoskeletal diseases (RMDs), right now. Besides this, I see a strong need to support the the network of young people with RMDs. They face particular problems and obstacles related to their age. EULAR has been doing a lot around the focus of work which resulted in the EULAR Charter for Work and related activities. For me, it will be very important to focus on the specific barriers for women in the working environment. Housekeeping and the care of children are still not really seen as work and women do not get enough support in this area.

Together with the EULAR Vice President representing PARE, Neil Betteridge, I will also focus on maintaining high standards for our key events, such as the EULAR



The new PARE Standing Committee Chair, Jacqueline Mäder, from Switzerland

Congress programme for PARE, the Autumn Conference and activities around World Arthritis Day. Even more so than in the past we aim to involve all EULAR pillars in the planning processes, which will benefit our activities and also support the concept of different stakeholders working together more closely within EULAR.

What can EULAR member organisations do to help PARE reach these aims?

A strong co-operation between all member organisations of EULAR is extremely important. We need to have the same aims to speak with a strong voice in Europe. The involvement of EULAR member organisations in our activities is essential as EULAR



Jacqueline in the front row at the 2008 PARE board meeting in Zurich

needs the input of the national leagues to reach its goals.

What are the major challenges for EULAR member organisations these days? How could EULAR's work help on a national level to overcome those?

Nowadays, we are all influenced by the economic crisis. Financial capacity has been reduced, which has put us in very hard situations on a national level. EULAR is not in a position to fund national leagues, but there are several EULAR projects and events for our members – the EULAR Congress, the Autumn Conference and the Educational Visit Programme – where people can get new ideas and tools for their work and exchange best practice. ■

Romania represented on the PARE Board

Codruta Zalaban, a 33-year-old economist from Bucharest, Romania, started her term of office with the PARE board in June 2010. Codruta has had arthritis since 1996 and started working with the Romanian League Against Rheumatism in 2006.

Codruta participated in her first EULAR meeting in 2008, where she came to understand the importance of the work of PARE and of working together. She hopes to represent people with rheumatic and musculoskeletal diseases adequately through her dedication to the work of PARE, contributing to new projects and lobbying. Codruta said that, among other things: 'Happiness for me is when you discover how to help people like yourself, as a member of your national league or by participating in PARE initiatives.' ■



Lessons for Innovative Policy-making in the European Union – EU Presidency Conference on Rheumatic and Musculoskeletal Diseases

By the EULAR EU Office, Brussels

The year 2010 was very fruitful for the EULAR community in terms of its EU Affairs activities. On 19 October 2010, the Belgian EU Presidency, in collaboration with EULAR, held the Conference on *Rheumatic and Musculoskeletal Diseases: Lessons for Innovative Policy-making in the European Union*.

The event brought together around 150 representatives of patient organisations, health professional associations, national and EU policy makers, scientific organisations and other stakeholders. As a result of this event, participants adopted the Brussels Declaration, a set of recommendations for both EU institutions and Member States for improving the situation of people with rheumatic and musculoskeletal diseases (RMDs) in Europe (see box).

The conference served as a pre-event of the Ministerial Conference on *Innovative Approaches for Chronic Illnesses in Public Health and Healthcare Systems*. It was the first time that rheumatic and musculoskeletal diseases have been on the agenda of an EU Presidency, and was therefore the first occasion of a close co-operation between EULAR and an EU Presidency. Mr Olivier Belle, a member of the cabinet of



(top, left) Paul Emery, EULAR President, moderating the panel discussion of expert speakers and (top, right) Nele Caeyers, ReumaNet, talking about living with a RMD

the Belgian Minister of Social Affairs and Public Health, said that: ‘It was a question of common sense to try to push this collaboration forward’ since the burden of these disorders on individuals’ lives and societies was now being more and more acknowledged.

The conference covered political, medical and social aspects of the prevention and management of RMDs. In the morning,

delegates had the opportunity to listen to a number of presentations given by well-known experts and patient representatives. In the afternoon, delegates discussed these issues in detail and further developed the recommendations that were finally adopted.

