

EULAR set to sparkle in Paris

This year, the host city of the European Congress of Rheumatology will be beautiful Paris, which will welcome around 13,000 delegates on 11-14 June to the Palais des Congrès. The Standing Committee of People with Arthritis/Rheumatism in Europe (PARE) has a full and exciting programme to offer to more than 200 delegates representing the national organisations of people with arthritis from all over Europe.

‘Although our programme reflects the relevant topics and needs of our member organisations and not the latest research results, we would very much like to encourage and welcome doctors to our



sessions as well. We believe that many of our practical and day-to-day themes, such as **Arthritis and pregnancy** or **Building patient-led advocacy groups**, could be very insightful and help improve the patient-doctor relationship,’ explained Maarten de Wit, EULAR Vice President, representing national organisations of people with arthritis/rheumatism. Maarten developed the programme in close consultation with members.

As in previous years, the programme includes the very popular joint sessions with allied health professionals and scientific societies as well as the highlight session 2008 on Saturday, summarising the congress programme in lay language.

Please find a detailed overview of the programme on page 4 of this newsletter. PARE will also hold a poster session during the congress featuring a selection of interesting activities from member organisations. Come and see our work in the poster area near the EULAR booth – a great opportunity to share experiences and a source for inspiration.

We would also like to welcome you at the EULAR booth. There will be a display of the activities of the Standing Committee of People with Arthritis/Rheumatism in Europe. You will be invited to fill in the World Arthritis Day 2008 online survey and be one of the first to see the new series of the Think Positive video diaries. ■



The Belgian bikers team at the finish line in Barcelona 2007

Make the Wheel Turn to Paris

From Brussels to Paris by bike – the *Make the Wheel Turn* project will for the fourth time be active this year, counting on an astounding number of more than 100 participants. An initiative by the Royal Belgian Society of Rheumatology and the Belgian user organisations, CLAIR and ReumaNet, this project was developed to serve as a means of creating awareness and mobilising people. The journey in tandem is a symbol of solidarity between physicians, paramedics and patients with chronic inflammatory rheumatism. Successful management of these chronic diseases is more likely when you search together for the best solutions. Please be there to welcome the tour when they arrive at the Palais des Congrès on Wednesday 11 June 2008 at 14.00. ■

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DEAR COLLEAGUES

by Sandra Canadelo



'Strength does not come from physical capacity. It comes from an indomitable will,' in Ghandi's words. It is nothing that we, people with arthritis/rheumatism, are unaware of. But as is true for many areas of life, we cannot achieve everything on our own – partnerships are crucial and a key element for success.

This was also the main thinking behind the restructuring process that integrated PARE Manifesto fully into EULAR. The EULAR Standing Committee of PARE has now taken over to represent the more than 100 million people affected by arthritis/rheumatism in Europe. The EULAR Congress is one of the most important events in our yearly activities and the ideal

platform for our partnership with allied health professionals and scientists. Have a look inside this newsletter to find out more about the programme and activities. We aim to continue our important work in this powerful structure and use the synergies of the other partners within the organisation to grow. We look forward to this new era and would like to thank you for all your support in the past, and count on you to continue helping us to make a difference for all people with arthritis/rheumatism in Europe.

We hope to see many of you in Paris – à bientôt.

Sandra Canadelo is the Chair of the Standing Committee of PARE

Securing the future

Future Chair of Standing Committee of PARE has been nominated

Sandra Canadelo, current Chair of the Standing Committee of PARE, will end her term of office at the EULAR congress in 2009. To ensure continuity, the PARE board meeting in Brussels in March took the opportunity to discuss the situation. Sandra Canadelo nominated Marios Kouloumas, President of the Cyprus League Against Rheumatism and member of the board since January, as her successor.

The Board welcomed this suggestion

and agreed to Marios' nomination. Maarten de Wit, EULAR Vice President of national organisations representing people with arthritis/ rheumatism, said: 'With Marios we have found a highly experienced and committed successor, and I am delighted that he has accepted the vote.' His nomination will be officially presented to the Standing Committee of PARE for ratification at their next meeting in Paris. Marios Kouloumas will start his term of

office as Future Chair in June 2008. Marios commented: 'It is a great honour to follow Sandra in this position and to represent the needs of organisations of people with arthritis/ rheumatism at the European level. I would like to thank all who have given me their trust and ensure you that I will do my best to continue the great work and achievements for people with arthritis/rheumatism in Europe.' ■

EULAR allied health professionals organise first Teach-the-Teacher Course

By John Verhoef, EULAR Standing Committee of Allied Health Professionals

Education is very important for EULAR. Due to the different standards of care applied across Europe, the existing educational activities did not meet the learning needs of the Allied Health Professionals in Rheumatology (AHPR).

