Facing the facts in Rome

The 10th EULAR Annual European Congress of Rheumatology is taking place on 16-19 June in Rome, at the Fiera Roma. With an expected attendance of more than 14,000 delegates, this year’s congress will again showcase advances in medical research and advocacy work. The Scientific Committee has done its utmost to put together an inspiring and informative programme.

Neil Betteridge, EULAR Vice President PARE and member of the Scientific Committee, said: ‘After the very successful PARE congress programmes of the past two years, it is quite a challenge to come up with something equally relevant. However, my colleague Marios Kouloumas and I are very happy to have the interactive workshop on Saturday run as a joint session together with our scientific and health professional colleagues for the first time. With Professor Paul Emery and Professor Désirée van der Heijde speaking at these two sessions which we have called Facing the facts – communicating effectively with patients from diagnosis onwards and Facing the facts – identifying and agreeing treatment and support options with patients we hope to have found themes which will attract and stimulate a broad audience.’

The first PARE programme sessions on 16 June will be: Diversity – engaging with all sections of society, and Work and leisure – achieving a balance between work and life. The PARE programme features prominent speakers such as Dame Carol Black, who will talk about the Fit for Work initiative, and Jane Asher, famous actress and at the same time President of Arthritis Care in the UK, who will give the delegates an insight into how organisations could best involve and reach out to celebrities. On Thursday, other topics of importance for the arthritis community will be Marketing arthritis – how to sex it up, Rheumatic diseases in the political arena and two joint sessions on Dialogue-centred care demands digital support and Implementing standards of care – the EUMUSC.NET project. One highlight of the day will be the PARE networking evening organised by EULAR, at the beautiful Villa Domus Magnanimi.

Please do not forget to visit the PARE poster area from 12.15-13.15 on Friday 18 June when the authors will be welcoming your questions on their work. The day’s sessions will cover areas such as Patient participation in research and Informed decision making. The PARE congress programme will be concluded on Saturday with the very popular Highlight session.

The PARE booth will be located in the EULAR village in Hall 5 and will feature recent Standing Committee projects and activities such as World Arthritis Day, EULAR’s Educational Visit Programme and material on activities from national EULAR member organisations. You can get your own copy of the 2010 EULAR Stene Prize booklet featuring a selection of the 2010 entries on the topic of Rheumatic Diseases and work – my daily reality and meet your European colleagues to exchange news and information.

London will be the venue of the EULAR congress in 2011. The PARE congress schedule will again offer a number of interesting topics for discussion and interaction. Please note that the congress will take place at an earlier date than it usually does, on 25-28 May 2011. All deadlines for submission of abstracts etc will be put forward respectively. For more information on the congress, please visit www.eular.org
DEAR COLLEAGUES

This year, 2010, is an exciting year for our movement in Europe. Once again, we are concentrating on the topic of work and rheumatic diseases. Collaboration with other EULAR standing committees, scientists and health professionals in rheumatology has led to outstanding results and we expect that this year rheumatic diseases will be high up on the health agenda of the European Union and greater raising of awareness will result from that.

The European Parliament’s informal interest group for rheumatic and musculoskeletal diseases discussed the subject of work at its first 2010 meeting and was presented with two major EULAR initiatives – the Charter for Work and the European Minimum Standards. The interest group’s second meeting, on 6 July in Strasbourg, will focus on discussing the Belgium Presidency covering the second half of the year and the initiatives of interest for the rheumatology community during this period.

Especially encouraging for me is the interest PARE organisations have shown in launching the EULAR Charter for Work at a national level and using the Working Wonders exhibition for their national campaigns. In addition, there was huge interest in the Stene Prize competition, the winner of which will be awarded at the Congress Opening Ceremony. I would like to express my great satisfaction for the work being done by our committee and also thank everyone for their commitment and active participation.

Marios Kouloumas is the Chair of the Standing Committee of PARE

The EULAR Standing Committee on Musculoskeletal Imaging (SCMI)

This Committee was provisionally established after the EULAR 2006 Congress and formalised in September 2007. This was in response to the growing use of imaging by rheumatologists (especially modern imaging such as ultrasound or magnetic resonance imaging – MRI) reflected in more scientific publications and demands for training. The inaugural Chairperson is Philip Conaghan (UK), and the Committee has links to radiologists via the European Society for Musculoskeletal Radiology.

