

Special interest group launched in the European Parliament

A European Parliament interest group on rheumatic diseases was launched on 13 October in Brussels to mark World Arthritis Day (WAD).



EULAR's Charter for Work and the WAD theme of Let's Work Together encouraged discussions that led to the founding of the interest group. The Let's Work Together theme encourages decision-makers to look at the challenges of paid and voluntary work, especially in a time of economic downturn.

An online survey for WAD was released on 12 October. It looked at how people with rheumatic diseases are treated at work. The survey had three separate questionnaires – one for people with arthritis, one for employers and one for healthcare professionals. Over 3,300 people from more than 78 countries filled in the survey. The results clearly show there is a need to raise awareness, among both employees with rheumatic diseases and their employers, of the challenges faced in the workplace. Greater awareness can make it easier for people to get suitable jobs and to secure government assistance and legislation for more adaptable and flexible working environments.

Inspirational examples of the value of work for people with rheumatic diseases were given through the Working Wonders exhibition. This was hosted by Jim Higgins MEP and held at the European Parliament on 13-16 October. The Working Wonders exhibition was based on the online EULAR photo competition Picture This, which showed the experiences people with rheumatic diseases have at work. François Dessy, a veterinary doctor from Belgium, was the winner of the online competition. An exhibition of 14 of the best photos is



Commissioner Vassiliou (centre) is guided through the exhibition by EULAR President Paul Emery (left), Nele Caeyers (far left), Kåre Birger Hagen (right) and Marios Kouloumas (far right)

travelling around Europe. The exhibition was displayed at the 12th EULAR Autumn Conference of PARE (5-8 November) in Tallinn, Estonia. The contents were chosen by a panel including Dame Carol Black (UK), Jim Higgins MEP (Ireland) and Professor Sayeed Khan, Chief Medical Adviser of the Engineering Employers Forum (UK).

EULAR was delighted to welcome the European Health Commissioner, Androulla Vassiliou, to the Working Wonders exhibition. Professor Paul Emery, EULAR President, stressed the importance of raising awareness of rheumatic diseases. This would help diagnose people in the early stages of the disease when appropriate treatment could prevent disability for many people. Commissioner Vassiliou said: 'I welcome the efforts of the European Parliament to ensure that people with rheumatic diseases benefit from the best practices available in the EU.' For more information on these

events, the Let's Work Together survey, the Working Wonders exhibition, and the country-level celebrations of WAD around Europe please see www.worldarthritisday.org and www.eular.org. ■

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DEAR COLLEAGUES

by Marios Kouloumas



This is my first editorial as Chair of the EULAR Standing Committee of PARE.

I am very honoured to be leading the Standing Committee for the next two years and I look forward to working closely with Neil Betteridge, EULAR Vice President representing national organisations of people with arthritis/rheumatism. I am delighted that there are some exciting developments in the first months of my term of office, such as the activities around World Arthritis Day in the European Parliament.

The launch of the European Parliament interest group on

rheumatic and musculoskeletal diseases, together with the EULAR exhibition Working Wonders, were very successful.

In 2010 we will continue our dialogue with European key stakeholders and work closely together to improve the quality of life of more than 100 million people with rheumatic diseases in Europe.

We would like to thank you for your commitment, support and contribution to our projects, and we wish all our readers a happy and healthy 2010.

Marios Kouloumas is the Chair of the Standing Committee of PARE

The EULAR Standing Committee on Epidemiology and Health Services Research

By Professor Angela Zink, Chairperson

The aims of the Standing Committee of Epidemiology and Health Services Research are to gather the best available epidemiologic evidence on rheumatic diseases, to standardise and validate methods for research, and to actively stimulate research in fields considered relevant for EULAR.



This is done in close collaboration with other EULAR Standing Committees, especially the one for Clinical Affairs and with PARE. We have four current activities.

