

Interview with the incoming EULAR President

EULAR's President is responsible for all areas of its work, be it scientific, educational, administrative or financial. The incoming EULAR President in June 2009 is Paul Emery, Professor of Rheumatology at the University of Leeds, UK.

Professor Emery was trained at Cambridge and at Guy's Hospital in London. Before specialising in rheumatology, he did 15 years in both rheumatology and internal medicine. His special area of interest is to understand the mechanisms driving persistent inflammation, with the aim of treating people early in the hope of preventing chronic disease. We ask Professor Emery a few questions about his forthcoming years as head of EULAR.

PARE: What main themes do you plan to focus on during your term of office?

PE: The first priority is to consolidate EULAR's very successful activities over the past 10 years. Specific initiatives will be based around the declaration of patient rights which is expected to be announced in Brussels in 2010. There will also be special initiatives for both patients and allied health professionals.

PARE: What are your plans for raising awareness of rheumatic diseases with decision-makers in Europe?

PE: For the past few years I have been heavily involved with the Alliance Against Arthritis initiatives, and this will continue. The declaration proposed for 2010 in Brussels should be an ideal opportunity to raise awareness.

PARE: How will people with a rare rheumatic disease like scleroderma benefit from EULAR's activities?



Incoming EULAR President Professor Paul Emery

PE: The rare disease initiative for scleroderma will focus some of the brightest minds in research on this disease – research which has been very underfunded until now (because of the apparent intransigence of the disease to therapy). The whole initiative is geared towards developing research which will have direct benefit for patients.

PARE: The alliance of scientists, allied health professionals and people with rheumatic diseases has been very successful in reaching decision-makers in the past. How can their co-operation

within EULAR be strengthened and the potential used for the full benefit of EULAR?

PE: A huge strength of EULAR has been the fact that it represents all stakeholders in the area of arthritis. The inclusion of people with arthritis/rheumatism in all decision-making – 'nothing about us without us' – will be strengthened, and we propose to hold focus groups on the delivery of multidisciplinary care.

PARE: What would you like to have achieved on behalf of scientists, allied health professionals and people with rheumatic diseases by the end of your term of office?

PE: If by the end of my term I have been as successful as recent presidents, then that in itself will be an achievement in these difficult times. However, if we are fortunate, EULAR will have gone from strength to strength and will be seen as the organisation to which people with arthritis turn for scientific support. ■

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DEAR COLLEAGUES

by Sandra Canadelo



Work is a very important part of life for everyone. It guarantees survival and should also be a means of personal fulfilment. Gandhi said that ‘we must be doing something to be happy.’

EULAR’s focus on the topic of work is very important. Without happy and productive citizens, society cannot develop. But it needs to, because it is an important goal for everyone. At a time of recession, this issue is even more pressing. We hope that the EULAR Charter for Work will make a difference. Please see the latest news on the Charter in this issue.

This is my last editorial. My term of office has been an enriching experience, thanks to the commitment of all of you to our projects and our cause. Thank you for everything that you have taught me.

I wish my successor, Marios Kouloumas, all the best for his period in office. I hope that he will be blessed with what I am grateful to have had: an excellent work environment and the chance of playing a small part in doing what we do best – working as a team.

Sandra Canadelo is the Chair of the Standing Committee of PARE

An overview of the EULAR Standing Committee of Paediatric Rheumatology

By Professor Taunton Southwood, United Kingdom, Chairman



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The mission of the Standing Committee of Paediatric Rheumatology is to improve the healthcare of children with rheumatic diseases by supporting high standards of care, education, training and research in rheumatic diseases across the age spectrum.

The Standing Committee works very closely with the Paediatric Rheumatology European Society (PReS) to ensure that this mission can be accomplished as swiftly and efficiently as possible.

1. Clinical excellence. We aspire to give high quality care to children and adolescents with rheumatic diseases throughout Europe. Ideally, this will be provided by competent and accredited multidisciplinary teams of paediatric rheumatology healthcare professionals within tertiary settings. Until such teams are available Europe-wide, care will continue to involve networks

of professionals which cross boundaries between paediatrics and adult care. An approved system for training, accreditation and re-validation of health professionals with expertise in paediatric rheumatology is a priority.