While much work is still ongoing to improve the technology associated with imaging, the aims of this Committee are to promote improved patient care through the appropriate use of imaging modalities; research and education on how imaging can improve understanding of arthritis; and the usefulness of imaging tools in the clinic. The Committee has developed definitions and rules for how to acquire images using ultrasonography in order to standardise use of this tool, which is increasingly available in the clinic. A similar approach has been taken with MRI. The ultrasound group also run a lot of educational activities for doctors learning to use ultrasound and have just surveyed European training and clinical uptake of this technology. As well, a taskforce set up by the Committee is currently examining the literature for evidence of what benefits imaging adds to clinical diagnosis and monitoring of rheumatoid arthritis, in order to develop recommendations on how to use modern imaging in a rational and cost-effective way.
Interview with Kåre Birger Hagen

Kåre Birger Hagen is EULAR Vice President Health Professionals in Rheumatology

Professor Kåre Birger Hagen, from Norway, took over from Peter Oesch (Switzerland) as EULAR Vice President Health Professionals in Rheumatology in June 2009. In this interview Kåre talks about projects for the health professionals (HPs) in EULAR and the cooperation between the different branches of EULAR.

PARE: Could you briefly introduce yourself to our readers?

KBH: I’m a physiotherapist by training and worked as a clinician for some years after I graduated. I have been working with research on musculoskeletal disorders for the past 20 years. I started my PhD studies at the Karolinska Institute in Stockholm, Sweden, in 1990, and defended my PhD thesis in 1994. At that time we had no Master or PhD programme for HPs in Norway and I'm still grateful for being so generously taken care of and supervised in Sweden. Because many HPs in Europe struggle with access to Master and PhD programmes, I think these kinds of exchange programmes are very important.

After finishing my PhD, I went back to Oslo and worked as a researcher at the National Institute of Public Health for some years. At that time I got involved in the Cochrane Collaboration, mostly within the field of back pain, which I think has influenced my view on clinical care, i.e. the treatment provided by HPs should be based on research evidence, and treatment decisions should be based on a shared process between providers and patients.

I’ve worked a couple of years as an executive director in the Ministry of Social Welfare and Health, but in 2004 I went back to research and started as researcher at the National Resource Centre for Rehabilitation in Rheumatology. The centre is affiliated to the Department of Rheumatology at the Diakonhjemmet Hospital in Oslo, and I’m head of the Research Unit. In 2007, I was appointed as a professor at the University in Oslo.

PARE: Could you give us an idea of the projects your Standing Committee will be focusing on in the next months? Are there any projects where a co-operation with the Standing Committee of PARE could be supportive?

KBH: I hope that we can soon produce EULAR recommendations or points to consider of special relevance for health professionals. Every day thousands of people with rheumatic diseases consult HPs across Europe and EULAR should take a leading role in defining standards of care within all areas. PARE is of course the most important stakeholder and collaborator in this work.

PARE: The three parties within EULAR have a joint programme at the EULAR congress each year, which fosters communication and better understanding of each other’s roles and capacities. In your view what can patients teach HPs and vice-versa? What do you think are the topics that most need to be covered still?

KBH: The main mission for EULAR is to improve the care and everyday life for people with arthritis. In that respect healthcare providers have a lot to learn from patients. I think all stakeholders in healthcare now have acknowledged and fully recognise Neil Betteridge's mantra 'nothing about us without us'. From my perspective, interdisciplinary work and advanced roles taken by HPs are topics that still need to be covered.

PARE: What are currently the major problems faced by HPs in Europe? What can EULAR do to help overcome these difficulties?

KBH: First, in many (probably most) countries in Europe HPs do not have access to academic achievement through Master and PhD programmes. Secondly, there are currently only five national member societies of EULAR Health Professionals in Rheumatology, i.e. in most countries we are not very well organised. I think EULAR can play an important role in helping HPs in these areas.

