

Think Positive on World Arthritis Day

People who live with a chronic rheumatic disease have times when they feel emotionally down. It takes a person with a strong resolve to face the challenges of everyday life when living with a painful chronic disease.



World Arthritis Day (WAD) falls on 12 October each year. This year's WAD theme was *Think Positive*. The aim of the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (PARE) is to draw attention to the psychological effects of living with arthritis/rheumatism, which are often overlooked. People with arthritis/rheumatism need psychological support and access to self-management courses to fully participate in society.

A survey was developed for the WAD website – www.worldarthritisday.org – for people with arthritis/rheumatism and their carers to register their views. For the first time there was also a section for health professionals to complete. The survey enjoyed great interest and was completed by over 4,000 people from 50 countries.

The results showed that 97 per cent of people with arthritis/rheumatism and carers think that the disease affects them and people they care for emotionally, and five per cent say that it may lead to depression. Even so, only 35 per cent of respondents



Robert Johnstone, representing the PARE Board during the Think Positive walk organised by ARAM for World Arthritis Day



(Left) The Cypriot Minister of Health, Dr Christos Patsalides, speaks to journalists after the meeting with a delegation of the Cyprus League

(Below) EU Commissioner Androulla Vassiliou (third on the right) at the opening of the World Arthritis Day commemorations in Cyprus, organised by CYPLAR



said they raise the issue with their doctor.

The findings from the survey were used by national member organisations in their campaigns. Marios Kouloumas, President of the Cyprus League Against Rheumatism and future Chair of the Standing Committee of PARE said: 'The call for better psychological support was very well received by our Ministry of Health. However, the recognition and official support on behalf of the Government regarding this issue was still missing. We are now talking with the Health Minister on how to design ways of having more institutional support.'

PARE member organisations were provided with tools to help promote WAD. These included a campaign poster featuring the survey results and a *Think Positive* leaflet with stories from people with arthritis/rheumatism, as well as practical tips. Marios said: 'We are using the leaflet as a tool to help bring the experience of people with arthritis to the attention of policy makers. It has proven to be very useful.' The WAD *Think Positive* survey is supported by an educational grant from Pfizer.

The activities prepared by the organisation of people with arthritis in Malta (ARAM) also received considerable attention. ARAM organised a walk around the new Mater Dei hospital, which was attended

by members, and their families and friends. The Parliamentary Secretary, Dr Joe Cassar, officially opened the event and joined the walk. The event was broadcasted on TV and published in the newspapers. ■

Video diaries – positive moments

As a part of the WAD 2008 campaign, people from across Europe created short films – video diaries – using special camcorders to 'show and tell' their physical and emotional challenges, how they overcome these and how they maintain a positive attitude. Edited highlights from video diaries from the Czech Republic, Poland, Portugal and England were featured at the EULAR congress in June 2008 and enjoyed a great deal of interest from delegates. The video diaries project is supported by an educational grant from Wyeth.

DEAR COLLEAGUES

by Sandra Canadelo



What do you think it is like to have a rare disease? The impact of knowing that you have a more common chronic disease like rheumatoid arthritis (RA) is already a burden. Just imagine what it would be like to have to deal with something only a handful of people in your country have to live with.

RA is a target of interest by scientific researchers and there are regularly updated guidelines for treatment. When I look at my friends with a rare disease like scleroderma, I have no doubt that it takes a strong person to manage the isolation, the physical change, and the lack of information and investment into research

in this field. It is for people like them that EULAR's initiative to support more awareness for rare diseases is so important.

In the coming years EULAR will concentrate on bringing to the surface the issues surrounding orphan diseases, both at research and awareness-raising levels. In the name of our friends and relatives with these rare diseases, we look forward to playing our part. For us they stand as examples of courage and resilience – an inspiration to us all.

Sandra Canadelo is the Chair of the Standing Committee of PARE

New PARE Board members



The Standing Committee of PARE elected two new members for the PARE Board in June 2008. They are Maria Batziou from Greece (top left) and Sesilie Halland from Norway (top right). David Magnusson, from Sweden, was re-elected.