2. Education and training. The planning and endorsement of training and educational courses is an important activity. EULAR regularly provides bursaries for paediatric rheumatology training, usually held with the annual PReS congress. There is an agreed curriculum which aims to cover

the main topics in paediatric rheumatology over a three-year period.

3. Research. It is increasingly recognised that many of the origins of adult diseases are based in the childhood years. A strategic and well structured approach to researching these origins is vital to the health of future generations. Supporting collaborative, multi-centre, long-term longitudinal research networks is becoming one of the most important tasks of the Standing Committee. Examples include the PRINTO network and CARRA. ■

Internal News

This year’s second PARE board meeting in Zurich will mark the end of term for three of its members, Sandra Canadelo (Portugal), Jolanta Grygielska (Poland) and Ute Kohl (Germany).

Jolanta Grygielska congratulated the newly elected PARE board members and said: ‘Being on the board is both a great honour and responsibility. Working in this group and representing different countries in Europe is a way of changing our world. I have seen great progress since I became involved.’ Ute Kohl says: ‘My time with PARE was exciting. I will continue to be involved through a working group.’ The leadership of the Standing Committee of PARE and the PARE board would like to thank the outgoing members for all their contributions to the work and development of PARE. ■



Ute (first left, first row) and Jolanta (third left, back row) in a PARE board photo in Athens

Alliance Against Arthritis active in Brussels

Alliance Against Arthritis 

EULAR's Alliance Against Arthritis members and representatives from EU institutions met on 3-4 March in Brussels.

PARE representatives and other EULAR stakeholders presented their case on rheumatic diseases, either through one-to-one meetings with EU officials and MEPs, or through organised events.

These included a parliamentary breakfast hosted by Dr Paul Rübige MEP, which covered the topic *Rheumatic diseases as an economic challenge – what can Europe do?* The discussion focused on the relevance of improving the work environment for people with rheumatic diseases and the economic and social issues involved. It highlighted the role that people with arthritis/rheumatism, politicians and the industry have in working closely to find ways to reduce the burden on society.

A lunchtime debate was held to receive guests from the European Parliament, the European Commission, Permanent Member States' representatives in Brussels, as well as other stakeholder organisations. The theme for this debate was *Healthcare and employment – ideas for a new policy approach*. The event created momentum for the presentation of EULAR's Charter for Work, which was launched by Maarten de Wit, EULAR Vice President representing organisations of PARE.



[Above]: Maarten de Wit, EULAR Vice President representing organisations of PARE, presented the Work Charter at the lunch debate



[Left]: Participants endorsing EULAR's Charter for Work

Maarten de Wit emphasised the economic and social burden of arthritis and rheumatism on both patients and society in general, which could be avoided through a higher priority being given to rheumatic diseases in future European policies. Everyone was given the opportunity to sign and give their support to the Charter for Work document. ■

EULAR Charter for Work officially launched in Brussels

EULAR's aim is for the Charter for Work to be a stepping stone for future European legislation and policy initiatives on the subject. More than 100 million people in Europe live with rheumatic diseases, and the charter is a tool to ask for the involvement of the European Union.

'From the patient perspective we are convinced that an integrated approach is needed to stimulate job retention and work rehabilitation. Most people with arthritis want to work,' said Maarten de Wit, EULAR Vice President representing organisations of PARE, at the launch of EULAR's Charter for Work on 3 March during Alliance Against Arthritis activities in Brussels.

'From the survey carried out by the Work Foundation in the UK we learned that work can be healthy when people with arthritis are widely supported by their doctors, their family, their employer

and their co-workers,' he said. 'Effective support includes early diagnosis and appropriate treatment, immediate adjustments in the workplace and of working hours, ergonomic interventions, individual training, and the education of everyone around the person with a rheumatic condition.'

