REPORT

20th EULAR Annual European Conference of PARE Lisbon, Portugal, 24th - 26th February 2017

eular

fighting rheumatic & musculoskeletal diseases together

Celebrating 20 Annual Conferences of PARE (People with Arthritis/Rheumatism in Europe) and the 70th anniversary of

the European **League Against Rheumatism** (EULAR):

In 1998 the first dedicated conference for organisations of PARE was held in Amsterdam, which has since been hosted by a different country each year. This year's 20th Anniversary Conference was held in Lisbon, Portugal and hosted by the Liga Portuguesa Contra as Doenças Reumáticas (LPCDR).



For the first time all three pillars of EULAR united under a new campaign, 'Don't Delay, Connect Today!', working together towards prevention, early diagnosis and access to care in rheumatic and musculoskeletal diseases (RMDs). The campaign was introduced at the conference by Gerd-Rüdiger Burmester, President of EULAR, before its official launch at the EULAR Congress in Madrid in June, allowing organisations of PARE time to prepare for their World Arthritis Day (WAD) events on 12 October.

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

Hans Bijlsma, EULAR President Elect Nele Caeyers, Host country 2018 Maarten de Wit, Task Force Member Claudine Goyens, Host country 2018 Marios Kouloumas, Vice President EULAR, representing PARE

Elsa Mateus, Host country 2017 Christina Opava, Vice President EULAR, representing health professionals in rheumatology

Simon Stones, Representative of Young

Dieter Wiek, Chairperson of the PARE Standing Committee

A highlight of the conference was the attendance of Manuel Delgado, Secretary of State of Health in the opening session. On Thursday, 24 February LPCDR hosted a political event at the Portuguese Parliament, which was attended by representatives from EULAR. The gala dinner was attended by **Dr Ricardo** Baptista Leite, a member of the Portuguese Parliament, who also gave a speech in support of people with RMDs in Portugal. This high level of political engagement helped to raise awareness of RMDs in Portugal and to highlight the importance of early referral so that the approved National Network of Specialised Rheumatology Services and Referral to Rheumatology Criteria in Portugal can be implemented by 2019. Raising awareness of the importance of early referral to rheumatology services was one of the LPCDR conference objectives, along with promoting the importance of the patient's perspective in Portugal.

Following presentations in the opening session, the conference programme focused on seven interactive workshops, five of which were repeated allowing delegates the opportunity to attend three different workshops. The workshops covered a range of hot topics including campaigning for prevention of RMDs and an EU perspective on access to work; engaging national organisations with the 'Don't Delay, Connect Today!' campaign; strategies to engage in the social media revolution; exploring how organisations can help increase rheumatology services and media interview skills training; and two Young PARE workshops - strategies to empower young people with RMDs, and enhancing self-management using innovative and accessible technologies.



The 2017 Annual Conference prelaunches the new **EULAR** campaign, welcomes Portugal's Secretary of State of Health and focuses on prevention, early diagnosis and access to care.







In his opening address. Marios Kouloumas, **EULAR Vice** President, representing PARE.

welcomed the delegates and speakers to the conference, on this special year which celebrates both the 20th anniversary of the conference and the 70th anniversary of EULAR. He also expressed his pleasure that the conference was hosting attendees representing all three pillars of EULAR people with RMDs, health professionals in rheumatology and members of the scientific societies.

@romeropazosvic: "Network of PARE is the #power of #pare2017" @Kouloumasm let's keep on strengthening and enhancing this amazing network @ligareuma

As in previous years the opening addresses, presentations, panel discussions, a selection of the workshops



Delgado welcomes delegates to Portugal

and feedback sessions after Friday and Saturdav's workshops, were all live streamed for those who were unable to attend the conference.

The **Twitter wal**l, displayed just outside the plenary room, allowed delegates and the external audience to engage via Twitter using the official conference hashtag #pare2017. Twitter engagement during the conference was high; nearly 1,500 tweets were shared during the conference, from 199 users, reaching a potential audience of approximately 2 million people.

In his welcome speech, Portugal's Secretary of State of Health, Manuel **Delgado**, acknowledged that the twenty percent rise in the prevalence of RMDs is not only due to the ageing population, but also the increase in young people being affected. He referred to the success of new treatments for newly diagnosed patients and the need to discuss new tools to help improve the quality of life of people with RMDs.