'I am very glad to be the representative of my country, Greece, on the PARE Board,' said Maria Batziou. 'I feel honoured and I would like to thank everyone who voted for me. It is a big responsibility and I intend to do my best at this post. Together we can have a very good and fruitful co-operation'.

Sesilie Halland introduced herself by saying: 'I'm very happy to become a part of the PARE Board and look forward to influencing the work done for people with arthritis in Europe. I have had juvenile arthritis since I was 14 years old and am active in the Norwegian Rheumatism Association, especially in their work for children, young people and families. I am especially interested in working for strong youth organisations and for the well-being of younger people with rheumatism.' ■

EULAR Standing Committee for Clinical Affairs (ESCCA)

by Professor Alan Tyndall, Chair, ESCCA
Head Dept of Rheumatology, University of Basel, Switzerland

The committee deals with all aspects of clinical activities. This ranges from recommendations, points-to-consider, criteria, endorsements, non-commercial investigator initiated clinical trials and special task forces. The committee has begun to work with the American College of Rheumatology. It was previously called ESCISIT (EULAR Standing Committee for International Studies Including Therapeutic Trials).

The past decade has seen the evolution of EULAR into a dynamic, science-driven organisation taking a lead in basic and clinical research of musculoskeletal disorders as well as being a partner in international organisations dealing with healthcare and politics. ESCCA has been at the forefront of this development, having been given a clear structure and systematic operating

'In the past decade EULAR has evolved into a dynamic, science-driven organisation'

procedures by the two previous chairmen, Prof Piet van Riel and Prof Maxime Dougados (Dougados M et al, *Ann Rheuma Dis* 2004; 63:1172-6). This has resulted in over 15 publications in high impact peer-reviewed journals over the past eight years, which have formed the basis for ongoing clinical research programmes.



(Above) Research and clinical trials are just part of the work that ESCCA undertakes

Professor Alan Tyndall, Chair of ESCCA

A full summary of activities is available in the 2008 EULAR annual report and includes collaboration with PARE and Allied Health Professional projects.

ESCCA represents EULAR in the European Science Foundation initiative concerning non-commercial clinical trials and is the entry point to EULAR for special task force activities such as the EULAR Scleroderma Trials and Research (EUSTAR) group. ■

EULAR present at 11th European Health Forum



EULAR attended this year's 11th European Health Forum from 1-4 October 2008, in Bad Hofgastein. The forum theme 'Values in Health – from visions to reality' included interesting topics such as: promoting health, preventing disease, health ethics, rare diseases, and promoting patient safety.

The strategy that is developed at an EU level may be strongly influenced by the effect of common values being debated by stakeholders, as well as the effect these values have on health policy and healthcare. This annual event in the area of European public health policies is an excellent platform to talk with other participants, including many experts, policy makers, interest groups and decision-makers.

EU Commissioner Ms Androulla Vassiliou addressed the participants. Tamsin Rose, an independent advocacy expert from Brussels, secured an opportunity for a meeting with a group of representatives from non-government organisations. Ms Vassiliou heard a short statement from each representative about their own organisation and then asked for comments on difficulties in working with DG Sanco, the Health and Consumer Protection Directorate General. After some discussion, Robert Johnstone, as a person with arthritis on behalf of EULAR,



EU Commissioner Androulla Vassiliou attended the European Health Forum and met with a select group of NGO representatives, including PARE Board member Robert Johnstone

said it would be good to concentrate on how organisations might help her work more effectively with groups around Europe. This was well received and she promised more time to hear individual issues at future events.

Before the forum started, the PARE Board benefitted for a third time from the

thoughtful and warm hospitality of Dr Christoph Köstinger and the Gasteiner Heilstollen. They kindly invited the group to hold their third board meeting prior to the forum in Bad Hofgastein. Once more we are very thankful for their kind support in helping to make the voice of people with arthritis heard. ■

Future EULAR projects

Alliance Against Arthritis 

In the next five years, EULAR will bring to the attention of EU decision-makers and officials the issues surrounding orphan diseases and the need for further investment into this area of rheumatology. The EULAR Public Affairs Group Leader, Professor Josef Smolen, is confident that the outcomes will have a big impact on Members of European Parliament and European Commission officials, especially through the personal input provided by people with arthritis.