During the first part of a workshop, EULAR stakeholders asked member organisations in Brussels to show how they planned to implement the Work Charter in their countries. The presentations and the debate that followed centred on the need for change and the possible next steps to implement the Charter on a European level. This was explained by the EULAR Brussels office representative, Sören Haar. The second half of the workshop focused specifically on the usefulness of the document and its national rollout. ■



Copenhagen is hosting the EULAR Congress in 2009. Views of the Bella Centre [top], the Danish Parliament [bottom left] and Soren Kierkegaard Square [bottom right] © Wonderful Copenhagen

European Rheumatology congress in Copenhagen

This year the European Congress of Rheumatology is being held on 10-13 June at the Bella Centre in Copenhagen, Denmark. Once again, the congress will serve as a hub for the exchange of medical information and the debate of pressing social and political topics in the field of rheumatic diseases.

The member organisations of the Standing Committee of PARE have a full programme, focusing mainly on children and young people with rheumatic diseases, and the value of voluntary work and patient participation in medical education. There will be a poster exhibition area which will be especially active on 12 June at lunchtime when the authors will be there to discuss their projects and answer questions.

The congress joint sessions will provide a useful platform for allied health professionals, people with arthritis, researchers and clinicians to discuss shared interests and find ways to work more closely together. Among the topics to be covered are work and rehabilitation, self-management

and pain, lifestyle changes, cardiovascular risks and the impact of musculoskeletal diseases on family life.

The PARE Highlight session is on 13 June. Professor Iain McInnes will present the key points of the scientific programme and Kate Llewelyn (Arthritis Care, UK) will give her perspective on the most impressive achievements in the PARE programme. ■

THE PARE BOOTH

The PARE stand (No. NP19) will be located in hall C5 of the Bella Centre. There will be information about the Charter for Work and the activities of several member country organisations. Delegates will be able to fill in the annual World Arthritis Day survey, this year on work and rheumatic diseases. The PARE member organisations' posters will be behind the booth, as will several interesting features such as the EULAR village, the history of the EULAR society, the NGOs in the field of rheumatism, and a cyber café.

Biking against rheumatism in Europe

From 6-13 June, rheumatologists, paramedics, volunteers and patients will be biking to the European Congress of Rheumatology to draw attention to inflammatory rheumatic diseases.

They want to promote research by raising funds, and to prove to decision makers and the media that with the appropriate treatment, it is possible to overcome the incapacity caused by rheumatic diseases and to remain fit and active. The biking event was first held in 2006 and has now gained an official status. A non-profit organisation was set up under the name of BaRIE (Biking against Rheumatism in Europe) to emphasise the European dimension of the project. ■

Stene Prize 2009 goes to Finland

The 2009 Stene Prize was awarded to Emmi Myöhänen from Finland. Emmi's essay, *My Rare Condition*, was one of the 16 entries in this year's contest. Sesilie Halland (Norway), member of the Stene Prize jury, said: 'The essays give a very good picture of how it is to get diagnosed and live with a rare disease in Europe. Some of the stories were heart-breaking and some were very positive. Many of the essays could have won the prize.' Emmi will receive the award from the EULAR President during the opening ceremony of the congress in Copenhagen. ■



2009 Stene Prize winner, Emmi Myöhänen from Finland © by Marja Haapio

Work together for World Arthritis Day 2009

World Arthritis Day 2009 on 12 October will encourage more supportive action to include people with rheumatic diseases in the labour market, enabling them to contribute to the successful development of an inclusive society.

'This is even more important because we are facing an economic recession,' said Sandra Canadelo, Chair of the EULAR Standing Committee of PARE. 'It is getting more and more difficult to access the labour market and in many countries people with disabilities and rheumatic conditions are the first to be affected.'

The Charter for Work, recently launched



by EULAR in Brussels during the Alliance Against Arthritis activities on 3-4 March, will be used to lobby policy-makers and stakeholders at

national and European levels. A toolkit will be available to help national organisations to plan their activities.

