Back in Berlin – EULAR Congress 2012

The German capital, Berlin, plays host to the EULAR Congress in 2012. From 6-9 June, more than 15,000 visitors are expected at the Messe Berlin.

The congress will provide a unique opportunity for the exchange of information between doctors, health professionals, professionals from the pharmaceutical industry, scientists and people with rheumatic and musculoskeletal diseases (RMDs) from around the world.

The PARE programme begins on Wednesday at 13:30 with a Pre-conference Outlook for delegates. This session will give an overview of the congress centre and the programme to help attendees find their way through some exciting and busy days ahead. “We know that the congress is huge and can be overwhelming for people with RMDs. We encourage delegates to join us and to use this opportunity to ask all their questions about the event,” says Maria Batziou, Chairperson of the Standing Committee of PARE.

A parallel joint session (13.30 – 15.00) will discuss the topic of Patient Involvement in research and give an overview of best practices on how to capture the patient perspective in RMD research. The last session on Thursday, Co-morbidity (15.30 – 17.00), aims at highlighting the impact and associated risks faced by people living with at least one other significant condition caused by, or linked to, their RMD.

Working in partnership
Friday’s PARE programme starts with the Abstract Session (10.15 – 11.45) which will present insight into the work of the national organisations. It will be followed by the joint session Impact of RMDs on Families, Partners and Friends, (13.30 – 15.00). From 15.30 – 17.00 the session Working in Partnership will discuss how to support the active involvement of patients in their own care, in research and in the development of guidelines.

On Saturday the day will start with a joint Move, Groove and Improve - Exercise and RMDs workshop (8.45 – 10.15). The PARE session on Inclusive Design (12.00 – 13.30) will focus on how society can design things to remove barriers to social inclusion. The Highlight Session (13.45 – 14.45) will conclude the 2012 EULAR congress.

Come and visit the PARE Booth in the EULAR village. It will be a meeting point for networking, discussions and information.

BaRiE 2012 – from Brussels to Berlin

In 2006 BaRIE (Biking against Rheumatism in Europe) was set up under the auspices of the three Belgian organisations: KBVR, CLAIR and ReumaNet. The main goal was to raise awareness of the needs of people affected by the various forms of inflammatory rheumatic diseases in an original way. BaRIE is a team of patients, rheumatologists, paramedics and volunteers biking on tandems and adapted bikes to the annual EULAR Congress. It is a powerful symbol of solidarity.

The tour starts in Brussels on 2 June 2012 and takes the cyclists through Verviers into Germany and via Düsseldorf to Berlin. They will arrive at the Congress Centre on Wednesday 6 June. Come and join us in a warm welcome to our brave cyclists at 14.30 at the South Entrance of the Messe Berlin.
The future depends on what we do in the present, said Mahatma Gandhi, who was himself a motor of change. Europe is going through painful changes for its citizens in these days. But at the same time it is an opportunity for everybody to be a positive part of the change and contribute to a better future.

People with rheumatic and musculoskeletal diseases (RMDs) have the power and the qualifications to improve their quality of life if they are willing to do so. Also the second year of EULAR PARE’s campaign ‘Move to Improve’ encourages people with RMDs to be physically and mentally active in order to improve their everyday life.

This will result in further inclusion and participation in social activities and powerful intervention in decision-making processes, as physical and mental health complement each other.

I am really happy that my term of office starts with such an inspiring campaign and I feel honoured to be working with a very ‘fit’ group of people. I’d like to thank them for their support and trust.

My personal goal is to meet their expectations and that, together, we will make our voice stronger and our work more effective. I would like to acknowledge the fabulous work done until now by my capable and gifted predecessors and thank them for their contribution.

Maria Batziou

Maria Batziou is the Chair of the Standing Committee of PARE
Introducing the Standing Committee on Education and Training

EULAR has always had a strong commitment to the field of training and education in rheumatology as this is the cornerstone for harmonising standards of care and fostering access to optimal care for people with RMDs in Europe.

The Standing Committee on Education and Training is led by Prof. Dimitrios Boumpas (Chairman) from Greece and Prof. Maurizio Cutolo (Past Chairman) from Italy, as well as Prof. Hans Bijlsma from the Netherlands, as Education Officer.