The overall initiative was very successful in getting political commitment from key decision makers at the EU level. High representatives of the EU Presidency, the European Commission and WHO were the main speakers at the opening and closing sessions, giving considerable political support to actions aiming to improve the health and social conditions of people with RMDs. Moreover, EULAR was invited to present the conclusions and recommendations to ministers and high-ranking Health Ministry officials who attended the Ministerial Conference the day after. Even more importantly, **these recommendations were taken into account in the EU Council Conclusions adopted in December 2010.**

In summary, the Belgian EU Presidency Conference was a great success for our community. As pointed out by EULAR President Professor Paul Emery: ‘This conference was very important, particularly for patients. They realised that their conditions have been taken seriously at the highest level in Europe.’

A detailed report of the conference can be downloaded from the EULAR website: www.eular.org ■

RECOMMENDATIONS INCLUDED IN THE BRUSSELS DECLARATION

1. The European Union and its Member States should recognise the socioeconomic importance of rheumatic and musculoskeletal diseases of all ages and assign them appropriate priority.
2. There is an urgent need to prioritise basic, and clinical research regarding the causes, predictors, management and impact of these chronic diseases.
3. The European Union and Member States should ensure that people with disabilities related to rheumatic and musculoskeletal diseases have the right to full inclusion in society; this encompasses optimisation of environmental and life-style factors, the availability of self-management tools and respect for the right to a flexible education and work environment.
4. People with rheumatic and musculoskeletal diseases should receive prompt access to high quality care, ideally in specialised centres, thus maximising long-term quality of life.
5. Management of rheumatic and musculoskeletal diseases should be in accordance with evidence-based recommendations in every European Union Member State.
6. People with rheumatic and musculoskeletal diseases are experts in living with their condition and should be involved in the design, delivery and evaluation of their services.

European Parliament Interest Group on Rheumatic and Musculoskeletal Diseases

By the EULAR EU Office, Brussels

EULAR continues running the Secretariat of the European Parliament Interest Group on Rheumatic and Musculoskeletal Diseases (RMDs). The Interest Group aims to promote parliamentary actions in this field by discussing relevant medical, social and economic issues related to these diseases with MEPs.

The 3rd Interest Group meeting was held in Strasbourg on 6 July 2010. The meeting focused on the priorities of the Belgian Presidency in the area of health, particularly regarding chronic illnesses, and RMDs. Mr Pol Gerits, from the Federal Public Service of Health, Food Chain Safety and Environment, presented the agenda of the Presidency regarding chronic illnesses, and RMDs. Professor Anthony Woolf reported on the first findings and challenges of EUMUSC.net, a project aiming to minimise the impact of musculoskeletal conditions by facilitating co-operation between Member States, particularly by means of the development of a health surveillance and information system and network. Following this meeting, Ms Antonia Parvanova, MEP from Bulgaria and vice chair of the Interest Group, addressed a parliamentary question to the European Commission on their envisaged actions for promoting 'early intervention policies and programmes for the prevention and management of chronic diseases' like RMDs.



The European Parliament Interest Group meeting on 30 November 2010 was well attended by a significant number of MEPs, Commission officials, Health Attachés from Member States' Permanent Representations and representatives of patient organisations, who discussed health inequalities and rheumatic and musculoskeletal diseases

The 4th Interest Group Meeting on 30 November 2010 dealt with health inequalities and RMDs. Paula Duarte-Gaspar, Member of Cabinet, and John Dalli, Commissioner for Health and Consumer Policy, presented on the Commission's actions to tackle health inequalities, especially in the field of RMDs. Professor

Ingemar Petersson, Research Director of MORSE, a Musculoskeletal Diseases Centre in Southern Sweden, provided evidence on the relation between health inequalities and RMDs. Ms Kaisa Immonen-Charalambous, from the European Patients' Forum, explained the patients' perspective on health inequalities. ■

2011 EULAR's EU Affairs in brief – main activities

Campaign for the implementation of the Brussels Declaration. Following the EU Presidency Conference, EULAR is developing support to campaign for the implementation of the Brussels Declaration at both EU and Member State levels. During 2011 and 2012, EULAR will undertake a number of actions at the EU level and will actively provide support to the campaigns led by national members.