The World Arthritis Day website www.worldarthritisday.org has been updated and will feature activities such as the new online survey on employment, a photo exhibition, and support material for national organisations on the theme of work. Please send in your activities to help to inspire your colleagues around the world. ■

World Arthritis Day survey targets employers

Because past surveys have been immensely successful, a new survey was launched on www.worldarthritisday.org in May. It has three target groups: people with a rheumatic disease, health professionals, and employers. It is available in several languages.

The survey is to collect information on how work affects the lives of people with rheumatic diseases, and on the role of the health professionals and the employer. Topics such as workplace adaptations, co-worker and employer support or discrimination, are addressed.

WAD working group member, Jacqueline Mäder from Switzerland said: 'We need to identify good and bad experiences, and the types of support that need to be provided. Work makes everybody feel more useful and has a major influence on people's self-esteem. People with rheumatic diseases need to feel they can contribute effectively to society.' The survey results will be available on 12 October. The survey will be available at the EULAR congress in Copenhagen. Please take a few minutes to fill in the survey at the PARE stand. ■

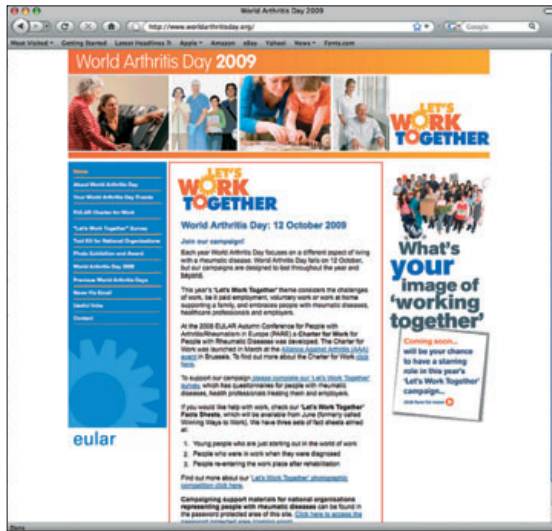


Photo contest highlights best practices at work

If you have the best colleagues, the most supportive team, a perfectly adapted workplace, or the most understanding employer – then PARE would like to receive your photograph and comment on what you think is positive about your workplace.

People with rheumatic diseases can have positive experiences at work and serve as examples of good practice in work relations. All entries from Europe and abroad will be made accessible in a gallery area on the WAD website. The most exciting, inspiring and innovative submissions will be featured as a photo exhibition that will travel across Europe.

'It's impressive to see how people overcome their limitations when they feel part of a team,' said Maria Batziou, WAD working group member from Greece. 'Feeling useful and that you belong helps people to be happy in their work and able to establish fruitful relationships with their colleagues and employers.' Please visit www.worldarthritisday.org for more information. ■



An image of the new World Arthritis Day website using the theme *Let's Work Together* to support people with rheumatic diseases in the labour market, along with a selection of images from the website

Work is the focus of Autumn Conference in Tallinn

In 2009, the EULAR Autumn Conference for PARE will take place at the Swissôtel in Tallinn, Estonia, on 5-8 November. The event will gather about 100 representatives from national organisations of people with rheumatic diseases who will discuss topics related to work and disability.

Before the conference, the Estonian Rheumatism Association will hold a national forum for about 100 participants from across Estonia. At the end of the day, there will be an EU reception on work and treatments. The European perspective on the issue will be covered by Siiri Oviir MEP. Neil Betteridge, chief executive of Arthritis Care in the UK, will talk about the implementa-



tion of a national strategy for rheumatic disease in Wales.

Ingrid Pöldemaa, Chair of the Estonian Rheumatism Association, said: 'We look forward to welcoming our colleagues and raising the awareness of local decision-makers on arthritis and the work of our organisation.'

The programme will address issues such as existing legislation and its implementation, adaptation of the workplace, and rehabilitation and reintegration into the workplace. The perspective of the employer will be represented by Dr Su Wang from Royal Mail in the UK. The impact of the EULAR Charter for Work on stakeholders and examples from projects in several countries will also be featured. ■

Patients want training as research partners

As the need for co-operation has greatly increased within the EULAR structure, there is a recognised need for suitable training and support.