- **American College of Rheumatology (ACR)/EULAR Taskforces.**

The new criteria for diagnosing rheumatoid arthritis are being validated and were presented at the ACR annual meeting in October 2009. A second taskforce is identifying the need and scope for referral guidelines for people with inflammatory polyarthritis.

- **Database on the burden of rheumatic diseases and their management.** We are working closely with the EuMuscNet project and the international World Bank Global Burden of Disease project to set up a database with the best available data on the occurrence, impact and availability of healthcare resources relevant to musculoskeletal disorders in different European countries.

- **Taskforce on Biologics Registers in Rheumatology.** The taskforce has finalised a paper called 'Points to consider when establishing, analysing and presenting data from observational drug studies'.

- **Workshop on patient-reported outcomes in rheumatology research.** In November 2009, a workshop with patients and rheumatology specialists discussed the need for EULAR's involvement in the development and evaluation of patient-reported outcomes. ■



New PARE board members: Morteza (first on the left at the top), Alison (in front of Morteza) and Jacqueline (front line in the middle) during the June PARE board meeting at EULAR House

PARE Internal News

Three new members were elected to the PARE board in June 2009 – Jacqueline Mäder (Switzerland), Morteza Abdeli (The Netherlands) and Alison Kent (United Kingdom).

'It was such a great feeling to be elected and I am very glad to use my skills for the work of PARE,' said Jacqueline. 'As a social consultant I am always focused on the social impact of rheumatic diseases. This is my main perspective on projects run by PARE.'

Morteza Abdeli has been on the board of the Dutch association for young people with rheumatism since 2004. 'I like to help young people with rheumatism, because other people have helped me,' he said. 'My main reason for wanting to join the PARE board was to represent the interests of young people.'

Alison is a former rheumatology nurse and has used her personal insight as a person with rheumatoid arthritis to help others. 'I was very fortunate to meet the members of the PARE board,' she said. 'It was a fantastic opportunity and gave me a great insight into their work. Everyone was so welcoming and it was great to meet others all working towards the same goals.' The Standing Committee of PARE wishes the three newly elected members a fruitful term of office. ■

European Parliament interest group on rheumatic diseases

By Laura Jakovljevic, Eacon

On 13 October 2009 a cross-party, pan-European interest group on rheumatic and musculoskeletal diseases was launched at the European Parliament in Brussels.

The group was set up by 20 MEPs to address the enormous social and economic burden these conditions place on society. More MEPs have since joined. The interest group will also raise awareness of rheumatic diseases and look at what the European Parliament and other EU institutions could do to ensure people with rheumatic diseases are better included in society.

At the launch of the interest group, Marios Kouloumas, Chair of the Standing Committee of PARE, stressed the importance of all parties working together to achieve full participation for people with rheumatic diseases in society.

The group is chaired by Edite Estrela MEP (Portugal), with Jim Higgins MEP from Ireland as co-chair. On the same day, Jim



Edite Estrela MEP (Portugal), speaking at the launch event of the European Parliament interest group on rheumatic and musculoskeletal diseases

Higgins also launched the Working Wonders exhibition linked to the EULAR Work Charter. European Health Commissioner Androulla Vassiliou also expressed her support and enthusiasm for the interest group and Working Wonders. The first meeting of the interest group was planned for 3 December 2009. ■

Health topic for EU Presidency

Every European country that hosts the rotating European presidency selects a health topic and holds several conferences about it. EULAR has been in close contact with the Belgian authorities for the past year on the setting of the Belgian presidency health agenda. EULAR met with the Belgian authorities over the summer to discuss a partnership for one of the major conferences. Discussions are still ongoing with the Belgian diplomacy office and the final decision should be announced by the end of the year.

Fit for Work campaign launch

By the Work Foundation

A new study has found that musculoskeletal disorders (MSDs) account for nearly half (49 percent) of all absences from work and 60 percent of permanent work incapacity in the European Union.