EULAR’s programmes are not limited to physicians, but also extend to health professionals and patients through their involvement in the education of rheumatology as systemic autoimmune diseases and osteoarthritis.

He has been active in the field of developing guidelines for patients with osteoarthritis and patients treated with glucocorticoids. He was chairman of the EULAR Standing Committee on Education and Training in 2009, having been an EULAR Education Officer since 2011. What is your impression of this event and why is this conference important for EULAR?

**Breakthrough:** You have been involved in the planning of the EULAR Autumn Conference for PARE for the last two years and also attended the conference in Athens in 2011. What is your impression of this event and why is this conference important for EULAR?

**Hans Bijlsma:** The Autumn Conference has two important goals that are very well served in the present set up: 1) to work together on a specific theme (e.g. keeping mobile), and 2) to be an international exchange of ideas, plans and solutions for patient organisations in all participating countries. It is a privilege to take part in this conference as a health care provider – especially to be involved in the first goal, but also really appreciate the chance to understand what is going on regarding the second goal.

**Breakthrough:** Do you have any thoughts on how patient education could be further explored and supported by EULAR?

**Hans Bijlsma:** This is a very difficult area: EULAR could be involved in setting the scene and some general recommendations. But translation to different countries with totally different health care systems is a challenge – let alone adequate translation for the many different individuals. I hope it will be put on the agenda for the new EULAR strategy – at least to make a start in this field.

**Breakthrough:** How should patients be involved in the education of rheumatologists? Do you have any current projects which count on patient participation?

**Hans Bijlsma:** Patients can play a very important role in the education of not only rheumatologists, but also other health care providers. The Patient Partners Programme is well known and very useful. I believe that patients should be stimulated to attend out-patients at University clinics, in order to actually help medical students, nurses in training and specialists in training learn about their disease, not only the somatic parts, but also the more emotional and psychological aspects of patients with chronic problems. Some of the encounters could be filmed (if patients agree of course) to be used in teaching.

**Breakthrough:** Informed – or shared – decision making is an increasingly common approach across Europe. What do you think EULAR can do to promote the model and to ensure patients are best supported to make informed decisions?

**Hans Bijlsma:** There is no clear-cut answer to this question – it very much depends on the individual. I think it is not specific for rheumatoid patients, but a more general attitude to health, especially your own health. These items should be discussed already at school, should be part of public actions. EULAR can help to make specific information on rheumatic diseases easily accessible, but I think influencing public awareness and attitude in general is most important.
Health professional research into osteoarthritis

By Mikko Väisänen, EULAR HP News editorial assistant

Recommendations on non-pharmacological management of hip and knee OA

Osteoarthritis (OA) is one of the most common musculoskeletal conditions. The treatment of OA has developed in recent years and the benefits of multidisciplinary health co-ordination and care of OA are well recognised.

Apart from the optimisation of drug therapy, the holistic care of OA involves patient education about lifestyle, including physical activity, stress and weight control, advice on the use of orthoses and braces, and other treatment modalities to decrease pain and promote functioning and quality of life.

Likewise, the national and international multidisciplinary recommendations on the management of hip and knee OA put much emphasis on non-pharmacological management provided by health professionals such as physiotherapists, nurses, occupational therapists, psychologists and nutritionists. However, recommendations are not sufficiently specific about the content, timing, intensity, frequency, duration and mode of delivery of non-pharmacological management.

Therefore, the EULAR Standing Committee of Health Professionals (HP) in Rheumatology started a project in 2011 with the aim of developing evidence and expert opinion-based EULAR recommendations for non-pharmacological management of osteoarthritis of the hip and knee. “The project will also determine a future research agenda,” tells the Chairperson of the HP Committee, Dr. Thea Vliet Vlieland, one of the convenors of the project, together with EULAR’s Education Officer Prof. Hans Bijlsma and EULAR’s Vice-President HPs in Rheumatology, Prof. Kåre Birger Hagen.

The Steering Group of the project includes health professionals specialised in rheumatology from various professional backgrounds – rheumatologists, orthopaedic surgeons, general practitioners, and people with osteoarthritis of the hip and/or knee, as well as researchers working in the field of osteoarthritis management.

The project, the new health professional recommendations under construction, will contribute to the quality of care for people with hip and/or knee osteoarthritis across Europe.