PARE: As EULAR Vice President HPs in Rheumatology what are the objectives you would like to see achieved within your four years of office?

KBH: My objectives are:

• that EULAR recommendations or points to consider of special relevance for health professionals are published
• that at least 10 national HP societies in rheumatology become official member organisations in EULAR
• to see better integration and co-operation between the three parties in EULAR.
Alliance Against Arthritis 2010

On 1-2 March 2010, EULAR held the 7th edition of the Alliance Against Arthritis (AAA) initiative in Brussels. This year’s focus was on the European 7th Research Framework Programme (FP7), launched in 2007 and lasting until 2013. Despite the gravity of rheumatic diseases, research in rheumatology at EU level is still not adequately funded. Applications from the musculoskeletal community have to compete with other chronic disease areas and are sometimes even excluded from certain calls under the FP7 programme.

The AAA FP7 workshop was well attended by EULAR delegates. For the first time, representatives from EULAR’s national scientific societies joined the event together with patient organisations as the topic was highly relevant for all. Officials from the European Commission were also represented. Patricia Reilly from the Research Commissioner’s cabinet and Dr Grigorij Kogan, Scientific Officer in Chronic Disease of the Directorate General Research, expressed their support for initiatives that raise public awareness of rheumatic diseases in Europe.

The workshop offered an overview of the different key stakeholders at a national and European level, best practice case studies and a toolbox to help EULAR’s delegates to be more successful in future FP7 calls. Furthermore, the meeting provided the opportunity for discussing the future FP8 for 2013-2019, for which first consultations will start this autumn 2010.

For more information on AAA please visit EULAR’s website (www.eular.org) and watch our video.

European Parliament Interest Group on Rheumatic and Musculoskeletal Diseases

The second meeting of the European Parliament Interest group on Rheumatic and Musculoskeletal Diseases (MSDs) took place during the Alliance Against Arthritis event on 2 March. It focused on MSDs and work and emphasised two recent initiatives – the EULAR Charter for Work presented by Marios Kouloumas, chair of the EULAR Standing Committee of PARE; and the Fit for Work campaign presented by Stephen Bevan, managing director of the Work Foundation.

The interest group was launched during World Arthritis Day 2009 (12 October) and the first meeting took place last December. The group is led by MEP Edite Estrela and co-chaired by five other key members of the European Parliament, Marije Cornelissen, Antonia Parvanova, Jim Higgins, Sir Robert Atkins and Takis Hadjigeorgiou.

This second meeting was well attended by MEPS, assistants and the European Commission. Armindo Silva, Director of the European Commission Directorate General for Employment, Social Affairs and Equal Opportunities, was a key speaker at the meeting and presented the future directive for MSDs related to work. The directive will bring the subject, which is currently referred to in different texts, under one single legislation. Nevertheless, Mr Silva mentioned that a legislative framework alone is not sufficient; it should be complemented by guidelines, especially for small and medium enterprises, on how to create accessibility in the work environment.

The next meeting of the interest group will take place on 6 July 2010 in Strasbourg, and its last meeting of the year is scheduled for October 2010.

For further information please visit www.eular.org

Rheumatic diseases and the European Union’s Belgium Presidency

From 1 July 2010, the Belgian government will lead the European Union for 6 months. Belgium is the second country to take over within the European Union Presidency trio with Spain and Hungary. One of the key health topics covered by the Belgium agenda for the first time is chronic diseases. In that scope, EULAR and the European Respiratory Society will both hold a conference in October 2010 which will look at musculoskeletal and respiratory diseases as major chronic disease challenges in Europe. Further information will be published at the beginning of July with the start of the Belgian Presidency.
Malta was the first country to host the EULAR exhibition Working Wonders in 2010. The EULAR member organisation ARAM, the Maltese organisation of people with rheumatic diseases, prepared a very successful launch of the EULAR Charter for Work and the exhibition on 29 January 2010.