Since the start of Alliance Against Arthritis there has been an increasing awareness on the part of the European Parliament (EP) and the European Commission of the huge impact that rheumatic diseases have on the lives of more than 100 million Europeans and on the community they belong to. This recognition was evident in the support given to two EP Written Declarations on rheumatic diseases and through the acceptance of the EU musculoskeletal network project recently presented by EULAR.

'These good steps must be followed through,' said Professor

'There is increasing awareness of the huge impact rheumatic diseases have on the lives of 100 million Europeans'

Smolen. 'Rarer diseases must be highlighted, and so must the need to find positive ways to improve the situation at the level of citizens' rights, disability and employment rights of people with chronic conditions.'

This position is supported by Ona Telyceniene, president of the Lithuanian Arthritis Association. 'People with arthritis can be useful citizens, fulfilling their role in society, as long as they are given a fair chance. A consistent approach to employment support measures and disability and/or chronic disease recognition across Europe will definitely be an objective to fight for.' ■



Bright results in the City of Light

From 11-14 June, more than 14,000 participants were welcomed to the Parisian Palais des Congrès for the EULAR congress. In its usual fashion, the glorious Ville-lumière welcomed the EULAR congress in 2008 with open arms.

The congress featured many interesting sessions and the latest state-of-the-art discoveries in European research and best practice.

Highlights included: oral and dental aspects of rheumatic diseases, aiming for remission in RA after TNF – new biologics, and drug safety – making the decision to withdraw a drug. EULAR allied health professionals looked at the theme of work in their session: overcoming work limitation and joint pain.

At the start of the congress, Maarten de Wit, EULAR Vice President representing national organisations of people with arthritis/rheumatism stressed the importance of building up and developing effective, open and equal relationships within EULAR.



The excellent attendance of PARE and joint sessions should be highlighted. The audience showed great interest in the congress themes and participated actively. The programme of the Standing Committee of PARE proved to be a source of important information and knowledge. The poster presentation session obtained an impressive

number of visitors. More than 200 delegates representing national organisations of people with arthritis attended sessions such as pregnancy and arthritis healthcare, and workshops on patient participation in the development of recommendations.

A high point of EULAR's union was the presence of all Secretariat staff members at the EULAR booth for the first time. It was a huge success to be able to feature the World Arthritis Day video diaries at such a prominent and significant location and the staff manning the booth received queries from interested parties. ■

Paris was highlight of the year



By Cathy Leibman, Director, Arthritis Foundation of the United Arab Emirates

As I reflect on my first year as Director of Operations, Emirates Arthritis Foundation (EAF), it is without a doubt that my professional highlight was attending the PARE Programme at EULAR in Paris this year.

EAF's objectives are patient education, community programming and establishing an endowment fund for people who are unable to receive the premium healthcare services they deserve. These are all important objectives which the Foundation continues to achieve since its launch in 2006.

However, the most important take-home message EAF received, and where we will now model ourselves on PARE, is to establish committees which are patient driven, thus increasing the awareness of policy makers and the public. As a newly established Foundation, it was beneficial to benchmark our work and obtain a wealth of knowledge from more established groups.

Although we are not a European member, I trust that an alliance will continue between the United Arab Emirates and PARE. I thank PARE for including us on your World Arthritis Day website where your survey was available in Arabic and look forward to a fruitful personal and professional association.

Following the Northern Lights

The 2009 EULAR congress will be from 10-14 June in Copenhagen. Connie Ziegler, from the local organising committee, said: 'We are eager to welcome our PARE colleagues to our beautiful capital



and promise they will be enjoying the best we have to offer.' The PARE congress programme will feature interesting themes such as: let's talk about sex, patient participation in the education of health professionals, and the socioeconomic impact of rheumatism. 'We are looking forward to seeing you there,' said Connie.



Data is a powerful tool

EULAR's project for the gathering of data for arthritis and rheumatism in Europe, was successfully received by the European Union. The EU informed EULAR of the application's success and steps are currently being taken to put the project into practice.