Research Framework Programmes. As a key element of the Brussels Declaration, EULAR will continue promoting the interests of people with rheumatic and musculoskeletal diseases in the research field. The aim is to raise awareness among EU policy makers about the necessity of prioritising basic and translational research on these diseases.

Collaboration with the Hungarian and Polish Presidencies. EULAR is organising a conference in collaboration with the Hungarian EU Presidency, the Hungarian Association of Rheumatologists and Fit for Work. The event will take place in Budapest on 21 April, following the High Level Conference *New Challenges in the European Disability Strategy 2010-2020*. In addition, EULAR is organising exchanges with the Polish government concerning their EU Presidency during the second semester of 2011.

European Parliament Interest Group on Rheumatic and Musculoskeletal Diseases. During 2011, three meetings of the Interest Group will take place. The first one, held during the Alliance Against Arthritis day on 22 March, focused on *Research Trends in Health - the Role of Rheumatic and Musculoskeletal Diseases in Current and Future Research Framework Programmes*. The two others will take place in June and October.



EULAR Congress held in London

Providing a fountain of educational opportunities

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London is ready to welcome more than 14,000 delegates expected at the 11th EULAR Annual European Congress of Rheumatology. Between 25-28 May, the ExCel Centre, located in the heart of London's Royal Docks, is the venue of a diverse scientific programme. This year for the first time there will be a two-day primary care event, focusing on early diagnosis, new management approaches and musculoskeletal hot topics, among other themes.



Also for the first time, a pre-conference outlook session will be held to provide participants with information about the programme and the venue. This session will take place on Wednesday 25 May at 13.30-14.30.

A regular feature with a new timing will be the Standing Committee of PARE Meeting on Thursday 26 May at 8.30-10.00.

The programme developed by the Standing Committee of PARE will showcase the following sessions:

- *Political campaigning – making positive change happen* on how to maximise effectiveness when seeking to influence policy-makers at the national and EU level;
- *Fundraising – hot tips in a cold climate* about how to most effectively communicate to external audiences the value provided by the work of patient organisations, so as to attract necessary resources;
- *Patient information* – intended to develop a shared understanding of how appropriate and timely patient information can be an essential part of the care package;
- *Patient safety – the unique challenges of musculoskeletal disorders* aimed at identifying the principal safety issues involved in surgery, pharmacological interventions and other forms of treatment and support for people living with musculoskeletal disorders;
- *Complementary therapies – supplementary or just rudimentary* which will try to identify the most relevant issues relating to complementary therapies from the perspective of



London will host this year's EULAR Congress, which will be held at the ExCel centre (pictured left)



people with rheumatic diseases, and in particular to deepen the understanding of the risks

and benefits that could be involved.

Neil Betteridge, EULAR Vice President representing PARE, and Chair of the PARE Programme Committee, said: 'We hope to provide up-to-date and useful information to participants. In an environment of economic crisis, we would like to draw attention to the session focused on fundraising. The work of patient organisations is of the utmost importance in dealing with policy makers and helping to establish best practice health policies, but without adequate funding it is difficult to fulfil our role. We must convince society of the fundamental role of patients as partners in the development of proper and cost-effective health-care systems.'

The congress joint sessions will again provide a setting for co-operation between the three pillars of EULAR – rheumatologists, health professionals in rheumatology and patient organisations. This year's session will cover innovating care by using patient

expertise, chronic pain management, sexuality and exercise. Lill Due, the 2011 Stene Prize winner, will present her essay at the *Exercise and rheumatic diseases – Move to Improve* session, held on Saturday at 12.00.

The PARE congress programme will conclude on Saturday with the very popular highlight session, which will feature the main perspectives of the congress from a scientific, health professional and patient perspective. Professor Paul-Peter Tak, Dr John Verhoef and Anna Ageberg will give their news from the congress.