The event was held in the main reception of the biggest and most modern hospital in Malta, Mater Dei. Professor Carmel Mallia, Honorary President of ARAM, welcomed journalists and invited guests to the press conference. ARAM was particularly grateful for the attendance of Dr Kenneth Grech, Permanent Secretary of Health, and the Head of the Rheumatology Department, Dr Franco Camilleri, and his colleagues. ‘Our organisation has only been in existence for 2 years and there is still a lot to be done to raise awareness on our island. We are very excited to have the support of Dr Grech and his government colleagues to make rheumatic diseases a health priority in the future,’ said Professor Mallia. He was the first rheumatologist of the island state and trained four more experts who now take care of Malta’s people with rheumatic diseases. He also was the founding force of ARAM and still is very supportive of their activities.

Regular information events are organised throughout the country to raise awareness of the first signs of rheumatic diseases so that people recognise these and avoid delay in seeing a doctor. These information talks are organised by Mary Vella, the President of ARAM and affected by rheumatoid arthritis herself. The information talks attract about 30-50 participants and besides raising awareness of rheumatic diseases are an opportunity for the organisation to gain new members. Ms Vella said: ‘An important next step for ARAM would be to have our own offices – at the moment everything is co-ordinated from our homes and only possible as we have such dedicated board members. But our organisation is growing and we hope to have about 300 members by the end of 2010. An appropriate service for them can only be guaranteed if we can work professionally.’

EULAR was represented by Marios Kouloumas, Chair of the EULAR Standing Committee of PARE, who was very impressed by the enthusiasm and professional organisation of the launch, but also by all other activities planned by ARAM. ‘Mary and her colleagues can be very proud of what they have achieved in only two years. It is also very inspiring to see the exemplary and close co-operation with rheumatologists and health professionals. It is so important for the overall success that we work united and to speak with one voice,’ said Marios.

The press event and launch of the Working Wonders exhibition was followed by a conference where Professor Mallia gave a short overview about ARAM and an introduction to rheumatic diseases, while Marion Rizzo, CEO of the Mater Dei, introduced the hospital and its many services to the audience. The President of the National Commission for Persons with Disabilities, Joe Camilleri, highlighted the issue that work is a right of all citizens. The day concluded with a very informative tour through the hospital with a special focus on occupational therapy.

The Working Wonders exhibition has since then been shown in the UK, France, Slovenia, Cyprus and Sweden. Croatia, Greece, Germany and Russia are planning activities around the EULAR Charter for Work and intend to launch the exhibition in the second half of 2010. To see photographs of the events and read more please visit www.worldarthritisday.org. If you would like to see the exhibition in your country, please contact Birte Glüsing at the EULAR secretariat on birte.gluesing@eular.org for further information.
This year the EULAR Autumn Conference for PARE will be held 5–7 November in Berlin and hosted by the Deutsche Rheuma-Liga. As one of the largest and most established national organisations of the PARE network, the Deutsche Rheuma-Liga will be able to share its perspectives, experience and best practices with delegates from all over Europe.

Work will continue to be the theme for the 2010 programme. About 120 delegates are expected to join the conference and to engage in sessions focusing on rehabilitation and younger people in education.

On 5 November the Autumn Conference will officially open with an address by Professor Angela Zink, Head of Epidemiology at the German Research Centre for Rheumatic Diseases in Berlin and Chair of the EULAR Standing Committee of Epidemiology. This will be followed by updates on EULAR projects including the Charter for Work, the Working Wonders exhibition and the political activities happening in Brussels during the Belgium Presidency, including the launch of the Brussels Declaration on Rheumatic Diseases. Delegates will be offered a choice of workshops looking at: targeting different age groups of people with rheumatic diseases; implementing the Brussels Declaration at a national level; the EU-MUSC.NET project collecting data on musculoskeletal diseases across Europe; and the status of the implementation of the UN convention of rights for people with disabilities across Europe.

Sessions on 6 November will focus on aspects of rehabilitation to help keep people with rheumatic diseases fit for work and life presented by Stephen Bevan, Managing Director of the Work Foundation in the UK and Professor Wilfried Mau, Director of the Medical Department of the University of Halle, Germany. There will be a panel discussion with country case studies with a choice of workshops to look at different aspects of rehabilitation or to develop European Minimum Standards of Care (EMSC) for people with rheumatic diseases. The EMSC is linked to the EULAR Charter for Work and will specifically look at how healthcare professionals can best support people with rheumatic diseases in gaining employment, remaining employed or re-entering the workforce. For organisations wanting to benefit from others’ experience, the Share Fair will be held after the presentation and workshops, followed by dinner.