Based on this study by the Work Foundation, the Fit for Work campaign was launched on 30 September at the European Parliament in Brussels by MEPs Edite Estrela (Portugal) and Antonya Parvanova (Bulgaria). 'Only co-ordinated action between governments, business, the healthcare community and patients will allow those living with MSDs to stay working, contribute to society and maintain a good quality of life,' said Edite Estrela MEP.

Antonya Parvanova MEP added: 'Once governments have agreed that MSDs are a priority, they should set out national welfare and public health plans addressing these conditions.'

The full socio-economic cost of MSDs in Europe is estimated to be €240 billion. The study was conducted across 25 European countries by The Work Foundation and found that 100 million Europeans have chronic musculoskeletal pain with up to 40 percent having to give up work due to their condition.

'As Europe now struggles to emerge from the global recession, policy-makers should look at how labour productivity in businesses is being undermined by these painful conditions,' said Stephen Bevan, managing director of The Work Foundation.



Stephen Bevan, managing director of The Work Foundation (UK), launching the Fit for Work campaign at the European Parliament

For more information, visit www.fitforworkeurope.eu or, alternatively, contact Jenny Taylor on +44 20 7976 3519 or jtaylor@theworkfoundation.com ■

Looking to the future

Neil Betteridge elected for second term as EULAR Vice President

Neil Betteridge (NB) developed juvenile arthritis when he was three-years-old. Long before he knew of phrases such as wheelchair accessible, he was facing disabling features like inaccessible transport and school buildings. Lucky enough to have recuperated well in his adult life, he was able to find a profession in which he could address some of the issues he encountered in his childhood.

Currently the chief executive of Arthritis Care, Neil was closely involved in creating the first disability legislation in the UK (Disability Discrimination Act 1995). He chaired the UK Government's Disabled Persons Transport Advisory Committee, and is still a Patient and Public Adviser to the Department of Health in England. From 2001 to 2005, Neil was EULAR Vice President representing the patient organisations, the former Chair of the PARE Manifesto board, and was also Chair of the UK national representative in PARE – The Arthritis and Musculoskeletal Alliance (ARMA). He is now serving a second term as EULAR Vice President.

PARE: Your key EULAR position is a huge commitment of time, energy and responsibility. What made the current work of PARE so attractive that you decided to come back?

NB: For me, this is a phase two project. From 2001 to 2005 my priority was to integrate PARE's activities into the overall work of EULAR. My mantra was 'nothing about us without us', meaning EULAR's work is most effective when the person/patient is at the centre of it. I was lucky enough to work alongside presidents such as Josef Smolen and Tore Kvien who completely recognised the value of greater collaboration, something which Professors Breedveld and Emery have continued to develop enthusiastically.

PARE: Which projects/activities would you like to see being developed and strengthened during the next four years?

NB: Now that EULAR's various stakeholders are fully and positively committed to



Neil Betteridge. (Left) Speaking in the European Parliament in Brussels at the 2005 Alliance Against Arthritis initiative, during his first term as EULAR Vice President

implement models of effective collaboration (it can be very intimidating to step up and work with world renowned clinical experts). Help with translation costs is sometimes needed. Doctors have to learn English for their profession, but volunteers with rheumatic disease associations do not.

partnership, we have new opportunities for pioneering work. For example, the model of involving people with rheumatic diseases in all of EULAR's work, including research and the production of guidelines, is a progressive model from which the whole world can learn. But there are challenges for all parties too, and representatives from PARE associations across Europe need support. This includes support to develop and

But it is on campaigning work where people with rheumatic diseases most need to lead. Politicians, journalists and the general public always listen more attentively to people who understand a particular condition first-hand, than they do to professional bodies who can sometimes be dismissed as lobbying for their own professional interests. We have already seen great partnership work within EULAR to persuade the EU to do more for people with

rheumatic diseases. In my view this increase in profile is set to rise dramatically over the next few years. These are very exciting times for us.

PARE: Europe is currently facing a time of hardship. Several PARE organisations are struggling financially and people with arthritis might feel the consequences in their daily lives. What activities are planned to support the efforts on a national level and to keep raising the profile of arthritis/rheumatism at the European level?