Professor Gerd-Rüdiger Burmester,

EULAR President, delivered the welcome on behalf of EULAR, mentioning the special anniversaries being celebrated this year, and also warmly welcoming Seth Ginsberg, a delegate joining the conference from the US - making this conference truly international. He mentioned the success of the event at the Portuguese Parliament and thanked everyone involved.

Dr Elsa Frazão Mateus, President LPCDR, the host organisation, extended her thanks to Manuel Delgado for attending the opening of the conference and expressed her pride in the Portuguese League being able to host the special 20th anniversary conference – particularly in the year in which the LPCDR is celebrating its 35th anniversary.



A live Twitter wall was displaying conversations using #pare2017 during the conference

Dr José Canas de Silva, delivered the welcome on behalf of the Portuguese Society of Rheumatology, as its President. He explained the benefits of focusing on prevention, early diagnosis and access to care, specifically in terms of saving resources later on, with costly treatments and overstretched healthcare systems.

"In the style of John Lennon; 'Give rheumatic patients a chance..."

Secretary of State of Health, Manuel

Delgado extended delegates a warm welcome to Portugal and to Cascais, formally declaring the conference open. His captivating speech highlighted the prevalence of RMDs in Portugal and welcomed the opportunity to focus on the importance of preventing RMDs as well as improving early diagnosis and access to care.

During her compelling speech, Professor Helena Canhão, Vice President of the Board, LPCDR, covered the epidemiology of RMDs in Portugal, the co-morbidities and associated costs and the issue that exists with under diagnosis of RMDs. She also raised awareness of the National Network

and to Cascais





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of Specialised Rheumatology Services and Referral to Rheumatology Criteria which will be implemented by 2019.

On his keynote presentation on behalf of EULAR, Gerd-Rüdiger Burmester introduced delegates to the new, 'Don't Delay, Connect Today!' campaign, including revealing the logo and campaign toolkit. In reference to the parliamentary event, Professor Burmester stressed the importance of redistributing funds to improve prevention, early diagnosis and access to care, rather than the need to campaign for more budget, pointing out that early treatment of RMDs improves outcomes, with a brief window of opportunity for optimal diagnosis and access to care - but that "it's never too late". Even with an estimated 120 million people with RMDs across Europe it was noted that the definition of RMDs is still unclear - a point that will be addressed when an agreed definition is announced in Madrid.

"I had the opportunity to attend different workshops with rheumatologists, HPs and delegates from patient organisations. I believe that it is extremely important to have this combination of representatives."

Panel discussion

Following the opening addresses and presentations on Friday morning, Dieter Wiek, Chair of the Standing Committee of PARE, moderated a lively interactive panel discussion with Gerd-Rüdiger Burmester, José Canas de Silva. Elsa Frazão Mateus and Professor Christina Opava (EULAR Vice President representing Health Professionals in Rheumatology). The panel discussed the lack of rheumatologists and rheumatology services across Europe, as well as the importance of shared decision making in the treatment of RMDs. Questions related to how to best ensure early referral and diagnosis, the advantages and dangers of information available on the internet and the importance of acting quickly.

Workshops, feedback and voting statements

Interactive feedback sessions were held following the workshops on Friday and Saturday. As in previous conferences, workshop leaders gave a short description of their workshop and presented controversial statements for delegates to vote on and to stimulate discussions.

Christina Opava moderated the informal, interactive workshop feedback session with voting following the workshops on Friday. A similar session was held on Saturday, moderated by Nele Caevers, Chair-elect, Standing Committee of PARE.

Special anniversary video workshop

In recognition of the 20th conference of PARE and the 70th anniversary of EULAR, EULAR generously provided bursaries for six representatives from national member organisations of PARE to create short videos for their organisations. On Thursday morning the six delegates attended a 'How to Make a Video' workshop led by Esmé Newton-Dunn, a communications consultant from Ruder Finn UK, supported by Karlo Dzeverlija and Marko Zovko of Streaming.hr. The workshop included how to plan a video and a practical exercise where the delegates formed three pairs to create short videos, which they then learned to edit using Windows Movie Maker. This workshop is being adapted into a training module and will be available later in the year in PARE section of the EULAR School of Rheumatology.