Maarten de Wit, EULAR Vice President (pictured above) representing organisations of people with arthritis/rheumatism in Europe, was part of the project development team. 'We are very happy that in the summer of 2008 the EU has awarded our application without any hesitation,' he said. 'We may consider this achievement as an important result of all our efforts to raise awareness of arthritis in the European arena.' Maarten kindly answers a few questions below, which we would like to clarify.

PARE: Why and when did the idea of developing a musculoskeletal atlas for arthritis come up?

MdW: The idea came up during the two most recent PARE autumn conferences. We looked at health economic arguments to campaign for better access to arthritis healthcare services. To build a case we need strong data demonstrating that better healthcare arrangements will improve the quality of life of people with arthritis and is cost-effective in the long run. But we were confronted with a huge lack of data. For a lot of countries in Europe, reliable and comparable data about health indicators such as the number of rheumatologists, number

of hip or knee replacements, support of specialised nurses, or waiting lists, are not available. Even basic information about the number of people affected by a specific rheumatic disease (epidemiology) is often not collected or very difficult to find and to read.

PARE: What do you consider the main focus of the EUMUSC.NET project?

MdW: It is an ambitious project with several objectives and a large budget. Over the coming three years the EU will co-fund the EUMUSC.NET project with one million euros to establish a sustainable surveillance and information network to collect and disseminate important arthritis healthcare information. EULAR as well as the collaborating partners will also contribute money, expertise and commitment. Part of the project is the development of standards of care for osteoarthritis and rheumatoid arthritis, based on evidence and best practice.

PARE: What are the next steps?

MdW: After we received the confirmation, a process of negotiation over the details of the project and the budget started, which is usual with these grants. The challenge now is to successfully undertake the different parts of the project – hopefully we can start at the beginning of 2009.

PARE: How and by whom will the project be implemented?

MdW: The project will be carried out by a unique consortium of academic

rheumatology centres and national patient organisations, across Europe. Professor Tony Woolf, from the Royal Cornwall Hospitals Trust (UK), is the driving force behind the project. Besides the academic institutes, five PARE members from Belgium, Lithuania, Netherlands, Sweden and the UK will actively participate in the project. The Dutch Arthritis Patient League (Reumapatiëntenbond) will take the lead in one of the work packages, concentrating on the dissemination of the outcomes of the project.

PARE: How will this project benefit the PARE membership?

MdW: At the end of the project we hope that all people working in the field of rheumatology, including all national patient groups, will have easy access to reliable and understandable epidemiological and health economic data on rheumatic diseases in their countries. These data should empower them to lobby for better healthcare provisions. With the outcomes they can contact high profile decision-makers and start the dialogue to improve the quality of care, for instance by promoting or developing comprehensive national strategies to reduce the burden of arthritis. On an international level, the project will help to harmonise standards of care of rheumatic diseases across all EU member states. And doing this, it will also raise the profile of rheumatic conditions among all stakeholders. ■



Views of beautiful Budapest – the location of the 11th EULAR Autumn conference for PARE

EULAR 2008 Autumn Conference for PARE

By Nina Rainold, Ruder Finn

The 11th EULAR Autumn Conference for PARE took place from 7-9 November in Budapest. Hosted by the Hungarian Arthritis Association (HAA), this year's theme was **Work and rheumatic diseases: your right to work**. While the focus was on paid employment, the definition of work included voluntary work, family care and education.



More than 100 delegates attended from more than 30 countries, including for the first time representatives from South Africa, Russia and the United Arab Emirates. Delegates were given insight into work and rheumatic diseases in Hungary.

Dr Tuulikki Sokka, a rheumatologist from Finland, gave the first keynote presentation on the impact of rheumatoid arthritis and the ability to work in Europe, based on the findings from her research study, QUEST-RA.

Dr Stephen Bevan, employment specialist and managing director of the Work Foundation in the UK, presented highlights from the *Fit for Work* report and informed the delegates about similar reports being prepared in other European countries.

A key outcome for the conference was

a Charter for Work for PARE. A framework for the charter was discussed by delegates in workshops with an opportunity to provide further comment throughout the conference.

