

REPORT

**17th EULAR Annual European Conference of PARE,
Zagreb, Croatia,
7th – 9th November 2014**



About the EULAR Annual European Conference of PARE:

Since 1997, a dedicated conference has been held for EULAR member organisations of PARE, which is hosted by a different country each year. This year's Annual Conference was held in Zagreb, Croatia and was hosted by the Croatian League Against Rheumatism, Hrvatska Liga Protiv Reumatizma. 108 delegates from 31 countries attended.

The main theme of the conference was Healthy Ageing with a rheumatic or musculoskeletal disease (RMD) with three main areas of focus; policy and campaigning; information and education; and capacity building and empowerment. With a total of eight workshops to choose from, each workshop was repeated, allowing delegates the opportunity to attend four different workshops. The plenary sessions and workshops attended by Croatian delegates were translated into Croatian.



108 delegates attended the conference in Zagreb

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

Hans Bijlsma, EULAR Treasurer

John Church, 2015 Ireland team

Frane Grubišić, 2014 Croatian team

Lena Maria Hreinsdóttir, 2013 Iceland team

Marios Kouloumas, EULAR Vice President representing PARE

Christina Opava, EULAR Vice President representing Health Professionals in Rheumatology

Ingrid Pöldemaa, PARE Board and representative of young people

Maarten de Wit, Task Force member

2014 EULAR Annual European Conference of PARE objectives

1. To inspire, educate and empower delegates and their national organisations to develop and execute campaigns around the topic of healthy ageing through:
 - 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 regional, European and international collaboration by:
 - 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 exchange knowledge and experience about the benefits of hydrotherapy and balneo-therapy* for patients with rheumatic and musculoskeletal diseases (RMDs) during the conference and to feature this as a case study in one of the workshops.
4. To inform participants from the Croatian League Against Rheumatism about EULAR activities and to inspire and empower them through:
 - participation in the conference;
 - attending a short internal meeting for Croatian delegates to be organised after the conference.

*Balneo-therapy is a term used in Croatia and some other countries for spa therapies involving hot and cold baths in medicinal and thermal springs, including mineral springs enriched with silica and other substances that can be absorbed through the skin. Balneo-therapy may involve massage through moving water and underwater therapeutic exercise. There is some evidence that balneo-therapy of various kinds may be helpful for a number of RMDs, including rheumatoid arthritis (RA), ankylosing spondylitis (AS) and osteoarthritis (OA). Balneo-therapy comes under the umbrella of hydrotherapies.

Thursday, 6th - Friday, 7th November



The networking ice breaker

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Thursday 6th November

On Thursday evening delegates were invited to participate in a networking

ice breaker. Using a grid with facts that could be related to people in the room, delegates were encouraged to talk to as many people in the room as possible to meet new people and learn a bit more about them by trying to match them to one of the facts on the grid. This first networking and get together session was well attended and enjoyed. Prizes were awarded to Nicola Lins and Nicole des Bouvrie for being the first to complete their grids.

"A practical approach which enables the participants to know each other in the shortest possible way - excellent tool! It was a great idea for new members to feel welcomed."

Friday 7th November

Diana Skingle, Chairperson of the EULAR Standing Committee of PARE, welcomed delegates and speakers and moderated the first session of the conference. This year, delegates were encouraged to engage in social media conversation around the conference, using the official conference hashtag #PARE2014. Twitter engagement during the conference was high; 291 tweets

about the conference were shared by the delegates, reaching a potential audience of approximately 163,000 people.

Prof. Christina Opava, EULAR Vice President Health Professionals in Rheumatology, delivered the opening remarks on behalf of EULAR and thanked the Croatian League Against Rheumatism for hosting the conference in the beautiful city of Zagreb. **Dr Frane Grubišić**, President of the Croatian League against Rheumatism, welcomed delegates on behalf of his league, and relayed a message from Ivo Josipović, President of Croatia, informing delegates that, although he could not attend the conference, Mr Josipović sent his best wishes and hoped that the conference would be successful. However, **Marija Coupe** from the Croatian Ministry of Health was able to attend the conference and assured delegates that the Ministry is aware that more than 120 million people in Europe

are affected by chronic pain from RMDs and the importance of the early diagnosis and treatment of RMDs.