After lunch, the delegates were filmed presenting their individual videos for their organisations. The aim of these videos was to promote their national organisations by featuring a campaign, activity or project being run in 2017, to show how the organisation supports people with RMDs and to encourage more people to join. Additionally, the videos will show how national organisations of PARE benefit from being members of EULAR and attending the EULAR Annual European Conference of PARE.

These videos will be used by the national organisations, but will also be featured on the EULAR website, with English subtitles.

Policy and campaigning

On Friday, the important topic of work for people with RMDs was highlighted by Neil Betteridge, a long standing member of the EULAR Executive Committee and EULAR's Liaison Officer for Public Affairs, in a workshop entitled 'Healthy workplaces, prevention of RMDs and



Delegates voting on whether they agreed (green card) or disagreed (red card), or were unsure how they felt about each statement (white card)



his workshop



access to work for people with RMDs - an EU perspective'. The workshop was run with support from Federico Torres, from EULAR Public Affairs in Brussels. Marios Kouloumas and Pedro Laires, who is studying for his PhD at the University of Lisbon, where he specialises in epidemiology.

Pedro Laires provided a case study from Portugal, highlighting research from his PhD on the association between rheumatic diseases and early retirement in the Portuguese population. He also discussed the measurement of productivity loss associated with early retirement attributable to RMDs in Portugal.

Federico Torres updated the delegates on the EU situation, introducing the European Commission Communication: Safer and Healthier Work for All (January, 2017) and mentioning the main action lines including updates to and enforcement of EU Occupational Health and Safety legislation.

Neil Betteridge ran through the EULAR advocacy goals on the topic; stronger EU legislation on prevention of RMDs in the workplace and better EU and national policies on retention of people with RMDs in the workplace.

Delegates then formed three subgroups and discussed any plans that their organisations are implementing related to the topic of work and RMDs. They were then tasked to develop a menu of ideas that organisations could use to become involved with the EULAR recommendations on work and RMDs.

The voting statements that were presented during the Friday workshop feedback session were:

- Every PARE Member should prioritise work as a policy issue and nominate a representative to form a new EULAR network (majority agree)
- PARE should establish a thematic campaign on Work (like WAD) and the members should be actively involved (majority agree)
- PARE should consider initiating an annual Best Practice competition for employers as this would incentivise them to improve their support for workers with RMDs (majority agree)

On Saturday, a workshop focusing on how patient organisations can work to increase provisions for RMD care was led by Christina Opava. The workshop, 'How can organisations help increase the number of rheumatologists, and HPs specialised in rheumatology care and RMD services in their countries?' was run with support from Dr Inês Cordeiro, representing rheumatologists, Ricardo Ferreira, representing health professionals in rheumatology and Henna Laito, from the Finnish Rheumatism Association, who provided a case study.

Christina Opava kicked off the session by highlighting the fact that 70% delegates felt that there was a lack of rheumatologists and health professionals specialised in rheumatology in their country and provided an overview of the number of rheumatologists distributed across Europe.

Henna Laitio presented an inspiring case study from the Finnish Rheumatism Association. The Association undertook a survey of arthritis nurses, rheumatologists and patients to gain insights, all groups were concerned with the lack of upcoming professionals in the field and it was decided that the image must be modernised. A nationwide multi-faceted campaign was designed and implemented with support from rheumatology professionals and pharmaceutical companies.

The delegates split into subgroups to discuss the potential causes for the shortfall in rheumatologists and HPs in RMD services, each group selected one potential barrier and developed a campaign strategy to overcome this.