The plan is to carry out a methodological evaluation concentrating on studies on effectiveness of relevant interventions. All evidence will be reviewed and expert opinion will be documented to find out where the evidence is insufficient or absent. “We hope that results of this project will contribute to the quality of care for people with hip and/or knee osteoarthritis across Europe,” Dr. Vliet Vlieland says.

The recommendations will be ready by June 2012.

EULAR Health Professionals

The EULAR Standing Committee of Health Professionals (HP) in Rheumatology was established in 1989 as a European platform for shared information among health professionals in rheumatology such as nurses, occupational therapists, physiotherapists, psychologists, social workers, nutritionists and podiatrists. The HP Committee promotes multidisciplinary collaboration in the treatment of RMDs in Europe and encourages health professional research. HPs also work to improve the patient’s role as the key expert of his/her own treatment.

Last year the HP Committee launched the EULAR HP recommendations on the role of the nurse in the management of chronic inflammatory arthritis (CIA).

More information on the HP Committee is available at: www.eular.org/st_com_health_professionals.cfm

“Patient-centred, state-of-the-art care is in the focus of all treatment,” says Vliet Vlieland

Thea Vliet Vlieland, Chairperson of the EULAR HP Committee, works as an associate professor at the Leiden University Medical Centre in the Netherlands

Does your country have a Health Professional Association in Rheumatology?

The EULAR HP Committee is running a member campaign for national health professional associations to join EULAR. So far the HP organisations of the Netherlands, Sweden, Switzerland, United Kingdom, Norway, Denmark, Serbia, Bulgaria, Italy, and Czech Republic have become official EULAR members.

Health professional associations often co-operate closely with local patient organisations. If your country does not have a HP association, please inform your local health professionals specialised in rheumatology about the EULAR member campaign. Being involved in EULAR offers the latest recommendations, knowledge and contacts for health professionals.

Download a flyer with instructions on how to become a EULAR member at www.eular.org/st_com_health_professionals.cfm.
European Parliament Interest Group on RMDs

In its role as the Secretariat of the Interest Group (IG), EULAR organised three annual meetings at the European Parliament during 2011. The first one, held in March, focused on research in rheumatic and musculoskeletal diseases (RMDs) in the current and forthcoming EU Research Framework Programmes. EULAR Past President Prof. Paul Emery presented the RMD community's perspective and demands, while representatives of the European Commission addressed current and future trends in EU research funding.

The second meeting took place in June. Here MEPs, representatives of the European Commission and stakeholders discussed RMDs in the context of the EU initiative on active and healthy ageing. Former Chair of the Standing Committee of PARE, Jacqueline Mäder, outlined the position of the RMD community, highlighting the strong link between RMDs and some of the main problems affecting older people.

The last meeting of 2011, held in October, was the opportunity to present the first results of the eumusc.net project. Dr. Loreto Carmona, Chairperson of the EULAR Standing Committee on Epidemiology and Health Services Research, provided evidence of prevalence, disability consequences and economic burden of RMDs. A representative of the European Agency for Safety and Health at Work (OSHA) presented a campaign on risk prevention at the workplace.

Three meetings are also on the agenda in 2012. The first one took place in March, while the others will be held in June and October. The first meeting focused on the ongoing Reflection Process on Chronic Diseases. The IG meeting's aim was to discuss the initiatives being undertaken by the European Commission and Member States in this respect and to debate with MEPs, European Commission, Member States, and other stakeholders on how to take into account the particularities, needs and recommendations of the RMD community. Prof. Maxime Dougados presented EULAR's perspective and recommendations regarding the reflection process.

Chief executives come together in Brussels

The Chief Executives/General Secretaries of 13 PARE organisations were, for the first time, invited by EULAR to come together to discuss similar challenges in their national work at a meeting held in Brussels 19/20 March 2012.

The organisations are well established and run by a professional team with paid staff. It had been a long-time idea to enable an exchange between their leading staff members and EULAR. The aim was to discuss their co-operation with EULAR, to give them a platform for an individual exchange about national issues and to engage them in talks with European key stakeholders.

For EULAR, it was important to learn more about the work of the organisations in order to be able to maximise the benefit of the co-operation for all involved. The discussions revealed that there is interest in supporting the smaller organisations through EULAR's Educational Visit Programme and the activities of young people with rheumatic and musculoskeletal diseases (RMDs).