Prof. Durdica Babić-Naglić, President of the Croatian Society for Rheumatology, Clinic for Rheumatic Diseases and Rehabilitation, University Hospital Centre, Zagreb

Other welcome addresses were provided by **Prof. Durdica Babić-Naglić**, President of the Croatian Society for Rheumatology, Clinic for Rheumatic Diseases and Rehabilitation, University Hospital Centre, Zagreb, who highlighted the need to promote the importance of RMDs for patients, families and societies, and **Tatjana Prenda Trupec**, General Manager of the Croatian Health Insurance Fund, who noted that there has been a recent increase in the funding for biological treatments for people with RMDs, with the Fund introducing eight biological treatments last year.

Dr Frane Grubišić, Head of the Department of Adult Rheumatology, Clinic for Rheumatology, Physical Medicine



Marija Coupe, Croatian Ministry of Health



Diana Skingle, Dr Frane Grubišić and Prof. Hans Bijlsma



Ljubica Žigman, a person with RA



Dr Frane Grubišić, Head of the Department of Adult Rheumatology, Clinic for Rheumatology, Physical Medicine and Rehabilitation, University Hospital Centre, Sestre Milosrdnice, Zagreb

and Rehabilitation, University Hospital Centre, Sestre Milosrdnice, Zagreb spoke about the role of rehabilitation in the treatment of RMDs. Dr Grubišić explained that rehabilitation is a complex and comprehensive process, involving a wide variety of health professionals that aims to maximise the physical, psychological, social and vocational ability of people with RMDs undergoing treatment. **Ljubica Žigman**, a person with RA, presented her personal experience of comprehensive rehabilitation and how this has enhanced her quality of life.

Prof. Hans Bijlsma, Professor of Rheumatology Utrecht and Amsterdam, The Netherlands, and Treasurer of EULAR, presented a strong, evidence based case for the role of rehabilitation in treating RMDs, but highlighted that not all countries have access to these treatments. Prof. Bijlsma used three types of RMDs, rheumatoid arthritis, ankylosing

spondyloarthritis and osteoarthritis, as examples to demonstrate the benefits of non-pharmacological interventions in the treatment of RMDs.

The presentations were followed by a lively interactive panel discussion around rehabilitation, which included answering several thought-provoking questions from the audience.

*"All the plenary sessions were good but Hans Bijlsma was the highlight."
"Very potent moderation and representation. Very potent messages."*

The opening addresses, presentations and panel discussion were live streamed and watched by 117 unique users. In addition, the session was made available on YouTube and by mid-December had been viewed almost 600 times.

"It was a very good idea of live transmission accessible on YouTube as recorded event - very professional transmission with pasted slides of presentation and translation."

As at last year's conference, the remainder of the programme on Friday and Saturday was taken up by a series of workshops on topics focused on providing organisations with ideas and information to enhance their activities in the areas of campaigning, education and capacity building.

Prof. Hans Bijlsma facilitated a workshop on **using recommendations to improve healthcare for people**

with RMDs at a national level, with support from **Dr Frane Grubišić** and **Dr Maarten de Wit**, Task Force member. The workshop helped delegates gain insights into using a systematic approach to implementing recommendations on a national level in order to provide organisations with practical steps for developing a national action strategy to improve standards of care. Hans described recommendations and how they can be used to campaign at hospital, national and European levels. **Prof. Loreto Carmona**, Vice-President of OpenReuma and Technical Secretary of the Spanish League Against Rheumatism, (LIRE), presented an informative case study on how Spain successfully used recommendations to implement a national strategy on health quality improvements for people with RMDs.

Delegates formed into groups to identify gaps in healthcare provision, focusing on topics including lack of information and education, and a lack of access to a specialised multidisciplinary healthcare team. The group discussing a lack of patient information and education noted the role of organisations in helping educate and empower patients, for example through mobile apps and social media. Doctors' role in patient education could benefit from better training on how to communicate the risks and benefits of treatments and the use of lay language.

Delegates agreed there is a lack of access to a specialised multidisciplinary healthcare team and an unequal distribution of all types of rheumatology-related health professionals in health



Workshop on using recommendations to improve healthcare for people with RMDs at a national level



Workshop on how organisations can make healthy eating easy and enjoyable for people with RMDs

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services at national levels. Communication between healthcare team members, such as GPs and specialists, also needs to be addressed. Delegates noted the importance of increasing awareness of RMDs and using patients as educators amongst the general public, through networking and other communications channels. It was noted, however, that many people with RMDs are reluctant or afraid to speak out through fear of losing their jobs or stigmatisation.