The statements voted on during the plenary session were:

 'Payback' could be requested from rheumatologists supported during training (*majority agree*)







Elsa Frazão Mateus provided a case study, discussing the pre-launch of the campaign at the Portuguese Parliamentary event, 'Early Diagnosis / Early Referral: Health, Social and Economical Impact of Rheumatic and Musculoskeletal Diseases' held on 23 February 2017

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- Nurses trained in rheumatology can take care of patients with RMDs independently of medical supervision (majority agree)
- A 'firefighter' calendar should be produced by PARE to change the image of rheumatology (unanimous agreement)

The new EULAR campaign, introduced by Gerd-Rüdiger Burmester in his keynote presentation, was the focus of a workshop run on both Friday and Saturday, 'Engaging national organisations in the 2017 'Don't Delay - Connect Today!' campaign'. Gerd-Rüdiger Burmester and Dieter Wiek led this workshop on Friday and **Professor** Hans Biilsma and Dieter Wiek on Saturday. Also supporting this workshop were Lurdes Barbosa, a nurse at the Rheumatology Day Hospital within Garcia de Orta Hospital, Lydia Tchambaz, Deputy Executive Director of EULAR, Elsa Frazão Mateus and Professor Victoria Romero-Pazos, who is the international representative and patient advocate for the Galician Rheumatological League and a member of the board and EULAR liaison person of the Spanish Rheumatological League.

The delegates were given an introduction to the campaign and the rationale behind it, as well as being asked for their feedback on the campaign toolkit shared with them in draft format prior to the conference.

Victoria Romero-Pazos followed this with a case study outlining the public launch of the campaign in Spain at an event scheduled for 13 June 2017. Focusing on the theme of connections and delays, the event will take place at the Madrid-Atocha train station.

The group brainstormed the key barriers to diagnosis, identifying the following as the key barriers: lack of information and awareness, lack of specialists, denial by

patients, lack of GPs being informed, policy issues in health care and costs for patients. Each group had one of these barriers and in the sub-group discussions were tasked with considering what their organisation could do to address the priority issue. Groups needed to consider how the ideas could be implemented, what the best channels would be and how the toolkit materials could be used.

The voting statements were drafted following both sessions of the workshop and presented in the Saturday feedback session, they were:

- Health care professionals can only qualify if they complete compulsory training by patient educators with RMDs (unanimously agree)
- Patient denial (not wanting to be sick, not recognising symptoms and not wanting to be stigmatised) is a key factor in delayed diagnosis of RMDs (mixed response)

Skills training and learning to engage with social media

Reflecting the growing importance of social media, demonstrated by the increasing prominence placed on it during the conferences, Simon Stones led two workshops, one aimed for beginners and one for those more experienced, 'The social media revolution: strategies to create and strengthen communication in a digital era'.

Dr Elena Nikiphorou, a consultant rheumatologist at the Whittington Hospital, in the UK and Chair-Elect for the Emerging EULAR Network (EMEUNET), and Nina Unesi, Press Secretary at the Swedish Rheumatism Association, delivered case studies focusing respectively on how healthcare professionals and patient



the social media revolution workshop, showing delegates how to set up a Twitter account

organisations can use social media effectively for a range of purposes. The workshop team delivered two tailored workshops, the first focusing on getting delegates feeling comfortable using social media and developing an effective digital and content strategy. The second workshop placed more emphasis on managing conflict and utilising social media analytics.

In both workshops the delegates were split into three sub-groups to undertake their practical challenges. In the beginner workshop, this was either setting up an account and learning the basics of Twitter; designing graphics using Canva and other software; or making social media efficient using online tools. In the more advanced workshop, the three sub-groups focused on strategy and branding; managing conflict; or using analytical tools.

The voting statements for the beginner workshop were:

 A strategy is not needed by a patient organisation to be successful on social media (approximately 90% disagree)





work Arthritis Ireland have done to engage

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• The focus of patient organisations should be on online communication (majority disagree)

The statements for the advanced workshop were:

- There should be minimal interaction between patients and health professionals on social media (approximately 75% disagree)
- When a conflict arises on social media, you should respond immediately (mixed response, 50/50)

Esme Newton-Dunn led a skills training workshop offering delegates the chance to hone their interview skills in small groups. The workshop 'Media interview skills' was offered twice on Saturday and was filmed by the streaming team.

Delegates were provided with an overview of media interviews and given tips for preparing for proactive and reactive interviews with journalists. The highly practical workshop included a safe place for the delegates to conduct roleplays in pairs, with everyone having a chance to play a journalist and also a representative from an organisation being interviewed by a journalist.