It was seen as important to develop lobbying material around the topic of ‘early intervention’ which could be used on national level to address policy makers and other key stakeholders. Earlier planning – e.g. topics and activities for World Arthritis Day – was agreed to be a key goal to enable a European-wide strategic approach or action to be implemented by all the organisations.

Being in the capital of Europe, the participants also received an introduction into EU affairs and discussed how their organisations could support the important work of EULAR at European level in the future. Additionally, all participants had the chance to meet with MEPs from their countries and to discuss initiatives that are of relevance to the RMD community.

Ailsa Bosworth, Chief Executive of the National Rheumatoid Arthritis Society in the United Kingdom commented after the meeting: “It was such a fantastic opportunity to meet my European colleagues and exchange views. I hope we can continue to collaborate.”

It was the wish of all attendees of this first meeting to meet more regularly in this group and to continue the collaboration.
Prioritising RMDs with EU policy makers

EULAR’s achievements and priorities in the EU arena

2011 was a successful year for EULAR in Brussels. As in previous years, the main goal of the EULAR EU Affairs activities has been to raise awareness among EU policy makers and stakeholders on the increasing burden of rheumatic and musculoskeletal diseases (RMDs) in our societies. More and more, politicians, public officials and advocacy organisations are coming to the conclusion that RMDs deserve more attention from public institutions.

Among the main outcomes achieved during 2011, two are worth highlighting. The first one was the Hungarian EU Presidency Conference: ‘The Burden of Rheumatic and Musculoskeletal Diseases (RMDs): Challenges in Work Capacity and Prevention of Disability in the EU’ held in Budapest on 21 April 2011.

The event was jointly hosted by EULAR, the Hungarian Association of Rheumatologists, and the Fit for Work Europe Coalition. As a result of the event, representatives of national governments, MEPs and key organisations (such as EULAR) signed a Declaration on Disability (30 June 2011). The Declaration calls on EU policy makers, amongst other things, to further support prevention, early diagnosis and effective treatment of RMDs.

The second outcome was the EU High Level Group on Disability which came together in Brussels on 25 October 2012.

EULAR was invited to present at the meeting of the High Level Group on Disability. The group is mainly comprised of representatives of Member States. The group’s aim is to monitor the latest policies and priorities of governments concerning people with disabilities as well as to provide advice to the European Commission on these issues.

EULAR President Prof. Maxime Dougados and EULAR Vice President, representing PARE, Neil Betteridge presented on ‘Rheumatic and musculoskeletal diseases and the disability challenge’, focusing on the disabling effects of RMDs as well as on EULAR’s contribution to the EU disability policy.

Looking to the future

For 2012, EULAR has two main goals at the EU level.

First, EULAR will further advocate for RMDs to be fairly recognised as one of the major chronic diseases and receive the attention they deserve in policy initiatives. So far, EU and national policies have considered mortality rates as the main criteria for prioritising chronic diseases. Nonetheless, as some prominent EU representatives and international institutions have started to recognise, it is time to shift the focus and especially consider the social and economic impact of different chronic conditions when it comes to deciding how to use public resources in a more effective and efficient way. In this sense, as one of the most prevalent, disabling and costly chronic conditions, RMDs deserve to be prioritised in EU and national policies.

The second objective of EULAR’s EU Affairs for 2012 is to raise awareness on the need to further invest in research and innovation (R+I) in RMDs, particularly in Horizon 2020, the new EU Research Framework Programme that will run from 2014 to 2020. Fostering R+I are crucial for our community, as it is the most effective and sustainable way to improve both primary and secondary prevention as well as disease management.

For the EU and Member States, prioritising R+I in RMDs would be a strategic decision, as RMDs – more than most other chronic conditions – are at the core of many societal challenges the EU aims to tackle in the coming years. Examples include disability, reduced mobility and dependency of the ageing population and efficiency of healthcare systems.
Edgar Stene Prize 2012 – award goes to Finland

‘Overcoming the challenges of getting around with a rheumatic or musculoskeletal disease (RMD): how to overcome challenges like moving around in the house, how to get to work, participating in social life such as meeting with friends and family or how to go to the cinema or on holidays’ was the theme of the 2012 Edgar Stene Prize. People received the topic with a lot of enthusiasm and the competition had the biggest response ever, with 19 entries.