John Church, CEO of Arthritis Ireland, facilitated a workshop to identify **how organisations can make healthy eating easy and enjoyable for people with RMDs**, with support from **Dr Maarten de Wit** and **Nele Caeyers**, CEO of RheumaNet. The workshop aimed to provide organisations with a menu of activities to encourage people with RMDs to choose, prepare and eat healthier foods and to provide ideas to help organisations develop and implement activities to encourage this.

John Church presented Arthritis Ireland's motivational 'Let's Cook' campaign as a case study, demonstrating what can be done to promote healthy eating at a national level. Delegates then identified several challenges organisations face when trying to develop activities to encourage healthy eating, which included a lack of knowledge, a lack of financial resources, a lack of professional staff, and a lack of volunteers.

To address a lack of knowledge, delegates highlighted the importance of providing information on topics such

as how to use assistive technologies. Organisations that are struggling to finance their activities should develop a good business plan and consider approaching the pharmaceutical, or food industry for sponsorship, coordinate fundraising activities, or ask EULAR, the EU or their national Health Ministry for assistance. If organisations are lacking professional staff, it was suggested that they could approach marketing students to conduct pro bono work or ask their sponsors. To address a lack of volunteers, delegates recommended organisations could use communications channels, such as local press or social media, to attract people to give their time and help. Expert volunteers could be sought from local cooking schools.



Adriana Carluccio, International Relations Coordinator of Associazione Persone con Malattie Reumatiche (APMAR) and Judith Cranford, head of global advocacy at Ruder Finn, presenting the workshop on online tools and social media

Adriana Carluccio, International Relations Coordinator of Associazione Persone con Malattie Reumatiche (APMAR), facilitated a workshop to help delegates **understand how organisations can use internet tools and social media to enhance their**

activities and communicate with their members and broader audiences, with support from **Judith Cranford**, head of global advocacy at Ruder Finn. At the start of the workshop delegates were given the opportunity to identify online tools from their logos. This stimulated discussion around the tools delegates have used in their organisations.

Adriana provided guidance on the most effective ways to use social media to support organisations' activities, whether it be campaigning or fundraising. Choosing the most suitable online platform should be determined by the aim of the organisations' campaign or activity, for example, smaller organisations may want to focus on driving engagement and awareness, whereas larger organisations may need to coordinate crowd sourcing or online advertising. Adriana explained that every organisation faces challenges in using social media and that the best way to approach social media activities is to develop a strategy and to identify exactly who you are trying to reach and why.

Adriana provided delegates with best practice case studies, such as a Facebook campaign by the APMAR around the closure of the rheumatology unit at the San Filippo Neri Hospital in Rome. Delegates were given an interactive demonstration on how to use specific online tools; Facebook advertising and Hootsuite for the more experienced organisations; and Facebook and Indiegogo for the less experienced organisations. Delegates showed interest in learning about new tools and benefited from Adriana's guidance and tips.



Question and answer session



Workshop on children and RMDs

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Marios Kouloumas, EULAR Vice President representing PARE

Nicole des Bouvrie, secretary of Youth-R-Well.com, supported by **Petra Bednarova**, volunteer and board member of the Slovak League Against Rheumatism (SLAR), led the Youth workshop on **children and RMDs**, which looked at how organisations can support children with RMDs and their parents and what steps organisations need to take to set up and run activities. Petra provided a case study on the Slovakian League's KidsKlub, showcasing how the project was formed and the range of activities it now provides for children with RMDs. Delegates then took part in an open discussion to share their experiences of setting up and running clubs for children, including the challenges they have faced.

Delegates worked in groups to look at different aspects of developing support for children with RMDs and their parents. The first group discussed what information and support could be offered and suggested talks and workshops could

be given at schools, parties and sports events. Additionally, organisations could set up summer or winter camps centred around sports, gardening, workshops or fundraising. An information pack could be developed and offered to all children and parents upon joining a youth club, which includes education for newly diagnosed patients.

The second group looked at what is required to be able to offer support for children with RMDs. The group highlighted that setting up a group for children is easier when done through a national organisation. Doctors and healthcare professionals have an important role in referring people to national organisations. Potential leaders could be identified from within the groups of parents, grandparents and other family members. The final group discussed ways in which organisations can approach children and parents to get them involved in activities. Delegates' ideas included websites for youth, clinic visits, having youth representatives in branches throughout the country and for children affected by RMDs to give presentations in schools. Delegates highlighted the importance of using social media to communicate case studies, including celebrity case studies, to help overcome the stigma associated with, and change public perceptions of, children with RMDs.

