About the EULAR Autumn Conference:

Since 1997 a dedicated conference has been held for EULAR national organisations of PARE, which each year is hosted by a different country. This year’s Autumn Conference was held in Zurich, Switzerland and was hosted by the Swiss League Against Rheumatism.

This year 145 delegates from 35 countries attended, 20 of whom were young people (under 35 years of age), or involved in working with youth in their organisations. As well as EULAR topics, the three-day programme focused on aspects of the World Arthritis Day theme, Physical Activity and RMDs and fundraising.

2012 EULAR Autumn Conference objectives

1. To inspire, educate and empower delegates and their national organisations to develop and execute campaigns around the topic of physical activity through:
   • Showcasing the activities of established patient leagues, e.g. the Swiss League Against Rheumatism;
   • Providing expert key note speakers;
   • Sharing best practices;
   • Developing practical materials that can be adapted for national activities and meet national needs.

2. To make delegates and their national organisations aware and receptive to the benefits of international collaboration through:
   • Clarifying and promoting the activities and relevance of EULAR;
   • Demonstrating how EULAR can support the interests of its member organisations on a national and local level.

3. To inform participants from the Swiss League Against Rheumatism about EULAR activities, so that the work done at a European level becomes more relevant and meaningful to them.

4. To improve cooperation and exchange between the German speaking countries (Switzerland, Germany and Austria) in order to support cross borderer activities and joint projects.

The Task Force responsible for planning this year’s conference:

Anna Ageberg, PARE Board member, representing young people
Maria Batziou, Chair, EULAR Standing Committee of PARE
Hans Bijlsma, EULAR Education Officer
Kåre Birger Hagen, EULAR Vice President, health professionals in rheumatology
Claudia Hagmeyer, 2012 Swiss team
Lena Maria Hreinsdóttir, 2013 Icelandic team
Valérie Krafft, 2012 Swiss team
Einar Ingolfsson, 2013 Icelandic team
Marios Kouloumas, Task Force leader
Kristín Magnúsdóttir, 2013 Icelandic team
Emil Thorodsson, 2013 Icelandic team
Nadia Tsiliakou, 2011 Greek team
Maarten de Wit, Task Force member
Friday, 2 November: EULAR day

Neil Betteridge, Vice-President, EULAR, representing PARE, opened the proceedings and moderated the Friday sessions. Heinz Marchasi, Executive Director, EULAR, provided a brief history of the Autumn Conference, previously known as ‘Arthritis People on the Move’ (APOM) and the restructuring of the EULAR Social Leagues with the PARE Manifesto in 2007.

Valérie Krafft, Director of the Swiss League Against Rheumatism, provided an overview of some of their key activities and projects. The Swiss League is an umbrella, not-for-profit organisation with 26 member organisations; six national disease-based organisations and twenty local, cantonal groups. Projects organised by the Swiss League include a national action week that has been running for the past five years, physical activity classes and train the trainer programmes for exercise instructors, but fundraising remains a key challenge.

Maria Batziou, Chair of the EULAR Standing Committee of PARE gave an overview of the PARE projects, including a review of the 2011 – 2012 World Arthritis Day (WAD) ‘Move to Improve’ campaign on physical activity for people with RMDs and introduced healthy ageing from birth through every stage of life as the new WAD campaign theme for 2013 – 2014.

Additionally, the first meeting of the professional CEOs of the 11 largest national organisations of PARE was held in March 2012 to provide a platform for them to share their knowledge and to strengthen their involvement with EULAR, in particular the EU activities in Brussels.

Nemanja Damjanov, Professor of Internal Medicine and Rheumatology from Belgrade, Serbia and Secretary General of EULAR, presented the EULAR 2017 strategy, which will cover the next five years and has seven objectives each to which have been assigned a total of twelve projects.

Professor Damjanov facilitated a workshop on the EULAR 2017 strategy enabling participants to add their thoughts to the objectives they felt were most important from a patient perspective:

Objective 1 – Research: clinical research funding through the European Rheumatology Research Foundation focusing on psychosocial research, Patient Research Partners and the knowledge transfer programme.