For more information about the Standing Committee of PARE, and its activities, please visit the PARE booth. The booth will be promoting activities such as the Move to Improve initiative for WAD 2011, as well as serving as a networking point for PARE delegates at the congress. ■

The 2012 EULAR congress will take place in Berlin, Germany, on 6-9 June. All deadlines for submission of abstracts and congress bursaries will soon be posted on the EULAR website. For more information on the congress, please visit www.eular.org ■



2011 Stene Prize – first time win for Norway

The theme for the Edgar Stene Prize essay competition in 2011, *How exercise improves my life with a rheumatic disease*, illustrates the importance of physical activity, including exercise, for people with rheumatic and musculoskeletal diseases and its added value to the good prognosis of the disease.

The topic had a great response and the Stene Prize Jury had the difficult task of choosing from 17 entries. Lill Due, from Norway, was chosen as the award winner for 2011. 'I wanted others to read about my feelings and thoughts about my life with a rheumatic disease; the importance of training and exercises in helping to have



Lill Due, a teacher from Norway, is the winner of the Stene Prize 2011

a better daily life; even how hard it is to accept a life with a rheumatic disease.' Jury member Iain McInnes, rheumatologist and Chair of the EULAR Standing Committee for Clinical Affairs, said: 'Listening to patients forms a part of my daily activity as a clinical rheumatologist – but it is uncommon for us to have the opportunity to listen at a deeper level – the essays submitted in the Stene Prize competition are a rare and treasured opportunity to hear the true voice of the patient and to allow a considered reflection on the significance of their remarks.' The Stene Prize will be awarded to Lill Due at the Opening Ceremony of the EULAR Congress in London. ■

EULAR pilot training for Patient Research Partners

By Nele Caeyers,
Patient Research Partner

In 2010, a team of doctors, health professionals and people with rheumatic diseases developed a list of eight recommendations to include patient representatives in scientific projects, which were published in the *Annals of Rheumatic Diseases*.

To make sure these recommendations are put into practice, EULAR has set up special training for people with different rheumatic conditions to prepare them for participation in scientific task forces. In October 2010, 15 trainees followed a two-day course in Brussels, led by Maarten de Wit and Dr Laure Gossec. The 15 participants were selected out of 32 applicants, sent in by EULAR members of the Standing Committee of PARE.

On the first day, the aims and expectations of the course were shared and all participants started work on a first assignment. The group discussed the value of patient participation. They also had a closer look at the *EULAR Recommendations for the inclusion of patient representatives in research projects* in small groups, which resulted in a lively discussion. The last topic on the day's agenda was an introduction to EULAR, its organisation and activities and a personal view on participating in a EULAR Task Force.

On the second day, the focus was on statistical data analysis. Dr Laure Gossec explained the most important elements of Patient Reported Outcome Research and qualitative and quantitative research. The roles of facilitator and reporter were analysed in two



'There should be more training like this, involving more patients.'

focus groups. After lunch, the group took a closer look at a case study – the RAID (Rheumatoid Arthritis, Impact of Disease Score) project and learned how to search for information on the

internet. A lively evaluation closed the training, leaving all participants full of useful information for future projects.

Several of the participants are already successfully involved in EULAR projects, which shows the value of this pilot training. The database of patient research partners is managed by the EULAR Secretariat, so in future the right candidates can be linked to the most suitable projects. We are sure this training will prove its value to all parties within EULAR. In this way, we can guarantee that the voice of people with rheumatic conditions will be heard. ■

Fostering activity in Athens

The 2011 Autumn Conference will be hosted by ELEANA, the Hellenic League Against Rheumatism, in the historic city of Athens. As previous home of the Olympics, what better setting to discuss physical activities and rheumatic and musculoskeletal diseases (RMDs), the theme for World Arthritis Day (WAD) 2011 and 2012.



14th EULAR Autumn Conference for PARE
25-27 November 2011, Athens, Greece

The key aim of the conference is to inspire, educate and empower delegates. 'We would like to encourage organisations to nominate young representatives to provide the views of the next generation of advocates. It is important to keep them involved in the work of PARE, and the energy and enthusiasm they can contribute has been very beneficial for previous events,' said Jacqueline Mäder, Chair Elect of the Standing Committee of PARE. This year delegates will also include representatives from EULAR scientific and health professionals in rheumatology. The first day of the conference will focus on EULAR activities, such as outcomes of the EUMUSC.net project.