Nemanja Damjanov, Professor of Internal Medicine and Rheumatology at Belgrade University School of Medicine, General Secretary of EULAR and member of the Stene Prize Jury said: “Reading the essays was an inspiring, moving, sometimes even dramatic experience. I learned a lot. I believe it helped me to be a better rheumatologist. It is a pleasure being part of this unique project.”

The winner of this year’s contest is Raija Heimonen, a 54-year-old Sciences major from Finland. Raija said: “I love writing and was very excited to learn about the Stene Prize on the internet. I think that real life stories can help support other people in similar circumstances and also help health professionals gain a better understanding of their patients.”

Raija was diagnosed with rheumatoid arthritis and Sjögren’s syndrome in 2003. She works full time as leading planner in the business department of a pensions’ insurance company. She is married, with three children – a girl and two boys. Her husband’s profession in the forestry industry meant Raija has spent many years living abroad and speaks Swedish, English and Estonian fluently. Twelve years ago the family returned to their home in Finland. Raija is a member of the Espoo branch of the Finnish Rheumatism Association.

The Stene Prize will be awarded to Raija Heimonen at the Opening Plenary Session of the EULAR Congress in Berlin.

In 2010, EULAR developed recommendations to enable the successful inclusion of the patient perspective in EULAR-funded scientific research projects. The eight recommendations provide a practical guidance for organising patient participation, capturing the role of the patient research partners, their involvement, the recommended number, the recruitment, selection, support, training and acknowledgement.

After a successful pilot training for 15 Patient Research Partners, there were several opportunities to put this experience into practice. The participants have been actively involved in EULAR Task Forces or have been reviewing projects for EULAR calls.

EULAR confirmed the relevance of the patient research partners network by launching an evaluation process in January 2012. To make sure the patient research partners network is well known and used in an optimal way among researchers, it is necessary to get a clear view on the expectations towards, and the experiences with, the patient network. Furthermore, not all researchers are aware of the existence of the network. This means appropriate stimuli, support and evaluation are needed. These will be developed during the year at different levels.

Involving patients as research partners

Nele Caeyers tells us how the patient research partner project is being put into practice

An evaluation meeting has been organised prior to the EULAR congress in Berlin with the 15 trained research partners so that they can exchange their experiences. In addition, four task force leaders who have been working with some of the patient research partners will be interviewed and give their personal opinion. As a next step, a large electronic questionnaire will be shared among different stakeholders such as EULAR Standing Committee Chairs, researchers and patient research partners.

With this diversified evaluation approach, it will be possible to get a clear overview on how the network and its contribution to the projects can be optimised. Based on the outcomes, an information brochure to promote the existence of the network and two checklists to support the better inclusion and preparation of patient research partners will be developed. Several national and international meetings in 2012 and beyond will be used to further promote the recommendations and to introduce the network and the developed material.
Zurich, home of EULAR’s headquarters, will welcome this year’s Autumn Conference for PARE and will be hosted by the Rheumaliga Schweiz (Swiss League Against Rheumatism).

Following on from the very successful 2011 Autumn Conference in Greece, the prime aim for the Autumn Conference is to educate and empower national organisations of PARE through presentations from expert speakers, participation in interactive workshops and networking with peers.

Friday will be kept as the day where presentations and workshops focus on EULAR initiatives, including updates on EU activities. Additionally, the Rheumaliga Schweiz will be holding a workshop on assistive technologies and examples of these technologies will be displayed for all delegates to browse during the conference.

On Saturday, topics will focus on the implementation of the EULAR Document on Physical Activity for people with rheumatic and musculoskeletal diseases (RMDs) at a national level. A draft framework of the EULAR Document on Physical Activity was reviewed and refined from the perspective of people with RMDs at last year’s conference before being passed to EULAR for further scrutiny and approval from representatives of its scientific and health professional in rheumatology membership.

**Lobbying tool**
The document will be available to national organisations as a lobbying tool, and workshops on Saturday will feature inspiring case studies and discuss aspects of launching and using the document locally. This year, each workshop will include the development of an action plan as an outcome for delegates to share and develop with their national organisations.