Objective 2 – Education: developing innovative learning methods via projects such as the Knowledge Transfer Programme, the EULAR Autumn Conference, Patient Research Partners and the PARE programme at the EULAR Congress.

Objective 4 – Advocacy: RMDs recognised at EU, national and global levels as equivalent to other diseases through EULAR EU public affairs activities and World Arthritis Day (See EU Affairs – Horizon 2020 workshop).

For more information on the EULAR strategy please visit: www.eular.org

The first European Musculoskeletal Health Days were held on the 16 and 17 October and co-organised with EFORT (the European Federation of National Associations of Orthopaedics and Traumatology), with which EULAR has recently formed the European Musculoskeletal Health Alliance. Two key events were a conference on preventing chronic diseases for a healthier Europe and a workshop tackling the burden of rheumatic and musculoskeletal diseases through research.

Young people with RMDs are the future generation for EULAR. Following a very successful youth meeting in Estonia in 2011, a project to identify the state of activities and structures for young people with RMDs in Europe and their needs was submitted to EULAR and accepted in March 2012. Since then, a Youth Task Force of highly motivated, mainly young people gathers information. The first part of this project will be completed by the 2013 EULAR congress.

To coordinate with the healthy ageing theme the topic for the 2013 Edgar Stene essay competition is ‘Growing up, or growing older: my secret for healthy ageing with an RMD’.
In the WAD workshop, facilitated by Maria Batziou, delegates identified incentives, such as competitions with prizes, and use of social media as being key to engagement in the Waving campaign, with the network of WAD Social Media Ambassadors to promote it being cited as a success in 2012. Organisations requested early, short, simple, step-by-step information about what is available, and what to do with it, as well as template materials with text that can be translated and artwork to produce resources locally, such as the toolkits produced for the 2012 campaign. A number of delegates were not aware of the range of resources available on the WAD website (www.worldarthritisday.org/resources/organisations).

It was agreed that the healthy ageing campaign (2013 – 2014) should cover physical, social and psychological elements, as well as education and prevention in terms of early diagnosis, referral and treatment, staying healthy through good diet and exercise etc.

Four other workshops were conducted following the presentations on Friday. For the first time, ‘Plan of Action’ (PoA) templates were used in workshops to help delegates capture key findings to feedback to their organisations.

In her workshop on assistive technologies, Verena Langlotz, an occupational therapist working with the Swiss League Against Rheumatism, presented participants with a range of assistive technologies. Not all countries have access to the full range of assistive technologies, but information can be shared by organisations. Organisations can work with companies and governments to finance and develop universal designs that are good for all. Organisations can also invite their members to share ways they have found to overcome challenges by adapting everyday objects, their environment and behaviours. Model apartments provide people with RMDs with an opportunity to try out adaptations and products and learn how to use them. The Swiss League Against Rheumatism is producing a training video on the use of assistive technologies.

The EU Affairs workshop facilitated by Neil Betteridge and Sören Haar, from the EULAR EU office in Brussels, looked at the Horizon 2020, the EU framework programme for research and innovation, which runs from 2014 to 2020 with an €80 billion budget. Delegates looked at the public affairs work EULAR is conducting at a European level and how this can be leveraged by national organisations at a local level by bringing key messages to national authorities and then feeding back reactions, successes and challenges to EULAR. Steps that organisations can take include creating platforms to coordinate national advocacy. To support organisations, EULAR could provide comparative European data, training and tools for campaigning, as well as helping to facilitate meetings with national policy makers.