Projects where patients and health professionals work together include the EUSTAR taskforce for the development of recommendations for the management of scleroderma, and the EULAR taskforce for the development of recommendations for the use of corticosteroids in rheumatic diseases. First steps towards the required training were taken at the EULAR congresses in 2007 and 2008 with workshops on patient participation in research, and on developing recommendations.

EULAR is now developing a project to explore the best ways to recruit, educate and establish a network of competent patient research partners. There is a need to create the appropriate conditions and guidelines for their effective involvement in EULAR or other international scientific research projects. Maarten de Wit, member of the EULAR taskforce, said: 'We hope that we can provide practical and – where possible – evidence-based recommendations for involving people with arthritis in new EULAR projects.' ■

EUMUSC.NET – recent developments

The EUMUSC.NET, EULAR's project application with the EU, was accepted in the summer of 2008 – a clear sign of the greater awareness of the impact of rheumatic diseases by EU authorities.

There have been follow-up negotiations with the European Commission, and the final details are being clarified with the EU.

The project is based on the need to collect health economic arguments that can be used to guarantee better access to rheumatology healthcare services. A clear picture from musculoskeletal data is essential to better understand diseases and to provide the optimal healthcare to minimise the effects on people's lives.

Maarten de Wit, EULAR Vice President for PARE organisations, said: '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. The project will develop standards of care for the major musculoskeletal diseases, osteoarthritis and rheumatoid arthritis, based on evidence and best practice.' ■



[Top and left] Tallinn is hosting the EULAR Autumn Conference in 2009

[Above] Ingrid Pöldemaa, (centre) with current PARE chair-elect Marios Kouloumas and Elpida Pitta, a local volunteer, during the Cyprus conference in 2005

Dedicated to improving living conditions

By the Danish Rheumatism Association

The Danish
Rheumatism Association

The Danish Rheumatism Association is dedicated to fighting bone and joint diseases and their consequences, and to ensure the best possible living conditions for people with rheumatism.

We have 74,000 members, and many of them actively raise awareness of rheumatism and support our cause. The association fights for increased awareness and attention to rheumatic diseases in Danish health policy, works with the media, and funds a substantial part of non-commercial rheumatology research in Denmark.

The primary focus is on rheumatoid arthritis and osteoarthritis, as well as muscular function and physical activity. Six times a year, we issue the magazine *LedSager* to members, doctors, the press, and supporters. We also publish pamphlets with facts about the most widespread rheumatic diseases and we offer a free telephone consulting service. We also run a hospital and three health centres, and distribute grants and financial support to people with rheumatism.

We recently launched AquaPunkt, a nationwide campaign on the treatment of



AquaPunkt is one of the successful activities of the Danish Rheumatism Association
© by Gigtforeningen

osteoarthritis. The concept was developed by the association's experts, who have long-standing experience of providing therapy to people with rheumatic diseases in hot pools. So far this unique knowledge has been implemented in 43 ordinary, cool water public pools to serve a wider target group.

Our top political objective for 2009 will be to secure higher and more consistent standards of diagnosis, referral to medical specialists and, when needed, initiation of treatment for people with bone and joint problems.

Visit us at www.gigtforeningen.dk (in Danish). ■

Networking at Tivoli Gardens

The annual dinner and social evening of the PARE Standing Committee members will be held in the Restaurant Grøften at the famous Tivoli Gardens on 11 June (by invitation only).

'Copenhagen is the congress host city this year, and we are excited with the prospect of welcoming colleagues from all over Europe,' said managing director Lene Witte from the Danish Rheumatism Association. 'We are trying hard to organise the event so members will be glad to have come.' ■



Entrance to the Tivoli Park in Copenhagen
© by Wonderful Copenhagen

Estonian Rheumatism Association visits Finland

By Ingrid Pöldemaa, Chair of the Estonian Rheumatism Association

EESTI REUMALIIT
Estonian Rheumatism Association

The Estonian Rheumatism Association (ERA) recently visited a hospital and rehabilitation institute that specialises in rheumatology, in Apila Kangasala, Finland.