The Sunday programme will look at ways of raising the profile of physical activity and RMDs through the experience of inspirational individuals, and looking at the organisation of physical activities that can also be used to raise funds for national organisations.

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**World Arthritis Day 2012**

EULAR continues to promote the importance of physical activity for people with rheumatic and musculoskeletal diseases (RMDs), under the theme ‘Move to Improve’. All World Arthritis Day (WAD) activities are run from the website (www.worldarthritisday.org) which provides interactive features, and information and resources for national organisations and individuals with RMDs.

This year, the area for national organisations and individuals wishing to promote their WAD events is being upgraded so it is easier to register and to search for what’s happening and where. The website is frequently updated and refreshed.

**Please support our big 2012 WAD campaign**
The key activity this year invites people in Europe and around the world to send us a photograph featuring supporters giving us a ‘Wave for World Arthritis Day’.

“Waving is a physical activity that everyone can do and one that also symbolises support for our ‘Move to Improve’ campaign. With a target of 10,000 individuals waving, we will be engaging traditional methods and social media to motivate and mobilise our networks to participate,” said Maria Batziou, leader of the WAD Task Force and Chairperson of the EULAR Standing Committee of PARE. “We will be counting the number of people waving in each picture, so the bigger the crowd, the more people we can register,” added Maria.

Help us spread the word and encourage participation from your medical centre or organisation, as well as from your wider network including schools, offices, sports teams, flash mobs and any other groups of people who support our campaign. A photomontage made up of the pictures with key campaign messages will be published on the website on Friday, 12 October – World Arthritis Day.

**Please support this year’s WAD campaign** by sending us your ‘Wave for World Arthritis Day’ pictures and spreading the word across your networks. Together we can make a difference.
The Working Wonders Exhibition visits the Czech Republic

Alena Slamova from the Czech League Against Rheumatism reports

The Working Wonders Exhibition was shown in the Czech Republic during the ‘Jachymov Days of Rheumatology 2011’ congress, which took place in the Jachymov Spa’s Akademik Behounek hotel, 7-9 December 2011. This very popular congress is organised every two years by the Czech Society of Rheumatology (CSR). The congress attracted about 400 rheumatologists, health professionals in rheumatology and representatives of organisations of people with rheumatic and musculoskeletal diseases (RMDs).

The eight selected panels of the Working Wonders Exhibition were placed in the lobby of the conference hotel, so all congress participants had to pass by them. Both full-time and part-time employees work for the organisation and cover specific work areas, such as fundraising. The representatives of ELEANA were very impressed by this set up and would like to try and implement a similar system.

Fundraising is one of the main resources of income for the Norwegian Rheumatism Association to pay for projects to support people with RMDs. Funds are raised through a lottery ticket advertised and sold wherever possible to the public, donations from members, legacies and donations from bank profits. Further income is gained through the sale of technical aids and branded materials through the organisation’s website.

Being back home, ELEANA plans to approach organisations and companies, such as banks and the pharmaceutical industry, to discuss if they would be interested in investing into their activities. In order to promote the activities of ELEANA, it would be useful to develop an e-newsletter to be integrated into ELEANA’s website. Another good way to raise funds and also awareness could be to organise a fundraising event such as a bazaar.

The Norwegian Association is trying to increase their membership by offering long-standing members a reward when they bring in a new member. This seems a good way for ELEANA to foster more participation of their own people in Greece. Overall it was a very valuable and interesting visit. It was a great opportunity for ELEANA to learn from such an established and successful organisation and many ideas where brought home to Athens.
BOPRD: A story of friendship and support

Everybody has felt lonely at some point because of the pain and all the hardship rheumatic and musculoskeletal diseases bring. Finding a group of people you can share your problems with may bring enormous relief. This was our experience in Bulgaria – the things that brought us together were unfortunately not good or pleasant, but they united us and made us friends in a really short time. Today we help not only each other, but other people with rheumatic diseases asking us for support.

We established the Bulgarian Organisation for Patients with Rheumatic Diseases (BOPRD) in 2010 and a year later we became a member of EULAR. We worked on several projects raising awareness among patients and the Bulgarian society. BOPRD also organised some group sport and rehabilitation events, and started organising charity events to finance physiotherapy sessions for low-income patients.