Sunday 7 November will focus on targeting young people with rheumatic diseases, with a presentation by Judy Ammerlaan, specialist nurse in rheumatic diseases in the Netherlands. She will look at the different approaches needed to communicate with, and support, young people with rheumatic diseases and a project developed by the University of Utrecht. The session will be followed by country case studies and workshops to help national organisations work more effectively with their younger members.

For the first time since Italy hosted the event in 2006 in Rome, the EULAR Autumn Conference for PARE is again taking place in a country of southern Europe. The Hellenic League Against Rheumatism, ELEANA, is preparing to host the conference in the city of Athens on 25-27 November 2011. Maria Batziou, PARE Board member and member of ELEANA, said: ‘The problems of southern European countries are often different from those of the rest of Europe and we hope to convey our perspective to participants and to get advice to find solutions to overcome these problems. Having the conference in Athens will also help us to raise awareness with politicians and other key stakeholders.’
Mark World Arthritis Day 2010

World Arthritis Day (WAD) continues to support the theme of work in 2010 and the introduction of the Charter for Work for people with rheumatic diseases across Europe. Cyprus, Malta, Greece and the UK have already successfully launched the Charter for Work. A best practice guide featuring these launches is being developed and will be available to all EULAR national organisations of PARE later this year. The guide will include information on how the launch events were planned and executed, what made them a success, plus hints and tips from the featured organisations.

Other resources being developed include a presentation and information pack for national organisations of PARE to use when introducing the Charter for Work and European Minimum Standards for Work (EMSW) to employers and their organisations, and a video demonstrating some of the simple and cost-effective adaptations that can help people with rheumatic diseases to work productively.

The WAD website has been given a fresh look. It provides the hub for news and information about WAD and repository for resources. Watch out for increased activity on the WAD Facebook page this year.

Denmark wins Edgar Stene Prize 2010

The Stene Prize 2010, rewarding the best essay by a person with a rheumatic disease, will be delivered during the Opening Ceremony of the Rome EULAR congress on 16 June. This year’s winning essay, with the theme Working with a rheumatic disease – my daily reality, comes from Denmark and was written by Karin Nørgaard, who said: ‘I thought it would be a fun challenge and an opportunity to see myself and my disease from the outside. A driving force was also to thank the clinic where I work for their comforting way of treating me when my batteries are a bit low.’

The Stene Prize jury was given the task of choosing from 18 contributions sent in by national patient organisations in countries such as Cyprus, Finland, Hungary and Iceland. Each national PARE organisation selected their best contribution. Standing in as a member of the UK judging panel for the first time, Sarah Rich, from ARMA, the national EULAR member organisation, said: ‘It was an amazing opportunity to be involved in the Edgar Stene Prize. The UK received 34 entries. All of the essays addressed the title and gave us an insight into the authors’ working day and how they individually cope and adapt. The essays were presented as inspiring stories from positive people. The UK judging panel chose Victoria Garratt as we felt she demonstrated how her chronic illness had a constructive impact on her daily reality of working with a rheumatic disease.’
EULAR events and activities

Pilot training for patient partners in research

By Nele Caeyers, Patient Research Partner

EULAR taskforces develop many guidelines and recommendations on management of rheumatic diseases. These taskforces have recently started to incorporate the perspective of patients into their research e.g. the EULAR/ASAS Taskforce for Recommendations on Ankylosing Spondylitis or the EULAR Taskforce on Glucocorticoids. Several EULAR projects have already benefited from taking the view of patients into account. Having personal experience with the condition often gives other insights into management and treatments – the impact of taking medication every day, and the pain and the fatigue. Despite their non-medical training, the input patients give into research projects is highly valuable.