The purposes of the visit were to learn about comprehensive methods of treatment, care, and rehabilitation for member organisations in different parts of Estonia; to exchange ideas and knowledge; and to compare the Estonian and Finnish health systems. ERA and the Finnish Rheumatism Association have a long-standing relationship, because ERA was founded thanks to the Finnish organisation in 1991.

A group of 45 people took part, including two physiotherapists, a Nordic walking instructor, two nurses, an occupational therapist, a rehabilitation doctor, a journalist and our executive team. The group visited



The Estonian group participating in the educational visit to Finland

the Finnish Rheumatism Association, the Heinola Hospital – a facility solely dedicated to the treatment of people with rheumatic diseases – and the Apila rehabilitation centre, owned by the Finnish Rheumatism Association.

A lot of new and useful information was provided about how the Finnish



Entrance to the Heinola hospital in Apila Kangasala, Finland

Rheumatism Association provide support to their member organisations, information about the newspaper *Reuma-lehti* and about the Heinola Hospital. The hospital has the slogan 'The Patient is the King', because nine health specialists work together with one patient, implying active participation of all parties in treatment. ■

Scleroderma – more than skin deep

By Ann Tyrrell Kennedy, Acting President, Federation of European Scleroderma Associations

In June 2008, EULAR declared that it would make rare diseases the focus of attention for the next four years, and that it would focus on scleroderma (systemic sclerosis).



This is an extremely severe condition with low public awareness. The name is really an umbrella term for a group of complex autoimmune diseases. It affects mostly women, but without geographical or age bias, and causes fibrosis (thickening) of the skin and internal organs. Its causes are as yet unknown, but it seems to run in the same families where someone has rheumatoid arthritis. Raynaud's disease is nearly always the first symptom.

PARE, the arm of EULAR that is composed of patient support groups, supports the Federation of European Scleroderma Associations (FESCA), as does the EULAR Scleroderma Trials and Research Group (EUSTAR). FESCA now has 16 member groups. More patient support groups are waiting to join and one of FESCA's tasks is to help these develop their own structures and strength. FESCA's mission is to represent the interests of those who have scleroderma, and its overarching goal is to promote the advancement of knowledge, research and information within medical, governmental and social arenas. Increasing awareness of the disease among the general public is a major aim.

In January 2009, plans were made to celebrate the first European Scleroderma Day on 29 June, the date that Swiss artist Paul Klee, arguably the most famous person known to have had scleroderma, died in 1940. Launching this event will proceed differently in each member country. The Minister for Health in Ireland will launch the



celebration, and France will have a media campaign on television. For all FESCA members, the theme will be More Than Skin Deep, to increase awareness of the impact of the disease on internal organs. The publicity will feature a Klee painting that forms an 'S'.

There will also be a programme launched called *very early diagnosis of systemic sclerosis* (VEDOSS). This is a programme that will involve GPs, other medical practitioners and rheumatologists. If GPs are aware of the early symptoms of scleroderma and refer those of their patients who have two of these symptoms to a rheumatologist for further tests and clinical assessment, then diagnosis would occur much earlier and treatment could lead to a better outcome. The education of GPs is therefore paramount because the average wait for someone with Raynaud's to see a rheumatologist is six years.

FESCA is planning a world patient



The FESCA board at their meeting in January 2009

congress in Florence in February 2010, at the same time and place as a World Scleroderma Congress for rheumatologists. There will be extramural events, such as a Klee exhibition and lecture. The FESCA activities will be held on 13 February and patients will be addressed by doctors attending the medical congress.

Together, FESCA and EUSTAR, EULAR, and PARE are actively promoting knowledge and education. As national associations share ideas and projects, FESCA is prepared to foster action, debate, and research. Our website www.fesca-scleroderma.eu aims to raise the visibility of FESCA as a European umbrella organisation, to increase the number of member organisations, and to serve as a centre for information exchange. We encourage interaction among FESCA, the European Parliament, and medical organisations. ■

BREAKTHROUGH

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EULAR supports the BJD: www.boneandjointdecade.org