Following this, the attendees were filmed while being interviewed in a more formal setting. The films were played back to the group allowing all delegates the chance to see themselves on camera with constructive feedback. This workshop is being adapted into a training module and will be available later in the year in PARE section of the EULAR School of Rheumatology.

The voting statements that culminated from this skills training workshop were:

- We don't need to prepare for media interviews because we don't know what journalists will ask (vast majority disagree)
- · Patients are just case studies for journalists (approximately 75% disagree)

Young PARE

The first Young PARE workshop, 'Young PARE: Strategies to engage and empower young people with RMDs at the earliest opportunity' was led by Petra Balážová, a board member of the Slovak League Against Rheumatism and a Board member of Klub Klbik, a patient organisation focusing on the needs of young patients, Dr Filipa Oliveira Ramos, a Rheumatologist and Head of Paediatric Rheumatology Unit at Hospital Santa Maria, CHLN in Lisbon, Christina Opava and Peter Boyd, Chair of Arthritis Ireland's Young Arthritis Network, an elected patient representative on Arthritis Ireland's board of directors and member of the EULAR Young PARE working group.

Peter Boyd presented a comprehensive case study from Arthritis Ireland, focusing on the work that they have carried out to engage early and empower young people with RMDs. The case study covered some of the barriers that can exist for young people, but moved on to discuss the ways the situation has been improved in Ireland with online self-management courses, a strong Facebook presence and specific workshops run on relevant topics like pregnancy, relationships and careers.

The delegates brainstormed challenges and barriers to organisations and doctors or health professionals working together to engage and empower young people. The sub-groups each selected one challenge and either considered it from the point of view from the doctor or health professional, or from the point of view of the patient organisation. Each sub-group was tasked with developing a strategy and tactics to help ensure young people with RMDs are given the support they need.

The voting statements presented back to the plenary session based on the workshop were:

- To improve communication between HCPs and patients we should not only empower patients, but also train doctors (majority agree)
- Engage patients and rheumatologists in eye-catching campaigns to change the image of (young) people with RMDs (majority agree)
- Patient organisations providing feedback to the HCPs (majority agree)

The second young PARE workshop 'Young PARE: Enhancing self-management in young people using innovative and accessible technologies' was also led by Petra Balážová, supported by Kristijonas Mazuras, a volunteer and Board member of the Lithuanian Arthritis Association and PARE Board member since 2016, he is also director of an IT company, which develops multimedia products, Mitchell Silva, a volunteer for ReumaNet in Belgium and patient advocate to promote the use of technology to empower patients, and Christina Fyhn, a volunteer at the Danish Association, FNUG where she is a board member and writes for and edits the FNUG magazine.

Kristijonas Mazuras began the workshop by discussing existing technologies that can help young people with RMDs monitor their health and communicate with their healthcare team and peers. Examples included RheumaTrack, MyRA, Know your DAS and tRAppen.







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Christina Fyhn presented a case study on RheumaBuddy, and the journey that the team went through to develop it, starting in 2013. First of all the team held workshops to discover what patients wanted, and then developed the app based on their key learnings, after the initial launch there were further changes and additions made based on feedback from users.

The workshops then offered delegates the chance to trial various apps for selfmanagement themselves, encouraging them to discuss the benefits and weaknesses of these apps and to consider how organisations could be involved in adapting or promoting these kinds of technologies.

The voting statements that were presented to the plenary were:

- If you were going to your third appointment at the doctor in a week, and this was becoming difficult with your employment, an app to feed your information to your doctor could be an alternative. Would you be more concerned about losing your job, or losing physical contact with your doctor in this situation? (most delegates voted that they would rather lose physical contact with their doctor)
- All PARE organisations should come together to create the one perfect app for all countries and all RMDs (vast majority agreed)
- Apps are a constant reminder of our RMDs (approximately 80% disagreed)

Closing the official conference programme

Marios Kouloumas and Dieter Wiek presented the conference closing remarks, with **Nele Caevers**, who will be taking over as Chair of the Standing Committee

of PARE in June 2017, thanking all delegates for their important contribution to the workshops. Delegates were encouraged to use their workbooks to disseminate what they had learned during the conference to their organisations.