Saturday featured two keynote presentations. Professor Sayeed Khan, a GP and expert in occupational medicine, sitting on a number of high-profile committees involved in work and well-being, and advisor to EEF, the manufacturer's organisation, provided an insight into the employer's perspective and shared tips on how people with rheumatic diseases can work with employers. Professor Paul Emery, president elect of EULAR and rheumatologist at the University of Leeds spoke about how doctors and the healthcare team can support people with arthritis/rheumatism to participate in work.

The presentations were followed by workshops to look at how organisations could develop collaborations and initiatives with employers, healthcare professionals and other organisations in their countries.

On Sunday, Dr Monique Gignac, a Canadian psychologist, who is involved in a number of exciting research projects into arthritis and work, provided insights on the psychological impact of employment

Stene Prize 2009 to focus on rare diseases

One highlight of the opening ceremony of the forthcoming European Congress of Rheumatology in Copenhagen, Denmark, on 10 June 2009, is going to be the awarding of the Edgar Stene Prize. Named after Edgar Stene, a founder of the Norwegian organisation of people with arthritis and a person with ankylosing spondylitis, the theme for the prize is 'Rare but not less severe – the challenge to cope with a rare rheumatic disease'.

The EULAR national member organisations of people with arthritis are invited to hold national competitions for people with a rare rheumatic disease (or parents caring for a child with a rare rheumatic disease under 16 years of age).

The European winner is to be announced by 15 April 2009 and will be entitled to a prize of 2,000 euros, as well as to travel to Copenhagen and accommodation. The jury welcomes many entries from all over Europe. Please participate by sharing your experiences.

Applicant essays to the Stene Prize must not exceed two typewritten pages and should be written in English, French or German. The essays should all be submitted at national level to the local PARE member organisation by 31 January 2009. A list of the member organisations can be found on the EULAR website, please visit www.eular.org for more information. Each national jury should submit the best entry to the EULAR Secretariat by 28 February 2009. The jury's decision is final. All persons connected professionally with rheumatology are excluded from the competition.

and unemployment. In the following workshops delegates were able to roleplay scenarios with employers and co-workers to help identify techniques to help improve communication.

The Standing Committee of PARE extends special thanks to platinum conference sponsors: Merck and Co, Roche and Wyeth, and gold sponsors: Abbott, Schering Plough and UCB, whose generous support by unrestricted educational grants made the 2008 autumn conference possible. ■

News from the cradle of the Western world

By Maria Batziou, ELEANA

The Greek League against Rheumatism is a non-profit organisation acknowledged by the Greek Government. It was established in 1979 and currently has 460 members.



The League has taken important steps during recent years, although there is a lot to be done in the future. Some of the most fundamental goals to be achieved in the near future are to motivate volunteers by showing them that their contribution in the League can benefit society; to encourage patient participation in the development of guidelines and recommendations; to motivate local politicians towards the improvement of standards of care for people with rheumatism; and create more NHS posts for rheumatologists. At the moment there are only 45 rheumatologists in public hospitals, only five of these are

paediatric rheumatologists.

We now have a helpline service, which has been successfully operating since May 2007. We aim to extend this service and to use the data obtained through it in other activities. There is a new film about the everyday life of people with rheumatoid arthritis, whose director is a prominent and health-aware Greek public figure. It came out in the autumn of 2008 and we hope it will attract a lot of interest in the community. Another project to be realised soon is an updated brochure on rheumatic diseases.

The election of a Greek representative to the PARE board from May 2008, the agreement of five pharmaceutical com-



The PARE board meeting in Athens – hosted by ELEANA and its President, Dimitris Kassimos (above, first from the right)

panies to sponsor the activities of the League for the first time in its history, and the enthusiasm of volunteers are very positive reasons to motivate us to achieve all the things that are still to be accomplished. ■

Exchange programme for Polish families

By Jolanta Grygielska, Association of People with Rheumatism and their Friends

Deutsche RHEUMA-LIGA
Bundesverband e.V.



In the scope of the EULAR Educational Exchange Visit Programme, the Association of People with Rheumatism and their Friends were invited by the Deutsche Rheuma-Liga (DRL) to participate in a disease management weekend for families with children with rheumatic diseases on 18-21 April 2008 in the holiday centre of Blossin, near Berlin.