NB: We all face a hugely serious challenge here. Just when people with rheumatic diseases need support more than ever, public and private funds are in much shorter supply. Support is in danger of decreasing because organisations are adversely affected by the economic downturn. Fortunately, we know that there is high-level political interest in the work agenda at the EU level.

EULAR can best support people by pushing even harder for support from policy-makers. The recent World Arthritis Day activities, at both national and pan-European levels, demonstrated how this can be done effectively. Politicians know it is better if people who can work are supported to do so. They would rather receive tax from people than spend money on benefits and additional health services. So we have a huge opportunity to generate more support in this area which will help people wherever they live. However, we must be equally vigilant to ensure that those who do voluntary work, housework, or those who cannot physically work, are not neglected along the way.

PARE: Looking four years ahead, what is your vision for people with arthritis/rheumatism within EULAR?

NB: I genuinely believe we will have such a well developed integration between health professionals and people with rheumatic diseases that the concept of collaboration will not even be discussed, except to keep improving it. I believe we will have a large group of well supported, passionate advocates of EULAR's work who will add value to the world class work which scientific members will doubtless continue to provide, in a culture of mutual respect. Towards the end of my term of office, I would like to hear EULAR members from all fields laughing in amusement as they say: 'remember the time of the "nothing about us without us" campaign?' I want them to be able to say: 'how could we ever have lived without collaboration?' ■



Emmi Myöhänen, winner of Stene Prize 2009, receives her award at the opening ceremony of the 2009 EULAR Congress

Edgar Stene Prize 2010

What support would you have appreciated when you were looking for work? What could have gone better? EULAR has launched the 2010 Edgar Stene Prize essay competition, under the theme 'Working with a rheumatic disease – my daily reality.' We would like to know about the positive experiences but also the daily challenges you went through when finding a job and staying in work, or looking after your family if you were not in paid employment. Entries should be sent to your national EULAR member organisation of people with arthritis/rheumatism by 31 January 2010. A national jury will select the winning essay for your country. This should be received by the EULAR secretariat no later than 21 February 2010. The award will be presented at the EULAR Congress 2010 in Rome. For competition rules and more details please visit www.eular.org. ■

Spain and the Czech Republic receive grants

Every year, EULAR provides grants to PARE organisations for educational exchange visits. The aim is for smaller groups to establish a fruitful mentoring relationship with another organisation – known as a teaching organisation – within the PARE European network. In 2009, grants were given to the Czech Republic and to Spain, whose plans must be put into practice before the end of 2010.

The focus of the Czech Republic application is structural development, communication and motivation strategies, as well as organisational growth. Germany will be the teaching organisation. The Spanish project, developed with the Netherlands, covers campaigning methodology, the development of patient support initiatives, and capacity building. A report on activities must be handed to EULAR by 30 November 2010.

The grants help smaller, less-developed patient groups supporting people with rheumatic diseases, to develop their skills by working with other PARE members. Groups that participate in exchange visits are able to learn from groups who are open to sharing their knowledge, projects and materials.

The projects developed under the educational exchange programme must demonstrate immediate and long-term benefits for people with rheumatic diseases in the organisation's regional area of influence. People with rheumatic diseases must be actively involved in the development and application of projects. The PARE Standing Committee would like to thank all organisations who applied this year.

The 2010 educational exchange visit programme is now open for applications. All entries must be presented to EULAR by 30 April. Please visit www.eular.org for more information. ■

12th EULAR Autumn Conference for PARE



The focus for the 2009 EULAR Autumn Conference for PARE was on working with employers.