To make sure patients are able to contribute a full 100% to research and guideline development, pilot training for patient research partners will take place in October in Brussels. Until now, there have been no training opportunities for patient representatives working in the field of research. Nevertheless, by providing appropriate support, EULAR could set a worldwide standard of exemplary involvement of patient representatives.

For this reason the Standing Committee of PARE is organising a pilot two-day training course in 2010. Sixteen people with a rheumatic condition will get acquainted with the basic principles of research and learn how to have an impact on the process of research. They will become familiar with the structure of EULAR and discover the value of their own experiential knowledge. The project manager, Maarten de Wit, from the Netherlands, said: ‘The final objective will be to establish a sustainable group of patient research partners who are able to represent the patient perspective in a variety of EULAR projects and activities.’ All PARE member organisations are being contacted in the search for pilot training participants to make sure there is a diversity of rheumatic conditions and geographical spread.

The pilot training course will take the EULAR recommendations for the inclusion of patient representatives in scientific projects into consideration. These will be published in the Annals of Rheumatic Diseases and be presented during the EULAR congress in Rome in the joint session Patient participation in research, to be held on Friday, 18 June, 13.45-15.15, Room 10D-E with presentations from Maarten de Wit, Lars Klareskog, Sarah Hewlett and Pamela Monty.
Every two years the Deutsche Rheuma-Liga (DRL) brings together leading representatives of the German youth group from all German Federal lands. From 4-7 June 2009 the city of Hamburg was the venue for the gathering of 20 young people. The set theme for the days ahead was Creative Energy and from the beginning it became very clear that young people with rheumatic diseases have a lot of it.

The first day saw the traditional opening evening reception. ‘The opening is always a highlight of the meeting. We try to find some funny acts or games fitting the topic of the whole weekend. This helps us get to know each other in a relaxed and interesting way,’ says Tom Amende, vice-chair of the board. The next day two workshops were held simultaneously. One was a movie-making experience. The aim was to make a short film about young people with a rheumatic disease, how they cope with the disease, their experiences since the diagnosis and the impact the disease has on their lives. A film producer and a cameraman filmed the ideas that came up. The second workshop was led by a journalist who showed the group how to write catchy articles about being young with a rheumatic disease.

The second day brought in a personal coach. This time the whole group worked together and learnt about inner structures and behaviour mechanisms. Through role-play and other techniques everyone had the chance to find out more about themselves. ‘It was so interesting to realise how others see me and how I see myself. And I’d never thought that I’d have a potential for acting. It was so much fun that I really would like to have more of it,’ said Gertie, one of the participants.

The weekend was a full success. Participants shared their energy, but they also took lots of it back with them into their daily lives. The outcomes, a film, a lot of pictures and an overview of the work of the Deutsche Rheuma-Liga’s youth group can be found on www.rheuma-liga.de

The right to work is very important to people with rheumatic diseases as it is essential for active participation in life. In Greece, the labour rights of people with rheumatic diseases are not clearly defined and not yet protected by legislation. This is the reason why implementing the EULAR Charter for Work in Greece and raising awareness about rheumatic diseases in society is an imperative need.

Members of Greek League against Rheumatism were invited to support the charter and the Let’s work together survey, which was conducted from June to July 2009. More than 356 people participated – 123 of whom were employers. The results were presented to the media, representatives of the medical community and state officials at a press conference in September 2009. More presentations followed in the larger cities in the south, west and north of Greece. Last December the results of the Greek survey were presented to the medical community at the Greek Annual Rheumatology Congress in Thessaloniki.

Future plans include launching the Charter for Work along with the results of the survey to the political community, pressing for new and fairer legislation to enable people with rheumatic diseases to enter, retain and/or rejoin the workforce.

EULAR Charter for Work launched in Greece

By Maria Batziou, ELEANA

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Introducing Arthritis Ireland

By Lisa Mehigan, Arthritis Ireland

Arthritis Ireland is Ireland’s only arthritis charity enabling people with arthritis to take their lives back. We empower people with arthritis and those caring for them to take positive actions to manage the effects of their disease on their lives.

Our key objectives are: supporting people with arthritis, finding a cure and lobbying for better patient care.