One of the main concerns of our patient community is related to having children. People with rheumatic diseases are very insecure and have a lot of questions regarding pregnancy, treatment and children. That’s why one of our main projects in 2012 is a survey established together with gynecologists, reproductive health specialists and rheumatologists. The aim is to reveal the options for becoming parents and spreading this knowledge.

Another goal is to develop activities in the area of social integration and the labour market for people with rheumatic and musculoskeletal diseases.

In comparison with other EU member countries, Bulgaria is one of those with extremely difficult conditions to live in for people with rheumatic and musculoskeletal diseases. The problems connected to access to treatment and rehabilitation, finding a job and other basic things are some of the main issues for the Bulgarian patient society. This challenging reality requires our everyday efforts to make a difference – but we are ready to fight for it.

Eastern European exchange

Jolanta Grygielska, President of the Board of the Association, Association of People with Rheumatism and their Friends shares the common passions of Poland, Lithuania and Latvia

The co-operation between Poland and Latvia started back in 2007 with a meeting between the Latvian Association of Bone, Joint and Connective Tissue Diseases Patients and representatives of our organization in Riga. We exchanged experiences, discussed proposals for a closer co-operation and planned to organise further educational visits.

The Latvians visited us soon in the same year. We invited them to meet with one of our regional organisations of people with rheumatic diseases in the little western Polish town of Zbaszyn. A three-day programme offered a lot of opportunity to discuss the situation of people with rheumatic diseases in Poland and Latvia, share best practice and to meet with regional stakeholders – the mayor and the regional council.

In 2011, it was decided to organise another exchange visit – this time not only involving the Latvian association, but also the Lithuanian Arthritis Association. In Vilnius, our group was welcomed by Ona Telyčienė, the President of the Lithuanian Arthritis Association. It was very interesting to talk and exchange views about the work of our associations – the opportunities, but also the threats, in particular, to do with the difficult economic climate.

Our members were interested in how the health service in Lithuania was organised, namely what access to specialists and access to the latest therapies is like. We also spoke about fundraising and the principles of co-operation with pharmaceutical companies. Also in Riga, where our group was welcomed by Marika Karlsone, the Vice President of the Latvian association, we had a very fruitful exchange with our colleagues.

Four of our Latvian friends returned in September 2011 and participated in a presentation at the International Autumn Congress of People with Rheumatism, organized in Zbaszyn.

We very much hope to continue this successful exchange in the future as the personal contacts and insights into the work of our colleagues is invaluable for all of us.
The three-year project eumusc.net began in 2010 to address the prevention and management of rheumatic and musculoskeletal diseases (RMDs). The project is focused on raising awareness of musculoskeletal health and integrating care of RMDs.

This November, eumusc.net was able to disseminate its workings and findings at the 14th EULAR Autumn Conference for People with Arthritis/Rheumatism in Europe. The conference, held in Athens, saw over 130 delegates from 36 countries participate in discussions involving the value and place of physical activity and exercise programmes in the management of RMDs as well as the strategies for information and lobbying.

This was the first time that an ‘outside’ project has attended the conference. We were very excited at the prospect of being able to disseminate our findings and future workings with such an important audience as the principal aim of the project is to improve the care of people with rheumatic and other musculoskeletal diseases (RMDs).

Health statistic factsheets
Our stand was available for delegates to visit throughout the conference and was staffed by Babette Anhalt and Katie Edwards who provided information and answered delegate questions. Key musculoskeletal health statistic factsheets containing all 27 EU Member States were available for delegates to read and take away. Leaflets giving the general overview of the project were also available and delegates were able to sign up to our mailing list to receive information on project progress, news and alerts for newly available data.

The stand attracted a great deal of interest and confirmed the high levels of encouragement and support which the project received throughout the conference. All of the ideas and comments that were raised have given us a great deal to think about and will help us to develop the project further.

The opening day of the meeting also saw a workshop centred on eumusc.net chaired by Prof. Ingemar Petersson. Over 30 participants were introduced to the eumusc.net project including the development of the European Standards of Care (SoC) and Healthcare Quality Indicators (HCQI).

The workshop was split into several groups. People were asked to answer a variety of questions including ‘What could be the role of the PARE network in the audit process within eumusc.net?’ This question in particular drew out many useful ideas including patients and patient organisations being involved in post-translational adaptations of SoC and HCQI.