The conference on 5-8 November helped EULAR national organisations of PARE to collaborate better with employers' organisations and individual employers. Su Wang, group head of health at Royal Mail, one of Britain's largest employers, informed delegates about RehabWorks, a highly successful programme for helping people with musculoskeletal conditions return to work. At the end of her presentation Dr Wang introduced the idea of European minimum standards of work for people with rheumatic diseases, which delegates then developed in a workshop. Presentations on legislation and work adaptations were given by Zinta Podniece from the European Agency for Safety and Health at Work, and Peter Oesch, head of ergonomics at the Valens Rehabilitation Centre in Switzerland. These were followed by workshops to help delegates build a business case for employing people with rheumatic diseases.



John McGregor from Arthritis Care (UK) presented his highly successful Preparing 4 Work training programme, which has also been adopted in Switzerland. In a following workshop, delegates discussed materials to support people with rheumatic diseases to gain employment. A tool kit with the support materials will be available for national adaptation and translation in 2010.

Other highlights of the conference were the Working Wonders exhibition, shown for the first time. It raised a lot of interest and will travel through Europe in the coming months. François Dessy from Belgium, the winner of the Picture This competition, was awarded his prize at the opening of the conference. François' winning entry will be included in the exhibition.

There was a poster session which allowed countries to showcase their 2009 projects and campaigns. It stimulated many fruitful discussions. The Share Fair sessions provided national organisations with the opportunity to share and learn from best practice and how to benefit from the EULAR educational visit programme in the future. ■

[Top] Tallinn hosted the EULAR Autumn Conference in 2009

[Left] The exhibition panel of the online photo competition winner – François Dessy from Belgium



What's up doc?
François (Belgium)

My world revolves around animals. As you can see I am a veterinarian. This wonderful job gives me the opportunity to learn every day and to meet all kinds of different people from all levels of society. If you know how to feel things, animals can give you a lot in your life and perhaps make it beautiful; animals never lie. When I was 15 years old I was diagnosed with arkylosing spondylitis but I have been lucky to benefit from new treatments and have been able to realise some of my dreams.

"I have been lucky to benefit from new treatments and have been able to realise some of my dreams."

2010 EULAR Congress in Rome

Rome is going to be a busy city in 2010 – and we are not talking about the traffic. The EULAR Congress in 2010 will present the latest scientific discoveries and offer many new themes on which to reflect. The PARE programme will feature several themes for discussion and participation. These will include diversity – engaging with all sections of society, and balance between work and leisure. Other sessions in the programme will look into the latest developments in the political area, how to improve marketing around rheumatic diseases, patient participation in research, and informed decision making. Please visit www.eular.org for more information. ■



Rheumaliga is here to help

By Rheumaliga Schweiz



Rheumaliga
Ligue contre le rhumatisme
Legg contro il reumatismo

Having arthritis/rheumatism changes your everyday life. Coping with pain and restricted movement take away vital energy and affect all areas of your life. Arthritis/rheumatism is usually invisible to other people. Through its services, the Swiss Rheumaliga is committed to those with rheumatism and provides the following support.

- **Information:** this is provided through a variety of publications and the website www.rheumaliga.ch
- **Advice:** is provided on all matters relating to rheumatism by telephone, email and face to face.
- **Rheumaliga courses:** these are attended by more than 25,000 people every year. Courses include back training, a special form of gymnastics for people with osteoporosis, water-based fitness training, specialised weekend seminars, workshops for families with a child with rheumatism, and patient training workshops.
- **Further training for specialists:** training sessions for course-leaders and family doctors are held regularly.
- **Self-help group work:** great emphasis is given to self-help group work in all regions of Switzerland.



Rheumaliga Schweiz provides a gym course for people with osteoporosis and information and support to its members

- **Everyday life assistance:** life with rheumatism often involves pain and a lack of strength and mobility. We provide information to help people to simplify day-to-day living.
- **Publications:** we make the public, the media and politicians more aware of the requirements of people with rheumatism through media work and publicity.
- **Social and health-policy commitment:** on a political level, Rheumaliga Schweiz is committed to a better quality of life, and better provision and support for people with rheumatism. ■



An overview of the Croatian League Against Rheumatism

By Frane Grubisic, Secretary General of the Croatian League Against Rheumatism

The Croatian League Against Rheumatism is a non-profit association founded in 1992 in Varaždinske Toplice. It was formerly known as the Association of Rheumatic Patients in Zagreb. The basic activity of the League is to provide ongoing education to members, through a number of popular lectures and social activities across the Republic of Croatia. People can obtain information about their condition and receive advice on treatment and self-management.