We also discovered a need for a post-qualification programme on the diagnosis and treatment of rheumatoid arthritis (RA) and osteoarthritis (OA), developed and delivered by AHPs. Therefore we decided to run a course focusing on state of the art diagnosis and treatment of patients with RA and OA, as well as on ways

to spread this knowledge at a national level. Good trainers are crucial for the dissemination of knowledge generated within EULAR, so a Teach-the-Teacher element was included.

Each participating team consisted of a nurse, a physiotherapist and an occupational therapist, from 15 different European countries. The course took place on 15-18 May 2008 at Leiden University Medical Centre, The Netherlands. The teachers were EULAR Executive/Scientific Committee or AHP Scientific/Education Committee members. ■



John Verhoef (left) and Peter Oesch, Chair and Vice President of the Allied Health Professionals.

Photo by U Palonen-Tikkanen

Brussels Declaration

EULAR calls for more recognition and enforcement of the rights of people with arthritis in Europe

Alliance Against Arthritis 

Although the past 10 years have seen significant improvements in the management of rheumatoid arthritis (RA), a shortfall still remains between the care available, and the treatment patients actually receive. In addition, there are substantial geographical differences across Europe in the care people with RA can access.

The 5th Alliance Against Arthritis day gathered EULAR's key stakeholders on 4-5 March in Brussels. EULAR launched the **Brussels Declaration**, which calls on the European Union and its Member States to recognise and enforce the rights of people with arthritis in the EU.

EULAR asked policy makers in the European Union to become fully aware of the needs of people with arthritis and guarantee access to adequate care for all Europeans with rheumatic diseases. Professor Josef Smolen, member of the EULAR Executive Committee responsible for European Affairs, said: 'Many European decision makers still tend to neglect the enormous burden rheumatic diseases represent for society, although indirect costs generated through early retirement and sick leave are endangering Europe's economic competitiveness. The Brussels Declaration is a clear call for action. It is time for Europe to respond now.' Please visit www.eular.org for more information.

There was a very well-attended lunch



Left: The EULAR lunch debate engaged the participants in lively discussions

debate **Is the EU prepared to address the challenge of chronic diseases?** with statements from several European Commission representatives and a lively discussion. Other activities included face-to-face meetings with key stakeholders, a press breakfast and the inauguration of EULAR's EU-office in Brussels. This had been a long-time goal of EULAR to develop long-term relationships with decision-makers and stakeholders at the EU level, as well as to intensify the contact with EU institutions.

EULAR also initiated a workshop, gathering experts in order to develop a specific project to address the lack of comparable and available data on musculoskeletal conditions in Europe. This project should be implemented with the support of the EU's Public Health Programme. ■



Below: Josef Smolen, team leader for the EULAR EU Affairs Group, defends the need for Europe to respond to the needs of people with arthritis

11th European Health Forum Gastein

Values in health – from visions to reality

The European Health Forum Gastein is an annual event in the field of European health policy. It is a platform for European key stakeholders, representing their ministries and other authorities in the EU member states and the WHO European region, to discuss their views and experiences.



Besides politicians, it brings together senior decision-makers, representatives of interest groups, as well as experts coming from government and administration, business and industry, civil society and science and academia.



The agenda for 2008 features a forum about the very important topic of rare diseases and orphan drugs as well as many other relevant themes. As in previous years, EULAR will be represented by a delegation on 1-4 October 2008.

Prior to this event, the Standing Committee of PARE will hold its third board meeting in the lovely village of Bad Hofgastein. We would like to warmly thank the director of the Gasteiner Heilstollen, Dr Christoph Köstinger, and his whole team for kindly supporting our meeting again.

Overview EULAR congress programme for PARE



What's on and where...

The Palais des Congrès Paris (above)

DAY 1 – WEDNESDAY 11 JUNE

Time	Room	Session/Theme
10.45-12.30		EULAR General Assembly
13.00-14.30	243	Building patient-led advocacy groups: challenges and pitfalls
15.00-16.30	243	A matter of facts and figures: filling in the gaps
17.00-18.30	243	Standing Committee of PARE meeting
18.45-20.00		Opening ceremony
20.15-22.00		Welcome reception

DAY 3 – FRIDAY 13 JUNE

Time	Room	Session/Theme
10.15-11.45	243	Working in partnership with industry: finding a healthy match
13.30-15.00	242AB	Joint session: pregnancy and arthritis healthcare
15.30-17.00	242AB	Joint session: patient partnerships – could we do better?