We would like to thank all of those who participated in the workshop and showed such a high level of engagement.

We also received significant support from delegates offering their help in translating and providing missing data for the key musculoskeletal health statistic factsheets. These factsheets are available for download on the project website (www.eumusc.net) making them highly adaptable for updating when new and relevant data is available. Indeed, one of the main aims for the project is to provide a live and sustainable source of information for all those wishing to gain knowledge regarding musculoskeletal health.

Involving patients
The input of people with RMDs and their organisations will undoubtedly help to not only increase the accessibility and quality of data/information but also secure the sustainability of the project in the future.

Certainly, we very much hope that our work with patients and patient organisations continues to grow, in the quest to create a sustainable and relevant network which will continue to provide a gold standard of information regarding musculoskeletal health.

From all of us here at the eumusc.net project, we would like to express our warmest thanks to all of the delegates and organisers for taking such high interest in the project and welcoming us so warmly to the extremely informative conference.

If you would like to be kept up to date with news, events and publications please visit www.eumusc.net
Agora starts fulfilling strategic goals

By the Agora Secretariat

After the inaugural meeting of the Agora on 23-24 September 2011, the newly-elected board of the organisation, chaired by Souzi Makri from Cyprus, started to look out for opportunities for implementing the strategic objectives set at the meeting.

These objectives, which will be applied over the next three years, cover awareness-raising, education and training, the creation of standards of care for the South of Europe, the development of the Agora and its national member organisations, and the establishment of partnerships with sponsors, health professionals and national and European organisations.

Three projects are already under way.

• The development of an Agora website.
• A rheumatoid arthritis (RA) patient survey, sponsored by MSD, comparing the situation of patients in the North and South of Europe. This survey is being directed to people living with RA in England, Sweden and Italy, which were identified as being representative of selected geographic regions in Europe. Other partners in the project are the Nordic Rheuma Council and NRAS (UK). Also contributing to this survey were Profs. Iain McInnes (UK), Carl Turesson (Sweden) and Marco Matucci-Cerinic (Italy).
• ‘Partners in Treatment’ – an independent educational programme designed to improve communication with doctors, which will be piloted in Romania and Spain. In the longer run, it will contribute to shorten the delay of referral, diagnosis and start of treatment, and to achieve a better management of rheumatic and musculoskeletal diseases. This project is done with the cooperation of students from the Executive MBA Programme at the IBO Business School, Amsterdam.

The member organisations of the Agora will meet for the second time at a conference that is being organised by the Agora Secretariat and a Congress task force for 21-23 September 2012 in Belgrade, with the support of BMS and Roche.

Let’s Act Now!

In June 2011, the youth exchange ‘Let’s Act Now!’ brought together 50 young people with rheumatic and musculoskeletal diseases (RMDs) from eight different countries in Estonia’s capital Tallinn. The main organiser was the Estonian Youth Rheumatism Association (EYRA) in collaboration with the Estonian Rheumatism Association. It was a great opportunity for all participants to share experiences, learn from each other and meet so many young people facing similar challenges in their daily lives.

Several workshops were organised during the week which discussed topics like comparing the different national situations of the participants, how to make the public better aware that rheumatic diseases can also affect young people and how to make people in general more tolerant adverse young people with disabilities.

The public event ‘Life with a Secret’ was organised by the participants as the final highlight of the week. The event took place in the main shopping mall in Tallinn and the young participants engaged visitors of the mall in talks, activities and had prepared an entertainment programme with exercise and singing.

It was highly successful and raised a lot of awareness. This project was funded by the European Union’s Youth in Action Programme.

Several participants of the Estonian event also participated in the EULAR Autumn Conference for PARE in November 2011. Together with other national youth representatives, they discussed the work of national youth organisations and how young people could be attracted to participate in activities and as volunteers.

Delegates of the Autumn conference voted the video collage featuring the work done during the Estonian Youth Event to be the ‘Most Innovating Poster’ in the poster competition – a great success.

EULAR continues to support the growing network of young people with RMDs in 2012.

A survey will be undertaken in order to collect information about the way young people with RMDs are organised in different European countries and to investigate the needs, obstacles, preferences and priorities of young people with RMDs and their organisations.