Our daily role is to help people with arthritis live their best life by providing support and high quality information. We provide a wide range of information leaflets covering different kinds of arthritis, giving useful advice on coping with the condition. We also have a Living Well with Arthritis programme. This award-winning workshop has been proven around the world to decrease pain, reduce reliance on health professionals and medication and significantly improve a sense of well-being.

Delivering and communicating messages to the public is of vital importance to Arthritis Ireland. We do this through our website, our helpline and by actively engaging in social media including Twitter, Facebook, Bebo, our blog, and YouTube. Information is also provided at events that are organised by our network of branches around the country.

A number of fundraising events are also held throughout the year. Our most popular events are: the annual Get your Joints in Motion walking challenge for 2010, the annual golf classic, and The Jasper Campaign which raises funds and lobbies for improved services for children in Ireland with juvenile arthritis.

The Czech educational exchange with Germany

By Alena Slamova and Hana Konecna, Czech League Against Rheumatism (Revma Liga v CR)

The Czech League has existed for 18 years, but we have only about 600 members, who do not all actively participate in our seven regional groups. We wanted to improve the structure of our organisation to make it more attractive to new members. The Deutsche Rheuma-Liga (DRL) was our Teaching Organisation in the EULAR Educational Exchange Visit Programme.

The first part of the educational exchange took place over three days in November 2009. We learnt a lot about the work done by the board of the German organisation and voluntary work in general. Topics such as different styles of leading a group, democratic decision making and solving problems were covered.

In addition we had a long and very fruitful discussion with Erika Christ, member of the DRL board, and Christel Christe, Secretary-General of the Deutsche Rheuma-Liga Rhineland-Palatinate, on the principles of their work and how to use their experiences in starting campaigns and changing mechanisms in our own league. We plan to copy the DRL’s approach to prescribed rehabilitation training for people with rheumatic diseases, as this would attract members.

The first results of this exchange were introduced to the membership in early December at the Conference of Czech Rheumatologists. The feedback was very encouraging and we worked hard to prepare the second part of our visit – a seminar for our membership to discuss the changes, which took place in February. Our German teachers were present to support the meeting.
ENFA members thank members of the EP for their support with the successful approval of the Written Declaration on Fibromyalgia.

The European Network of Fibromyalgia Associations (ENFA) is comprised of 14 members from 11 countries at present. Its aim is to lobby for speedier diagnosis and more effective treatment for all European citizens with fibromyalgia.

Fibromyalgia is a complex disease with a variety of symptoms in addition to the defining symptom – chronic widespread pain. Fibromyalgia imposes large economic burdens on society as well as on affected individuals. A study showed that an average patient in Europe consults up to seven physicians and takes multiple types of medication over 5-7 years before receiving the correct diagnosis. The debilitating symptoms often result in lost work days, lost income and disability payments. ENFA successfully supported the Written Declaration on Fibromyalgia, accepted in December 2008 by the European Parliament (EP), which called on the European Union to recognise fibromyalgia in Europe as a disease, as WHO did in 1992. This declaration called for: the European Council to help raise awareness of the condition and facilitate access to information by health professionals and patients through awareness campaigns; member states to improve access to diagnosis and treatment; research on fibromyalgia to be facilitated through the work programmes of FP7 and future research programmes; and the development of programmes collecting data on fibromyalgia.

Following on from this, ENFA now has to lobby for the necessary commissions to take action and encourage national associations to do the same in each member state. Our first aim for 2010 is to increase the membership from all member states, assisting some countries to set up their own national organisation. We are also forming an advisory board of medical professionals so that information and advice is readily available to the commissioners as required and documented evidence can be produced.

We will still be ensuring that MEPs remain aware of the problems faced by people with fibromyalgia so that pressure is sustained to provide the improvements so desperately needed.

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EUMUSC.NET project going steady after kick-off in March

By Prof Anthony Woolf, EUMUSC.NET co-ordinator

The EUMUSC.NET project, which kicked off in Luxembourg in March 2010, is progressing. The 3-year project is being co-ordinated by Professor Anthony D Woolf, Royal Cornwall Hospitals Trust, UK. EUMUSC.NET is being supported by a grant of over €950,000 from the European Commission, a grant of €300,000 from EULAR, and time commitments from professional, scientific and patient organisations in 22 centres across Europe.