DAY 2 – THURSDAY 12 JUNE

Time	Room	Session/Theme
10.15-11.45	243	Innovations in patient education: who is responsible?
13.30-15.00	242AB	Joint session: innovative models of delivering care
15.30-17.00	242AB	Joint session: what is quality of life and how to measure it. A team perspective
18.00-22.00		PARE social evening

DAY 4 – SATURDAY 14 JUNE

Time	Room	Session/Theme
10.00-11.30	243	Patient participation in the development of guidelines: a workshop (part 1)
11.45-13.15	243	Patient participation in the development of guidelines: a workshop (part 2)
13.30-14.30	243	PARE highlight session by Gabi Udrea and Gabriella Constantin
15.00		Farewell drink at the Palais des Congrès



'The small things matter' theme under discussion in Rome for WAD 2007

Think positive on World Arthritis Day

Most people are aware that arthritis/rheumatism presents a number of physical problems, but the psychological challenges faced by people with arthritis/rheumatism are often overlooked. We hope we can help address this issue with this year's World Arthritis Day (WAD) theme of Think Positive.

Our call to action is to ensure that people with arthritis/rheumatism are offered psychological support, as well as treatment for their physical symptoms. We also want to learn from people with arthritis/rheumatism what they do to help themselves when they are feeling low, so we can share this with others in similar situations. To find out more about the psychological challenges and coping

Think Positive

strategies of people with arthritis/rheumatism we are running a Think Positive online survey on the WAD website. Please encourage people with arthritis/rheumatism and doctors in your country to complete

the survey questionnaire – our aim is to have 50-100 completed questionnaires from each country. The World Arthritis Day survey is supported by an educational grant from Pfizer.

What activities are you planning on World Arthritis Day? We would like to hear about your events and add them to the website. Thank you for helping us to make World Arthritis Day bigger and brighter in 2008.

Visit the World Arthritis Day website at www.worldarthritisday.org

Video diaries update

At the end of April, the video diaries support material was revised to reflect the Think Positive theme. This will be posted on the password protected area of the WAD website for countries running the project to download and translate. Video diaries from a number of countries will be featured on the EULAR exhibition stand at the EULAR congress in June. Would your EULAR national organisation of people with arthritis/rheumatism like to engage in this exciting project? If you have any questions, please contact Birte Glüsing or Florian Klett at the EULAR secretariat. The video diaries 2008 are supported by an educational grant from Wyeth.

Video diaries being filmed in Portugal

By Sandra Canadelo, LPCDR

The clear success of Arthritis Care's video diaries project in the UK has encouraged other countries to follow this inspiring example. One of the countries answering the call to get involved was Portugal.

Thanks to a generous contribution by Wyeth, which partnered with a local organisation – the Portuguese League (LPCDR), Portugal has eight stories of people's experiences of different rheumatic diseases. The plan is to use these statements during WAD celebrations in the country, and at other occasions.

Along with other member countries, the Portuguese stories will be featuring on a European-wide film to be shown at the EULAR Congress in Paris this year. As the newsletter goes to print, the video diaries of Spain and Italy are being edited. Come and watch the European stories of people with arthritis at the Rheumatology Congress in Paris at the EULAR stand or visit www.worldarthritisday.org



Following the success of Arthritis Care's video diaries project, Portugal is going to produce eight stories of its own



View of beautiful Budapest – the Hungarian Parliament

Budapest hosts XI EULAR Autumn Conference for PARE

The XI EULAR Autumn Conference for PARE (formerly known as APOM – Arthritis People on the Move) will this year be hosted by the Hungarian Arthritis Association on 7-9 November 2008 in Budapest. ‘We have changed the name to emphasise the start of a new era. But as before we are continuing to provide education and training opportunities for our member organisations in order to strengthen their voice at a national level,’ said Sandra Canadelo, Chair of the Standing Committee of PARE.



‘We are really excited that Hungary has been chosen to host the 2008 conference,’ said Dr Judit Ortutay from the local planning team. Her colleague, Beata Garay, added: ‘It is such an important event in the calendar of the European arthritis community and we are proud to welcome our colleagues to Budapest.’ Budapest waits to welcome more than 100 representatives – most of them with personal experience

of living with arthritis and key stakeholders in their national member organisations.

This year’s conference programme will focus on work and rehabilitation as an overarching theme, and feature it in the context of the impact of arthritis on family life, stress management and standards of care. Rehabilitation is a very important topic in Hungary. With excellent natural thermal resources, it is a very famous and

‘It is such an important event in the calendar of the European arthritis community’

popular country for many Europeans to travel to and benefit from attractive prices for the treatment in comparison with home. But how do Hungarian people with arthritis benefit from this situation and how is rehabilitation organised? We all

look forward to getting a closer insight into the daily life of our Hungarian colleagues.

The 2008 conference will again see a poster competition – all delegates will be invited to display their activities and can look forward to the chance to win one of the attractive prizes. Robert Johnstone, member of the planning team for 2008, has been impressed by the local support team. ‘It is great to work together with Judit, Beata, Timea, Pál and Sándor. Their enthusiasm is inspiring and their warm hospitality will welcome everybody to this lovely city,’ he said.