"Great job with the workshops. I wish we could attend more workshops. Using examples from experienced countries is a great idea. If they had more time they could be more detailed. Skilled experts could be included in workshops."

"I was excited by the youth workshops, especially the first one that had to do with kids! Congratulations to all! We need more of these examples and as the next conference will be held in Dublin where there has been very good work with this sensitive age group, I strongly believe that workshops like this are more than important. In addition, the social media workshop made a good effort to introduce us to new ways of funding and expanding knowledge."



Adriana Carluccio, John Church and Hans Bijlsma answering questions in the feedback session

Following the workshops, **Marios Kouloumas** moderated an informal, interactive workshop feedback session with time for delegates to ask the workshop leaders questions relating to each of the workshop topics.

In the evening, delegates attended the **poster exhibition**, which consisted of 10 inspiring posters and two short videos. Delegates were invited to join the 'poster rally', where they had to match each poster to a fact about the campaign provided in a list. This encouraged people



Poster exhibition

Saturday, 8th November

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to read the posters, watch the videos and ask the presenters about their campaigns. The winner, with all correct answers in the quickest time, was Boryana Boteva, from Bulgaria, who won a prize.

Prizes were also awarded to the posters from Malta, for the most successful/innovative campaign around the theme healthy ageing, presented by Mary Vella; from AGORA, for the most successful/innovative campaign (open theme), presented by Souzi Makri; and from Finland for the most beautiful poster (open theme), presented by Sini Hirvonen. Each of the poster winners received a prize.

Saturday 8th November

The workshop **'how can organisations build a case for rehabilitation?'** was led by **Prof. Christina Opava**, with support from **Dr Frane Grubišić**. Christina began the workshop by explaining what therapies constitute rehabilitation and the term 'Comprehensive Rehabilitation'. Delegates discussed the range of rehabilitation services available in their countries, as well as identifying those that are not offered. The main types of rehabilitation which are lacking across Europe are comprehensive medical rehabilitation, podiatry, hydrotherapy, social and lifestyle counselling, psychotherapy and self-management education.

Dr Tatjana Kehler presented an informative case study on what is being done in Croatia to campaign for rehabilitation therapies on a local level. In light of the economic climate

and cuts to health budgets, delegates talked about their own experiences of reductions to rehabilitation services offered in their countries. In sub-groups delegates then discussed how organisations can campaign to maintain or improve rehabilitation services for people with RMDs.

Delegates agreed that one method is to establish relationships with politicians and to lobby using case studies, statistics and national databases. Delegates highlighted the importance of the media as a powerful tool for lobbying. Upon setting up a campaign, organisations first need to identify scientific studies, economic data and medical information to provide evidence. The next step is to hold public talks or meetings with patients, policy makers and medical experts. Once a comprehensive action plan has been developed, organisations should then build alliances with other national organisations and create

networks at a European level.

Judith Cranford facilitated a workshop looking at **how to develop a successful communications strategy**.

Judith explained to delegates the benefits of developing a communications strategy and presented case studies of successful communications strategies within larger organisations. She raised the point that planning is crucial, as it allows organisations to develop and communicate messages and information that support organisational goals in a consistent manner, allowing organisations to be proactive, not just reactive. **Jean-Noél Dachicourt**, General Manager of Association Française de Lutte Anti-Rhumatisme, presented a case study on how the National Alliance against Osteoarthritis in France has used a communications strategy to increase knowledge around osteoarthritis and improve patient care. He explained that communication is essential in all activities within organisations, for example advocacy, campaigning, media relations, education, research and fundraising.

Delegates from smaller organisations identified the elements needed to develop a communications strategy. They noted that organisations need to have a clear aim or objective in order to be able to develop a strategy and also have specific, measurable tactics. Organisations also need to identify their target audience and develop clear key messages, ensuring that their story is compelling. They also need to know their budget, how many volunteers



Christina Opava leading the workshop on how organisations can build a case for rehabilitation



Workshop on how to write and submit a PARE abstract

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or permanent staff are available and develop realistic timelines. Organisations should select the most appropriate channel of communication for their objective, keeping social media channels in mind. Delegates also talked about the importance of presenting the needs and benefits of a communications strategy to organisations' decision makers.