The Patients in Research workshop facilitated by Maarten de Wit looked at the benefits of patient involvement in research and the importance of including patients’ perspectives and expertise when designing research projects. This helps ensure that health professionals have a better understanding of patients’ needs and patient-orientated questions are included, leading to improved health services. There are currently 15 patient research partners in EULAR, but more are required and there is a need for agreement on how to identify patient research partners. Future requirements include making health professionals value patients’ expertise, developing a common language so patients can fully participate in their role as a collaborating partner, more resources, including money, to help organisations set up research agendas and reimburse patients for their time. Organisations should compile and present best practises showing the benefits and value of patient involvement. Training and education of patients, as well as researchers, would also be useful.
Rikke Helene Moe, a physiotherapist from Oslo and researcher on EUMUSC.NET, facilitated a workshop on this EU research based project, which is supported by the Executive Agency for Health and Consumers (EAHC) and EULAR involving 22 institutions in 17 countries, with the aim of improving Standards of Care for people with RMDs through various work packages. So far EUMUSC.NET has produced a report on Musculoskeletal Health Status in Europe, factsheets for each EU member state, user focused Standards of Care for OA and RA and Health Quality Indicators. In this workshop delegates looked at the facilitators to implementing Standards of Care. Important facilitators identified by this group were, access to care, easy to find, prioritised recommendations, education to understand the content and importance of recommendations, economical resources, information that is easily accessible and translated at a national level, a positive attitude. It was agreed that EULAR has an important role in helping policy makers understand the implication of recommendations.

The annual Share Fair features the EULAR Knowledge Transfer programme which provides an annual grant to help national organisations wishing improve their skills. This mainly involves a visit to another organisation in the EULAR network with the required experience and skills. The programme is open to EULAR member organisations of PARE and organisations with co-opted delegates in the Standing Committee of PARE. Topics covered in the Share Fair included a case study, ‘From project idea to grant award’, from Romanian League representative, Codruta Filip – Zabalan, information on changes of deadlines to send in applications to participate in the programme. Maria Batziou took on the lead for this Task Force from Marios Kouloumas.

The conference gala dinner was held at the Zunfthaus zur Meisen, one of Zurich’s old city guild houses. This special evening included speeches from the President of the Swiss League Against Rheumatism, Franz Stämpfli, and Chairperson of the EULAR Standing Committee of PARE, Maria Batziou.

Although physical activity is vitally important to people with RMDs and helps prevent co-morbidities such as obesity and osteoporosis, a worldwide study indicates that only one in five people is physically active enough. The EULAR ‘Call to Action’ is a lobbying tool aimed at policy makers. In two of the workshops following the presentations, delegates discussed how smaller and larger organisations could launch and use the ‘Call to Action’ in their countries.
Hans Bijlsma facilitated the workshop for larger organisations which felt that increasing access to physiotherapists and specialist centres is an important step to making people with RMDs more physically active and good call to action for policy makers. The ‘EULAR Call to Action’ could be used to ensure physicians are aware of the benefits of exercise for people with RMDs by including this in their medical education. To help achieve this, organisations can work with a range of stakeholders including national ministries in the areas of health, education and finance and local policy makers, as well as health professionals, their societies, patients and organisations representing people with other chronic diseases with similar challenges and goals. Publicity can be very helpful in influencing policy makers.

It was suggested that a committee should be convened to consider aspects of launching the ‘Call to Action’ including timing, funding for an event.

Kåre Birger Hagen’s workshop looked at what smaller organisations could do and had many commonalities with Hans Bijlsma’s group. They felt that both health professionals and patients need to be informed and excited about the benefits of physical activities for people with RMDs. New patients can be provided with information about existing physical activity programmes, teachers can be trained to manage children with RMDs within school physical education programmes and employers can be educated about the benefits of physical activity in preventing musculoskeletal conditions and helping those with RMDs manage their condition at work. It was agreed there would be great value in having research showing the cost benefits of physical activities and providing this as evidence when launching the ‘EULAR Call to Action’ to policy makers.

‘From Research to Action’, is a report produced by the Swedish Rheumatic Association. It provides evidence-based information and advice on the best type of exercise for people with common types of RMD, which could be used when presenting the ‘EULAR Call to Action’ to policy makers and other audiences. Anne Carlson and Magdalena Olsson each gave short presentations about the report in the respective workshops.

Sören Haar delivered a highly informative perspective on EU policies on physical activity.

Article 165 of the Lisbon Treaty covers sport, but is not legally binding. Organisations can use research data and best practice in other countries to highlight under-performance and exert pressure in member states that are not actively creating opportunities for people with RMDs to be more physically active.