The conference is currently supported by unrestricted educational grants from Roche and Wyeth (platinum level) as well as Schering Plough (gold level).

A call to apply for hosting the conference in 2009 and 2010 went out in March, and the EULAR secretariat has received lots of interest and positive feedback. The final decision will be made in June – come and visit us on the EULAR website www.eular.org to find out who has been chosen. ■

Crossing borders with arthritis

By Ursula Faubel, Deutsche Rheuma-Liga

Without borders – being young with rheumatism in Germany and in neighbouring countries was the motto of a meeting of young people with arthritis on 27-28 October 2007 in Cologne. Once a year, young people with arthritis from different German regions meet to exchange experiences. In 2007, guests from the Netherlands and Switzerland were invited as well. Talks and workshops were the basis for a lively cross-border exchange of experiences.

The meeting focused on three aspects of living with arthritis as a young person: state support for people with arthritis who continue to work in the different countries; information about support for young people with arthritis in education and

Deutsche RHEUMA-LIGA
Bundesverband e.V.



studies; and which medication should be taken into consideration by young people with arthritis when planning to have children. Besides working on the three main themes, there was a lot of room for the young people to develop new ideas for working together across borders.

A vision workshop showed a common wish to work against the misconception that arthritis is a condition of older people and to get other young people to become active in organisations. The meeting was deemed a complete success and will hopefully be the start of future co-operation between young people with arthritis. ■



Young people with arthritis/rheumatism having fun at the 'Without Borders' event

Patient passport launch in Belgium

By Nele Caeyers, ReumaNet

ReumaNet and Clair, the two Belgian patient organisations, were very proud

REUMANET.be

Ensemble, c'est CLAIR.be

to present the pilot of the first patient passport for people with rheumatic conditions as the theme of World Arthritis Day 2007. The results showed us people were happy with the document and found it very useful in their communication with their healthcare team.

Taking into account all comments from participants in the pilot, a working group sat together to adjust the document to the needs of the patients. It was good that we could adapt parts of the passport according to our needs; for example, we added a calendar and an agenda to note appointments. An educational grant from Wyeth enabled us to make a very attractive, high-quality booklet.

The Belgian patient passports were launched on 4 March in Brussels at a well-attended press conference. All media covered the story and, in both the French part and the Flemish part of Belgium, the response was great. People can order the passports free of charge and ReumaNet and Clair have both had many requests. For countries that might be interested in having a look at our achievements, please contact Nele@ReumaNet.be. We will be very happy to send you some copies. ■



The Patient Passport was launched in Belgium

A word about FESCA

By Kim Fligelstone, FESCA



The Federation for European Scleroderma Associations (FESCA) was founded in Amsterdam in June 2006 after our first meeting at the EULAR Congress in 2005. Membership of FESCA is open to all patient organisations in Europe providing support for people with scleroderma, with a maximum of two organisations per country. To date FESCA has 16 members from 13 countries.

Our most pressing projects are the set up of our website – which is still under construction – www.fesca-scleroderma.eu, a leaflet about FESCA, participation at the EULAR congress in Paris 2008 (stand B15 on the third level facing the Scientific Café), to lobby Brussels, to produce and

circulate a newsletter, and to plan the first EU Scleroderma Awareness Day to be held on June 29 2009. The theme for the day will be More than Skin Deep. We hope that as many countries as possible in the EU will promote awareness of scleroderma on the date. This particular date is very pertinent to scleroderma as the most famous person in Europe, and very possibly the world, to have lived and died of



Kim Fligelstone (third from the right) with the other members of the FESCA Board at the Instituto Salesiano in Florence

scleroderma is the German-Swiss artist Paul Klee, who died on 29 June 1940.

A word about ASIF

By Jon Erlendsson, ASIF



The Ankylosing Spondylitis International Federation (ASIF) is a central body for 29 national or regional ankylosing spondylitis (AS) patient societies, representing more than 50,000 people with AS. Founded in 1988, the core message of ASIF is that the better informed patients, health professionals and the public are, the better the outcome for the people affected by AS.

As the disease is chronic and still without cure, patients who are mostly aged between 20-40, have recognised the value of meeting to exchange information, provide support and to do the exercises, which are an important part of treatment. This holds true both on a national and international level.

ASIF has regular council meetings of del-



Jon Erlendsson, ASIF President, gave an interesting presentation on ASIF activities at the 2007 EULAR congress

legates, covering the following topics: exchange of information, how to work with the media to get coverage of patient issues and ASIF's contribution to research. ASIF has initiated or taken part in several scientific investigations on AS in

co-operation with leading rheumatologists. ASIF News is sent biannually by email to members. Among other things it contains information on results of scientific studies written in a user-friendly language. More information on ASIF and our activities can be found on our website: www.spondylitis-international.org

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