Marios attended his first PARE conference in 2002. He has chaired the conference Task Force for a number of years and has been instrumental in evolving and building the conference to its current high standard. Christina has been an active and valued contributor to the PARE conference Task Force for the past four years, ensuring that the role of health professionals in rheumatology is integrated into the conference. As well as their roles in the Task Force, both Marios and Christina have been session moderators and workshop leaders at the conference. They will be much missed by all who have had the pleasure of working with them. Christina will be pursuing new areas of interest, but we are pleased that Marios has agreed to maintain a consultancy role on the Task Force for next year's conference.

@alessia_alunno: An inspiring experience, a chance to know so many people, and to learn a lot. All this was #pare2017 Grateful to have been part of that

Networking and social

With many delegates new to the conference, an icebreaker was held on Thursday evening. This provided a fun way to engage with new people and find out more about their role and organisations, as well as a few light-hearted personal facts. This networking session was well attended and enjoyed.

On Friday afternoon delegates had the opportunity to participate in the Best Practice Fair, an exhibition for posters and videos focused on presenting and sharing organisations' best practice campaigns and activities. The posters and videos were displayed in three rooms, each grouped by different audiences; health professionals, people with RMDs or the general public. There were 16 posters and 10 videos presented, all of which were inspiring and informative.

Delegates were encouraged to read the posters, watch the videos and ask the presenters about their campaigns and to vote for the campaign from each category they would most like to hear more about – the presenter of the highest voted campaign from each category was invited to join an interactive discussion, moderated by Dr Maarten de Wit, a member of the conference Task Force, during the following plenary session.

Theodora Papastavrou and Theodora Seitanidou from Greece presented their campaign 'Intimate relationship with RMD' from the category for campaigns targeting the general public. Their campaign focused on young people and the problems they can face with intimate relationships. "Love alleviates pain, and being happy is very important to us!" explained Dora.

Basak Somnez was selected to present the poster from RomaTurka from the category for campaigns targeting people with RMDs. She explained the collaborative design project that was undertaken to create tools that could aid the lives of those with RMDs.

Fran Carreira from LIRE in Spain was chosen to present the campaign from the category for campaigns targeting health professionals. REUMAPPA is an interactive map, available also via a website and mobile app that allows professionals and patients to easily find resources in a certain area.







The Portuguese delegates whose hospitality and support made the event such a success

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@EMEUNET: Congratulations to all abstract prize winners and to bringing insights in RMD burden and offering ideas to help in daily life #pare2017

After all their hard work delegates attended a gala dinner on Saturday evening and were treated to an uplifting performance of Portuguese dancing before being invited to take to the floor themselves!

An informal networking session was held for delegates on Sunday morning and moderated by Maarten de Wit, giving another great opportunity to share knowledge and experiences, make connections and exchange contact details to stay in touch.

@martinusdewit: What a fabulous family! Thanks all for your sharing and friendship! Together we can make our world better for people with RMDs @PARE2017

In memory of Theodora (Dora) Papastavrou



Theodora (Dora) Papastavrou 04 November 1983 - 13 March 2017

Dora Papastavrou attended her first EULAR Annual Conference in Zagreb, in 2014. Her engaging smile, enthusiasm, drive, determination, positivity, infectious sense of fun and humour and sheer joy of life drew in everyone who met her.

Dora was committed to improving the lives of young people with rheumatic and musculoskeletal diseases, not only in her native Greece, but everywhere. Dora was a PARE Board member, Greek representative to the EULAR Standing Committee of PARE and an active member of E.L.E.A.N.A., the Greek member organisation of EULAR PARE.

At this year's conference Dora and Theodora Seitanidou presented their strong and engaging campaign on Intimate Relationships aimed at young people with RMDs and their partners, which won the Best Practice Fair in the category aimed at the general public.

Dora's father, Anastasios, who was with her this year, and her sister, Athina, acted as personal assistants when she attended PARE conferences. Our thoughts go out to them and her family and friends.

Dora will always be remembered and greatly missed by all who knew her.



"I can only emphasise again how fantastic this conference was. Already, collaborative work opportunities have arisen from the conference and I have lots of new and consolidated ideas for work at a local, national and international level."

The next EULAR Annual **European Conference of PARE** will be held in Brussels, Belgium from 16 – 18 February 2018 and

hosted by ReumaNet.