Delegates will have the opportunity to

learn from expert speakers and discuss best practice and opportunities in a series of related interactive workshops. Networking and sharing best practice are encouraged through the 'Share Fair' EULAR exchange programme and the poster exhibition.

Under the lead of Professor Hans Bijlsma, EULAR Educational Officer, and Professor Kåre Birger Hagen, EULAR Vice President representing the Health Professionals, the Task Force is preparing a first discussion paper on European Minimum Standards of Physical Activities and RMDs to be introduced and

discussed at the conference. 'At least for OA, RA and AS there is an increasing amount of evidence showing that exercise is beneficial for people with these conditions,' said Kåre Birger Hagen. Hans Bijlsma added: 'It's the first time we have looked at putting together some standards or guidelines around this topic, which is a very exciting step.' ■



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The EULAR Autumn Conference for PARE 2012 will be held in Switzerland on 2-4 November. 'The Swiss League against Rheumatism is very proud to welcome the Autumn Conference to Zurich in 2012,' said Valérie Krafft, General Secretary. ■

Move to Improve – WAD 2011

Celebrated on 12 October, World Arthritis Day (WAD) is an ongoing, year-round campaign. In 2011 and 2012 the focus for WAD is physical activity and rheumatic and musculoskeletal diseases (RMDs) under the theme Move to Improve.



Physical activity is broadly defined as leisure activities including sport and dancing, occupational activities, activities at or near home and activity connected to transport. 'You can be physically active in many ways, unless you sit or lie still, it is physical activity and we want to promote how easy and inclusive this is,' said Christina Opava. Christina is a member of the EULAR health professionals in rheumatology, is herself affected by a RMD and a new member of the 2011 EULAR World Arthritis Day Task Force.

'With the Olympics and Paralympics coming up in 2012, this is an ideal opportunity for national organisations to spotlight the importance of physical activity for people with RMDs,' commented Maria Batziou, who chairs the WAD Task Force. 'We want to motivate everyone to become more active, as well as providing national organisations of PARE with resources to support their WAD projects.'

The WAD website – www.worldarthritisday.org – is the hub for all activities, including two exciting new projects launching in 2011: **Activity of the Month** and a Move to Improve photographic competition. The Activity of the Month will feature different forms of



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physical activity with information and tips for people with RMDs. Visitors to the website will be able to add their own photographs or videos with comments about their experience of a featured activity to inspire others. The **Photographic Competition** will also invite people with RMDs to upload pictures of themselves performing a physical activity with a brief description. Entrants will be judged by online voting and an independent jury. The online winner will receive a prize and, with eleven other winners, will feature on a special EULAR 2012 calendar. Keep checking on the WAD website and moving to improve! ■

Working Wonders broadcasted to Russian hospitals in Moscow

The last country to host the EULAR exhibition *Working Wonders* in 2010 was the Russian Federation. EULAR and the Association of Rheumatologists of Russia have a long history together.



The director of the State Institute of Rheumatology of the Russian Academy of Medical Sciences (RAMS), Professor Valentina Nasonova, was President of EULAR from 1979-1981. With the State Institute of Rheumatology of RAMS in Moscow being Russia's leading centre for the development of new methods of diagnosis and treatment and seeing about 45,000 patients annually, it was the ideal institution to display the popular EULAR exhibition. PARE was invited by the Russian patient organisation, Nadezhda. Nadezhda was founded in 2006 and has about 4,000 members today. Not everybody can afford the membership fee but there are many people who are not registered officially but who support the organisation actively. For Nadezhda there is no difference between members and non-members if people need their help. One of the main ways Nadezhda provides support is advice on how to overcome the bureaucratic hurdles to access free medication.



Nadhezda's President, Natalia Bulgakova, and Professor Evgeny Nasonov speaking at the launch of the Working Wonders exhibition in Moscow

The organisation started with only 12 regional branches and has grown substantially with 47 branches all over Russia today. 'I personally travelled to 30 regions of Russia and visited the local rheumatology centres of the central hospitals. We organised conferences about new methods of treatment and the importance of patient activities. Our rheumatologists, and namely Professor Nasonov, were instrumental in moving patient activities ahead and we are very grateful for this ongoing support,' said Natalia Bulgakova, President of Nadezhda.