DRL usually organises two events a year, one in Spring and a second one in the Autumn. The training consists of three sessions with invited professionals, as well as social events for networking. The place and subject of the meeting are chosen by the parents according to their personal needs and the whole family is required to participate. Some of the lectures are attended by parents alone and there is the possibility of getting advice from the speakers on their individual problems.

For the meeting in April attended by the Polish Association, parents invited a



Polish exchange visit participants valued the experience of the German disease management weekend for families in Blossin

physiotherapist and an occupational therapist. During the session with the latter, it was possible for participants to try out the technical aids and tools to make daily tasks easier, such as special knives for slicing bread and adapted scissors.

In the end, the Polish delegation visited the regional office of DRL in Berlin and learnt how the German organisation for children with rheumatism and their

relatives is structured and develops its work.

The educational visit in Germany provided very important and useful information for the development of a new structure for securing assistance to children with arthritis in Poland. It provided new ideas for the work developed by our Association of young people with rheumatic diseases and their families. ■

Fibromyalgia in the spotlight of the European Parliament

By Laura Jakovljevic, Eacon

The European Network of Fibromyalgia (FM) Associations (ENFA) was officially founded in September 2004 and represents people with fibromyalgia in Europe. ENFA is composed of member associations from 11 countries: Belgium, UK, Denmark, France, Germany, Israel, Italy, Netherlands, Portugal, Spain and Sweden.

It is estimated that between 10 and 14 million people in Europe are affected by fibromyalgia. Approximately 87 per cent are women, mostly between 35 to 60 years of age. Fibromyalgia has a devastating impact on both those who have to live with it and their carers. Moreover, it also imposes a large financial burden on society. ENFA's mission is to raise awareness of fibromyalgia among politicians, policy-makers, the scientific community and the general public at the European level.

Currently, people with fibromyalgia in Europe are struggling to see their illness recognised as a real disease, as it often takes up to seven years and seven physicians for a proper diagnosis.

At present the Members of the European Parliament are being asked to officially support a European Parliament Written Declaration on fibromyalgia. This initiative was developed during a lunch debate to mark the first European World Fibromyalgia Day and brought together members of the European Parliament and member associations of ENFA.

In the past there have been efforts by patient group associations who have joined international organisations and professional associations to raise awareness of this condition. They have managed to achieve some goals:

- The American College of Rheumatology produced criteria for the diagnosis of fibromyalgia in 1990;



ENFA aims to improve access to diagnosis and treatment for fibromyalgia by making it a focus of debate at the European Parliament

- The disease was recognised by the World Health Organization (WHO) in 1992;
- Treatment guidelines for fibromyalgia were issued by EULAR in 2007.

The European Parliament initiative will provide a good opportunity to see fibromyalgia recognised at European level, by developing a community strategy for fibromyalgia. It will aim to get a disease status recognition for the condition, helping to raise awareness and facilitating access to information for health professionals and patients through European and national awareness campaigns. It will also encourage member states to improve access to diagnosis and treatment, facilitate research on fibromyalgia through the EU's seventh Framework Programme for Research and Development as well as future research programmes, and facilitate the development of data gathering programmes on fibromyalgia.

For further information please visit ENFA's website www.enfa-europe.eu or contact them directly at contact@enfa-europe.eu ■

Changes to youth with rheumatism

By Anna Ageberg, IOYR

The International Organisation for Youth with Rheumatism (IOYR) was launched in 1995 by eleven different nations, all represented by young people with rheumatism. The aims were to make contact with young people with rheumatism, to exchange experiences and information, and to set up contact networks and self-help groups in those countries where none existed. Every third year IOYR's International Youth Congress (IYC) is organised by a different member organisation. In 2004, the Congress was held in Switzerland and the event organisation was taken over by Sweden in 2007.



At earlier congresses, a board had been elected in order to develop the work to be done on important issues between the general assemblies. Last year, however, it was decided that IOYR would pause its activities as an organisation until the following General Assembly, which will take place in 2010. IOYR should instead be used as a platform for communication and meetings. Newsletters will still be given out by the member organisation in charge, which will change every year. ■

BREAKTHROUGH

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