Delegates from larger organisations discussed how programmes can be measured for success, for example using email feedback, evaluation surveys or competitor comparisons. They highlighted the importance of knowing when to revise a communications strategy, what steps need to be taken and who needs to be involved. Delegates agreed that it is also important to have a plan in place to manage unexpected issues and be able to respond in a timely manner.

Prof Hans Bijlsma, with support from **Nele Caeyers** and **Lara Poethig**, Account Manager of EULAR at MCI,

facilitated a workshop informing delegates **how to write and submit a PARE abstract** using the EULAR submission system. Hans provided delegates with useful points to consider when writing an abstract, including the types of information and data to put in each section of the abstract and how to effectively present the results of a study. Hans noted the importance of an abstract having a compelling title and conclusion, as these are the first things people will read. If these are not interesting they will not read any further.

Delegates were presented with sample abstracts, which Hans talked through, highlighting the strengths and weaknesses of each. Delegates then looked at frameworks for an abstract and agreed the best were well structured with a precise title. The introduction should be brief, explaining why the study was necessary and making the reader want to keep reading. In the results section tables can be used to provide

the data, whereas text should be used to describe the results. Interpretation of the results must not be included in the results section, instead this should be placed in the discussion section, along with the strengths and weaknesses of the study and an explanation of the practical implications of the study.

Lara introduced the EULAR submission system and gave delegates a practical step-by-step demonstration on how to submit abstracts using the system. Delegates also received a guide which included detailed steps and helpful tips to aid those who are planning to submit an abstract. Lara reminded delegates that anyone can submit a non-clinical abstract and that applications for travel bursaries are available separately.

The second youth workshop '**From plan to action: taking the Youth Group strategy forward**' was facilitated by **Linda van Nieuwkoop**, chair of Youth-R-Well.com, and co-chaired by **Petra Bednarova**. The workshop aimed to share the outcomes of the Youth Group strategic meeting and to gain practical insights into integrating young people with RMDs into the work of EULAR. Linda and Petra provided an introduction to the outcomes of the Youth Group strategic meeting and highlighted the key findings and main questions that need input from the delegates. **Dr Anna Molto**, chair-elect of EMEUNET, joined the workshop via Skype to provide an insightful case study on EMEUNET, the network for young rheumatologists, which has a number of similarities which could be of interest to Young PARE and provide ideas



Judith Cranford leading the workshop on how to develop a successful communications strategy



Hlapa Grdelin performing at the Gala dinner

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on how to build and strengthen the Youth Group within EULAR.

Delegates discussed the outcomes of the strategic meeting and provided input into the Youth Group draft strategy. Delegates discussed establishing a European exchange and support network of national youth organisations and representatives. They agreed that the goals would be to share best practices, empower members, foster connections and provide training consisting of sponsoring, lobbying and how to involve volunteers. They recommended that the first step to reaching key audiences should be using online platforms and social media.

Delegates agreed that the vision of Young PARE is to empower youth groups and youth representatives to increase understanding that RMDs affect young



Linda van Nieuwkoop, chair of Youth-R-Well.com, and Dr Anna Molto, chair-elect of EMEUNET presenting in the youth workshop 'From plan to action: taking the Youth Group strategy forward'

people and to support the roll out of vibrant national youth programs that meet the needs of young people. Delegates discussed how youth representatives can be structurally integrated into EULAR

and PARE activities. They suggested that one seat on the PARE board should be dedicated to a Youth Group representative, there should be a youth representative in every Task Force and that new leaders should receive training.

Marios Kouloumas and Diana Skingle

presented the conference closing remarks, thanking all delegates for their important contribution to the workshops. Delegates were encouraged to use their workbooks to disseminate what they have learned during the conference to their organisations. A short film was then displayed of a flash mob dance in Antwerp station, Belgium, to raise awareness of young people with RMDs, coordinated by Nele Caeyers, ReumaNet and everyone joined in creating an uplifting end to the conference.

The gala dinner was held at a traditional Croatian restaurant, Okrugljak, where delegates were treated to a truly special performance by Hlapa Grdelin, Frane Grubišić's professional and highly talented a cappella group. The gala dinner included speeches from Marios Kouloumas, Diana Skingle and Frane Grubišić, who thanked everyone for attending and making the conference such a huge success.



Malahide Grand Hotel, Dublin County

The next EULAR Annual European Conference of PARE will be held at the Malahide Grand Hotel, Dublin County from 24 – 26 April 2015 and hosted by Arthritis Ireland.