With the Russian Federation being the largest country in the world, there are unique challenges for Nadezhda to overcome. While in other countries a general assembly is usually organised annually, Natalia can only invite members every 5 years as travel is very expensive – it takes about 7 days to travel from the furthest branch, in Vladivostok, to Moscow. 'However, many members of the organisation are treated in Moscow over the year so while they are in hospital we try to meet as often as possible,' explained Natalia. In the future she aims to continue their mission and to found branches in the remaining 36 regions of the Russian Federation.

The launch of the *Working Wonders*

Russian national delegates with the PARE delegation (Florian Klett and Birte Glüsing, second and third on the left, and Marios Kouloumas at the centre), visiting Nadhezda



exhibition, on 8 December 2010, was accompanied by several lectures and transferred by tele-video to 53 rheumatology centres of regional hospitals all around Russia. About 1,500 patients and health professionals could participate and connect to the broadcast. One of the main problems of people with rheumatic and musculoskeletal diseases (RMDs) in Russia is the lack of rheumatologists, especially in the countryside, so telemedicine is used as way to solve this problem. Marios Kouloumas, Chair of the Standing Committee of PARE gave a presentation on behalf of EULAR and stated: 'We are very impressed by the Russian activities and how modern technology is used to overcome such barriers as distance. It is very inspiring to witness the excellent co-operation between doctors and patients to improve the quality of life of people with RMDs in Russia'. ■

The *Working Wonders* exhibition is continuing to travel across Europe to create awareness of the issues of people with rheumatic diseases at work. Slovakia, Hungary, Croatia, Germany and the Czech Republic are some of the countries where the exhibition is going to stop in 2011. EULAR member organisations interested in hosting the exhibition in their country should contact the EULAR Secretariat for more information at birte.gluesing@eular.org ■



The children's ward at the Institute of Rheumatology is visited by the delegation

EULAR's Educational Visit Awards become more popular

Every year, EULAR provides Educational Visit Awards for EULAR member and other patient organisations in the field of rheumatic and musculoskeletal diseases (RMDs). These awards are designed for patient organisations who wish to develop their skills (learning organisation) by learning from the experience of other organisations (teaching organisations) in the PARE European network.

The programme has been so successful that the working group found it difficult to select the projects which most applied to the established criteria and aims of the programme.

This year's successful applicants come from Germany/The Netherlands, Greece/Norway, and Romania/Cyprus. The winners have been awarded €5,000 to conduct their projects. The German-Dutch exchange will focus on translating the Dutch self-management programme into practice in Germany, providing people with RMDs



Training on self-management with the Portuguese League and the Cypriot League, which were awarded a grant by the Educational Visit Award in 2007-2008

strategies to cope with their disease on a daily basis. Greece will rely on the Norwegian organisation's know-how in the field of fundraising, motivation and recruitment of members and patient support. The Romanian-Cypriot project will concentrate on the knowledge needed for organisational

development and the maintenance of an effective volunteer database by applying the Cypriot volunteer strategy (recruitment policy and motivation).

The award rules have recently undergone changes and the results of the work done by the task force will be online at www.eular.org. The new rules will mean that applicants will need to demonstrate the long-term benefits of the project. Ovidiu Constantinescu, a member of the task force from Romania, said: 'We will have to work hard in order to come up with a new set of rules that are easier for applicants to follow in the future. We have to make the selection criteria clearer, more precise, quantifiable, measurable and therefore more transparent.'

The Standing Committee of PARE would like to thank all the organisations who have come forward and applied this year and encourages new applications before the deadline, which will soon be provided on the EULAR website. ■

Journey in the Dark

Deutsche RHEUMA-LIGA
Bundesverband e.V.