There are a number of departments in the European Commission that can be engaged. DG SANCO covers health, but DG Education and Culture covers sport and DG Mobility and Transport cover accessibility, all of which can contribute to maintaining a healthy population and workforce that has a major economic impact.

A role play between Sören and Neil Betteridge highlighted a number of campaigning tips including the limited time policy makers have to see representatives from any number of patient groups trying to engage with them. To stand out when approaching policy makers you need to be well prepared. Have all your facts and figures at your finger tips to answer questions such as, ‘Who does this affect? What is the size of the problem? Why does this matter? What is the societal burden / cost to the government? What can the policy maker do? How will this help?’ etc. Other tips included finding out about the policy makers before you approach them so you can personalise your approach; getting your two or three key messages across in the first five minutes in case the meeting time is cut; being persistent; being clear about what the policy maker can do and how you can help them do it. Policy makers can be more receptive to approaches around election times when they are looking for votes. It is advisable to approach policy makers jointly with a physician who can answer medical questions.
Marianne Krijgsman, project manager at st. Reuma Perspecties and Hans Bloo, a sports physiotherapist and human movement scientist, presented Reumanetwerk, a highly successful programme developed in the Netherlands to provide physical activities for people with RMDs and a stimulating example of what can be done with good collaboration. The Reumanetwerk was built slowly starting with small projects with new goals. It has been hugely successful and has grown from 60 patients to 570 to date. In their presentation Marianne and Hans described how the Reumanetwerk was set up in the Netherlands and could be used as a model for other countries wishing to start something similar. A step-by-step plan for setting up a Rheumatology Network has been prepared by Reumapatiëntenbond, Reumapatiëntenvereniging Zuid Veluwe and Paramedisch Instituut Rembrandt (Rembrandt Paramedical Institute) in Veenendaal.

In the following workshop, Marianne and Hans were joined by Claudia Merkies, the President of Reumapatiëntenvereniging Zuid Veluwe, who has been instrumental in setting up and running the programme Reumanetwerk. Key feedback from the workshop was that the initiative should be led by a patient organisation; the aims and benefits of the programme should be clearly communicated when approaching healthcare professionals and other stakeholders; accredited training for health professionals who are going to be running classes should be provided (a train-the-trainers programme for physiotherapists is available); funding is a challenge so start small and build up; offer a variety of exercises and use measurement to help keep individuals motivated, as well as to demonstrate benefits.

Based on a case study on successful programmes run by Arthritis Ireland (AI), Nichola Mullen ran a workshop to look at ways to change individual behaviour and help people with RMDs to become more physically active. To change perceptions of physical activity AI ran a series of seminars explaining the difference between structured exercise and increasing movement in daily life and to help people focus on their abilities rather than their disabilities. Arthritis Ireland runs walking groups and other activity based classes. Videos of these activities can be found on their website (www.arthritisireland.ie). Nichola recommended that organisations develop a strategy around exercise for people with RMDs, seek sponsorship and develop a network of partners including other organisations with common goals. Logos, branding and statistics help promote projects and gain media coverage.

This year’s poster exhibition attracted twenty eight high quality posters. Those receiving most votes in the three categories were, the Deutsche Rheuma-Liga (Germany) for the most successful / innovative campaign around the theme of physical activity; NORA (FYRO Macedonia) for the most successful / innovative campaign (open theme), and ELEANA (Greece) for the most beautiful poster.

Sunday, 3 November:
Fundraising:

Diana Skingle, PARE board member and trustee of the National Rheumatoid Arthritis Association (NRAS) in the UK, moderated Sunday’s session which focused on fundraising. To begin the final session, inspirational speaker, Jenny Christensson from Sweden described how, through her passion for horses, dedication, determination and hard work, she overcame the challenges of her rheumatoid arthritis to continue her extraordinary career as a champion dressage rider.
Successful fundraising: Arthritis Ireland (AI) was founded 31 years ago, but since Nichola Mullen joined in 2005 it has transformed from a small charity raising around €350k a year, mainly from legacies and sporadic services, to a leading Irish charity raising around €1.2m today.