The project was initiated in March 2008 with a preparatory workshop held by EULAR. The project was developed to tackle the fact that although musculoskeletal conditions have a great impact across EU member states and can be effectively diagnosed, prevented and treated, this is not happening equitably across Europe. It is important to stress that this is the first project to be successfully funded by the EU that has been developed as a collaboration between patients, health professionals in rheumatology, researchers and clinicians since its beginning, which was key to a successful application.

The EUMUSC.NET project will specifically: identify the burden on individuals and society of musculoskeletal conditions across EU member states; set standards of care for healthcare provision for people with osteoarthritis and rheumatoid arthritis; assess whether these standards are being achieved in countries across Europe; and help overcome the barriers to achieving these standards to enable the effective and equitable prevention and management of these conditions in member states. Policy recommendations for the implementation of a community strategy on musculoskeletal conditions will be proposed, and examples of good practice will be highlighted so that they can be copied. A sustainable European Musculoskeletal Conditions Surveillance and Information Network will also be created that will be embedded within EULAR, and involve key stakeholders in Europe on musculoskeletal conditions.

The outcomes of the project will be widely disseminated through a web-based health information system, through reports and by presentations at various meetings including EULAR. There will be a joint session on EUMUSC.NET during the EULAR congress in Rome on Thursday 17 June, 15.45–17.15 in Room 10 D-E.
Scleroderma Patient Congress, Florence

By Ann Tyrrell Kennedy, President of FESCA

In Florence on 12 February 2010, the Federation of European Scleroderma Associations (FESCA) held the first World Scleroderma Patient Congress. It was part of a dual event organised with EUSTAR (EULAR Scleroderma Trials and Research) — a 3-day scientific congress and simultaneous 1-day patient congress. Over 1,300 people attended the congresses – 143 of them were patients. Patients came not only from all 14 FESCA countries and its 19 separate organisations, but also from Canada, the USA, and Australia. Nine speakers addressed patients, focusing on different areas of the disease, and question-and-answer sessions followed each session.

The congress was a very positive event in more ways than one for patient organisations. Some of the organisations were newly formed, like those in Poland, Denmark, and Portugal, while others were well-established, like France and Ireland. For some, like Germany, support and advocacy work had been entirely national until recently. Kathleen Polfliet, a patient representative from Belgium, said: 'The World Congress helped me a lot, because although being among other patients intensely in a situation like this was quite emotional, it was also very supportive. It was comforting to be among people who understood what I go through, because they too live with the problems of scleroderma every day. Normally, nobody understands.'

The opening ceremonies honoured patient support groups as a valuable part of the team fighting this debilitating disease. The congress steering committee invited both the president of EULAR and the president of FESCA to speak. This was a congress where both patient and doctor input was respected.

The Ankylosing Spondylitis International Federation (ASIF) was founded in 1988 and is based in Denmark. ASIF brings together patient groups for people with AS throughout the world. Currently membership is predominantly from European countries plus Australia, Canada and the US. ASIF meets regularly every 2 years and has a number of important functions which carry on throughout the year. One of the most vital has been the ASIF contribution to research so ably led by the ASIF scientific adviser, Prof Dr Ernst Feldtkeller.

Members of the ASIF Executive, the majority of whom are individuals with AS, have worked with the Assessment of SpondyloArthritis international Society (ASAS) and EULAR to produce a patient version of the ASAS/EULAR recommendations for the management of AS and to develop a new tool to assess the impact of AS on quality of life.

ASIF is now a co-opted member of the EULAR Standing Committee of PARE and we look forward to working with PARE to raise awareness of the issues confronting people with inflammatory arthritis and in particular the impact on work and life for both the individual and those around them.

ASIF produces a newsletter twice a year which brings together contributions from member societies. If you run a national organisation for people with AS and would like to join ASIF please go to the website www.spondylitis-international.org for more information on the work of ASIF and links to member societies.

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