The Croatian League contributes to the education of their members through lectures and other initiatives



The League has 12 regional branches across the country with more than 3,600 members. Our main office is at the department of rheumatology, physical medicine and rehabilitation at the Sisters of Charity hospital in Zagreb. The referral centre for spondyloarthropathies is based at the Croatian Ministry of Health and Social Welfare. The League has four com-

mittees: economic and promotional activities; legal services; publishing activities; and social and humanitarian activities.

Our future plans include a more active participation in international meetings and conferences, and the national implementation of the EULAR Charter for Work. We also want to establish links with other patient organisations in Croatia and other

countries. The official website of the League is www.reuma.hr. It has some of our very popular booklets with important information that is designed and written for people with specific rheumatic diseases (rheumatoid arthritis, ankylosing spondylitis, painful shoulder, and many others). The Croatian League Against Rheumatism also publishes a magazine, *Reuma*. ■

The role of Lupus Europe



By Lupus Europe

For over 20 years, the European Lupus Erythematosus Federation (ELEF) helped to link all people with lupus across Europe. Since September 2008, the group has worked under the name of Lupus Europe.

The vision of Lupus Europe is that all people with lupus throughout Europe are given the support they need to live a comfortable life. Lupus Europe wants to raise awareness of lupus and the impact it has on the lives of people living with the illness. Our new website is expected to be online by the beginning of December.

On World Lupus Day on 10 May each year, many countries organise activities to help make our voices heard. During other occasions such as the EULAR Congress, the International Congress on systemic lupus erythematosus (SLE) or other patient-centred gatherings, Lupus Europe's presence gains a lot of attention for this sometimes overlooked condition. The organisation has an annual convention in September, where delegates from the 22 member organisations meet and share experiences. Topics such as fundraising, medical updates and awareness, were on the agenda in Strasbourg in September 2009.

The majority of the board of Lupus Europe are lupus patients themselves. In this way the organisation is a real user-led group. A medical advisor supports the team when medical issues arise. One of the highlights for 2010 will be the ninth International Congress on SLE in Vancouver in June. ■



The board of Lupus Europe

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Celebrating Scleroderma Day across Europe

By the Federation of European Scleroderma Associations (FESCA)

Scleroderma Awareness Day on 29 June was created by the members of FESCA to tell people what it means to have this disabling disease. On this day, we celebrated the gifted Swiss artist Paul Klee and all others struggling with scleroderma. We campaign for a world in which such rare diseases are not forgotten – and demand equal treatment and care across Europe.



The day was designated throughout Europe to recognise the bravery of those who live with scleroderma. Twelve FESCA countries held celebrations with very positive feedback. Despite financial shortages, national conferences were organised for either patients or doctors in Belgium, The Netherlands, France, Hungary, Cyprus, and Portugal. Press conferences and advertising campaigns were held in Belgium, Italy, Hungary, Spain, Ireland, UK, and Cyprus, including a 30-second TV commercial in France, run on five channels.



In Spain, a decorated van drove around cities to give out information, and there was a subway poster campaign. In Ireland, the Minister of Health launched Scleroderma Awareness Day simultaneously with the very early diagnosis of systemic sclerosis (VEDOSS) project. In Italy, information tents were set up in cities. An identical poster and leaflet showing a Klee painting was used in all EU campaigns and translated into national languages. The first awareness day was a huge success. ■



European activities on Scleroderma Awareness Day included a mobile information unit in Spain and the launch of the VEDOSS project by the Minister of Health in Ireland

BREAKTHROUGH

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