Like other countries, Ireland has had financial problems, but raising funds has to be a priority, because without money an organisation can’t do anything. As a professional fundraiser, Nichola sees her job as facilitating the ask for money and delegating tasks – everyone in the team plays a part in fundraising from those running the helpline and collecting names for the database to the volunteers who help run events. Money can be raised in a number of ways; by taking advantage of other people’s events, such as marathons, and finding people to raise money for your organisations, or organising your own events. AI organises events such as Cycle 300 and ‘Get Your Joints in Motion’. Long-running events are carefully monitored to ensure they continue to do well. Nichola’s ten key steps to successful fundraising are:
1. be clear about what you are raising funds for;
2. what works for your organisation;
3. budgeting;
4. time planning,
5. delegate tasks;
6. just ask!
7. collect the money;
8. say thank you;
9. stay in touch;
10. re-evaluate.

Stories about children always attract a high level of attention and help dispel myths that arthritis is only an old person’s disease. AI’s ‘Jasper Campaign’, is promoted through schools and recruiting teenagers to give up a day to sell pins. People can be incentivised to volunteer by adding their work experience with your organisation to their CV. Family and friends can also be recruited as volunteers to help organise and run campaigns and events.

Magdalena Olsson facilitated a workshop looking at ways experienced organisations could improve their fundraising using presentations from Cyprus, Germany and Iceland: Marios Kouloumas, President of the Cyprus League Against Rheumatism (CYPLAR), Dieter Wiek, Board Member of the Deutsche Rheuma-Liga (DRL) and Emil Thoroddsen, Executive Director from Gigtarfélafílag Islands, the Icelandic League Against Rheumatism.

Nichola’s workshop looked at fundraising in less developed organisations. In some areas there is still a mentality that is ashamed of fundraising, seeing it as begging for money, but to be successful you need to develop a budget and publish all income and expenditure. Organisations that don’t have skills to develop business plans and programmes or design materials can work with universities, design collages and business schools taking a charity problem to be worked on as a project.
CYPLAR provides a number of services for its members, including self-management courses and day centres, and runs multi-sponsored awareness raising activities. Funding comes from a mix of sources including state contributions, events, pharmaceutical and other companies, legacies, the public and subscriptions from members. CYPLAR keeps in regular contact with sponsors and holds an annual meeting and dinner of thanks for them. Nevertheless, fundraising continues to be a challenge in the current financial climate and where companies are cutting their budgets.

DRL receives most of its funding from member fees and payment for its magazine. Other key sources of income are from public institutions, such as the Ministry of Health, health insurance funds, pension funds, foundations and lotteries. Funding provided by these institutions has to be applied for annually and the DRL employs professional staff with the special skills needed to complete these applications and provide information on the benefits of projects in a way that is clear and appealing to funders. Additionally, the DRL cooperates closely with public institutions. Representatives from the pension fund and health insurance fund are members of the DRL national level board.

Gigtarfélاغ Islands had 2,500 members in 1996 with no lottery funding or direct mail and in a country with a population of 320,000 and 100,000 households. Using direct mail, a ‘selective bill’ in everyone’s online bank and contacting people four times a year and focusing on small donations (€12 – 20) the Icelandic League now has over double the number of members and a database of 80,000 in 70,000 homes. Other sources of funding are from the lottery and through the sale of cards. The challenge for 2013 is to develop new and closer relationships with loyal donors.

The summary conclusions from this workshop reflected many from the workshop for less experienced organisations, with challenges including the highly competitive landscape and limited resources; rebranding RMDs whilst being sensitive to cultural traditions; gaining contact information and stimulating loyalty; being cautious about Corporate Social Responsibility. Possible solutions included regularly asking for small amounts; watching what other organisations are doing and copying good ideas; connecting membership fees with benefits; having a broad range of funding sources to maintain credibility and independence; hiring professional fundraisers as well as working with volunteers, and involving celebrities.

Reykjavik, capital and largest city in Iceland and the northernmost capital of a sovereign state

The 16th EULAR Autumn Conference for PARE will be held in Reykjavik, Iceland from the 15 – 17 November 2013 and will be hosted by Gigtarfélاغ Islands, the Icelandic League Against Rheumatism.