By Gudrun Baseler, National spokesperson of young people with rheumatism, Deutsche Rheuma-Liga

'How does it feel to be young and live with a rheumatic disease?' This was the overarching question young people within the Deutsche Rheuma-Liga (DRL) tried to answer. For the 40th anniversary of the DRL they created an interactive project – Journey in the Dark.

The room was completely in the dark and only a lightened pathway served to show visitors the way. On several stations, young people with rheumatic diseases invited visitors to observe, ask questions and listen to their personal stories. They talked about daily life issues, challenges at school, leisure and about pursuing a career. They asked visitors to lift a fully-packed schoolbag – an impossibility for many people with a rheumatic disease – or to listen to cruel comments they had to hear at school from other pupils, because they had a rheumatic disease. Jessica Schneider, one of the young organisers, explained: 'Our aim was to raise peoples' awareness and open their minds to barriers in our life.'

All young people were dressed in black and had bright yellow sentences on their backs, stating how long they had been living with rheumatism. Their joints were highlighted by brightly coloured dots in yellow and pink – pink for pain and yellow for joint replacements. A visitor asked: 'This is a joke, right?' One of the young



(Above) The yellow sentences state how long each participant has lived with a rheumatic condition and (left) the Deutsche Rheuma-Liga received a voluntary work award for this project

people there, Denise Schäfer, answered: 'No, it isn't. I am 28 years old and I have had a rheumatic disease for 24 years. I have already had five joint replacements. This is my reality.'

The Journey in the Dark was professionally documented by a film team. The result is available on the website of the Deutsche Rheuma-Liga (<http://geton.rheuma-liga.de>). The project won the first prize for a voluntary work award in Germany. ■

Membership boost in Macedonia

By Dragan Chichich, President of NORA

The Non-governmental Organisation for Rheumatism & Arthritis (NORA) was founded in early 2008. After the break up of Yugoslavia, there was no organisation to represent the point of view of patients in Macedonia. The complexity and toll of rheumatic diseases, the need for patient education and support and the high socio-economic cost of treatments are some of the many reasons why patient input and representation is needed.

Our first main challenge, however, was to face social prejudice – that only elderly people have rheumatic diseases and that these are not serious diseases. We addressed these issues by establishing an active young volunteer network and organising activities for this group. We obtained 800 members in 2 years, with an average members' age of 39 years.

Another success was the celebration of



Dragan Chichich, President of NORA, in front of the WAD airplane. Visitors to the event were given a free flight

The airplane was branded Airborne World Arthritis Day 2010, the name of the campaign

WAD 2010. We rented a plane during an air show, prior to the WAD event, and branded it with the message Airborne WAD 2010. It flew during the show and attracted the attention of around 2,000 event participants.

We marketed both events with a video commercial broadcasting one week before on national TV. The estimate is that half of the country's population saw the video (about 1 million people). NORA is now full of young people that fly airplanes, are active and have fun. This activity cost only €300, to pay for the fuel for the plane.



Everything else was donated, which proves that money is not always imperative for having a good campaign.

Becoming a part of EULAR was a great milestone for NORA. EULAR and PARE give NORA a sense of belonging and partnership with other organisations who have the same aims and mission – to improve the lives of people with musculoskeletal diseases. It also gives us a sense of support and understanding, which are a true motivation and inspiration for pursuing our work. ■

The Icelandic League against Rheumatism

By Emil Thorodsson, Chief Executive Officer

The Icelandic League against Rheumatism – Gigtarfélag Íslands – was founded in 1976 and has approximately 5,200 members. The League is an umbrella organisation for people with different kinds of rheumatic diseases. Most activities occur in the capital area, Reykjavik, and its neighbourhood, where two-thirds of the population of Iceland lives. The league has five organised local branches outside the capital area.

The league is organised into several groups – there is a group for parents of children with rheumatic diseases, groups for rheumatoid arthritis, osteoarthritis and fibromyalgia. The groups' mission is to give support and exchange peer-to-peer information, as well as to organise meetings with the head office.

At the league's head office in Reykjavik, courses are held, there is a telephone advisory service run by health professionals and rehabilitation is offered by physical and occupational therapists to people with rheumatic diseases and their families.

Members of the PARE Board visited the Icelandic member organisation in July 2010 and were introduced to their many activities. Marios Kouloumas, Chair of the Standing Committee of PARE, was very impressed by the excellent service the league offers to their members. 'To have access to a rehabilitation centre with physiotherapists, a rheumatologist and other specialists



The famous singer Johanna Guðrún (right), who has RA and came second at the Eurovision song contest in 2009, participated in a walk organised in Reykjavik

directly linked with the organisation is an excellent idea and so valuable,' Marios commented.

The main goal of all the activities is to improve the quality of life of people with rheumatic diseases in Iceland, to fight for more effective treatment and to support the funding of scientific research in rheumatology in the country.

The league's board would like to raise more awareness for rheumatic diseases and for the work done by the organisation.

In recent years the league has organised events in the centre of Reykjavik, for example a walk for people with rheumatic diseases, with dancing, singing, flags and drums. The league also publishes information brochures and a bi-annual magazine. They are trying to increase focus on their website – www.gigt.is – as a source of information for members. ■

The EUMUSC.net developing an online assessment tool

By Babette Anhalt,
Project Dissemination Co-ordinator

On 24-25 January 2011, rheumatologists and researchers met in London to discuss the development of an online assessment tool for collecting information on the impact of musculoskeletal conditions. This tool, alongside a report about the burden of musculoskeletal conditions, is being developed under the EUMUSC.net, the European musculoskeletal surveillance and information network.



Participants from across Europe talked about an extensive list of indicators to measure the impact of living with a musculoskeletal condition and how to collect this data from all countries within the EU. Every aspect was discussed – the different conditions, drug use, number of surgeries, accessibility of health care and social consequences. There was an emphasis on equality and the difficulties in finding comparable data and meaningful indicators.

The EUMUSC.net project started a year ago, funded by the EU Community in partnership with EULAR. The EUMUSC.net is a unique collaboration between patients, health professionals, researchers and clinicians across Europe, and has an ambitious agenda aimed at optimising musculoskeletal health across Europe by setting and monitoring standards of care, identifying barriers to achieve these standards and providing information on the impact of musculoskeletal conditions. Its ultimate goal is to improve the lives of people living with musculoskeletal conditions throughout Europe. Patient research partners participate in every step of the research. Ruth Hawkins, a patient research partner present at the meeting in London, said: 'A patient or two being in the room reminds doctors to think about the patient. You almost don't have to do anything.'

Although musculoskeletal conditions can be effectively diagnosed (in most cases), prevented and treated, this is not happening equitably across Europe. The EUMUSC.net project will help to make this inequality transparent, hopefully leading to the implementation of an EU community strategy on musculoskeletal conditions. The project's first results will be published during the first quarter of 2011. ■

AGORA — a new member in the family of organisations for people with rheumatic diseases

By Maria Batziou, Agora representative for Greece

In November 2008, an informal meeting – set up by representatives from Portugal, Cyprus and Spain with the participation of Greece, Italy and Malta – took place in Budapest in order to discuss the need for a coalition between countries in southern Europe. The common socioeconomic problems that southern European countries face and the similar cultural attitudes made this need imperative.



The aims of the new platform are:

- to provide southern European organisations for people with rheumatic diseases with a stronger voice at a European level
- to encourage and assist in the foundation and development of user-led organisations in southern Europe
- to change cultural attitudes towards rheumatic diseases and allow patients to become a part of the decision-making process.

Organisations from Croatia, Montenegro, Romania and Bulgaria have now joined the founding members and other southern European countries are welcome to join.



The founding members of Agora at their first meeting in Budapest. Photo by CYPLAR

During the last two years, the Agora Steering Group has been looking for financial support for the organisation of the inaugural meeting of its members in Malta, September 2011. On 6 November 2010, the members met with industry representatives during the EULAR Autumn Conference for PARE in Berlin and both sides were very enthusiastic and eager to contribute to the accomplishment of the platform. All parties agreed that a strong Southern European voice of people with rheumatic and musculoskeletal diseases can benefit and refresh the European network leading to an exciting and promising future. ■

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BREAKTHROUGH

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