



REPORT

21st EULAR Annual European Conference of PARE
Brussels, Belgium, 16th – 18th February 2018

eular

fighting rheumatic & musculoskeletal
diseases together

In 2018, the 21st Annual European Conference of PARE was held in Brussels, Belgium and hosted by ReumaNet.

Continuing the campaign that unites all three pillars of EULAR, the theme of the 2018 conference was *'Don't Delay, Connect Today!'*, working together towards prevention, early diagnosis and access to care in rheumatic and musculoskeletal diseases (RMDs). The campaign was launched in 2017 and while last year's conference mainly focused on early diagnosis, this year the key emphasis was on prevention; encompassing primary, secondary and tertiary prevention.

On Thursday 15th February, ReumaNet hosted a very successful event in the Belgian Parliament, launching their national exhibition on the topic of *Don't Delay, Connect Today!* Professor **Johannes W. J. Bijlsma**, EULAR President, **Nele Caeyers**, Chair Standing Committee of PARE and **Dieter Wiek**, EULAR VP, representing PARE, all delivered captivating speeches and the event was featured on national radio and TV stations.

Making the most of the Brussels location, a visit to the European Parliament was organised for delegates on Friday morning. This special opportunity provided many delegates with their first chance to visit and learn about the European Parliament first hand.

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

Johannes W. J. Bijlsma, EULAR President

Nele Caeyers, Chair Standing Committee of PARE, Host country 2018

Maarten de Wit, Task Force Member

Claudine Goyens, Host country 2018

Marios Kouloumas, Past EULAR VP, representing PARE

Tanja Stamm, EULAR VP, representing health professionals in rheumatology

Simon Stones, Representative of Young PARE

Dieter Wiek, EULAR VP, representing PARE



126 delegates representing 45 organisations from 32 countries attended the conference with over 25 young representatives (under 35 years of age) and 27 Belgian delegates



In his official opening, **Johannes W. J. Bijlsma**, welcomed the delegates and speakers to the conference in Brussels, as well as those watching the conference via live streaming.

The attendance of **Marianne Thyssen**, Commissioner for Employment, Social Affairs, Skills and Labour Mobility in the opening session was a highlight of the conference. Her welcome address was motivational and insightful, emphasising the importance of working together as EU citizens and learning from each other, and imploring the delegates to continue raising awareness of RMDs on a national and EU level.

Gerd Jacobs, Chair of ReumaNet, the host organisation, welcomed the delegates to the conference, and to Brussels, 'the heart of Europe'. She re-iterated the importance of making connections, and working collaboratively, sharing the news that very soon the Royal Belgian Society of Rheumatology will be joining ReumaNet at the Reuma House, enabling both organisations greater opportunities for more collaboration and closer working.

Professor Bernard Lauwerys, President, Royal Belgium Society of Rheumatology, welcomed delegates on behalf of the RBSR and shared his happiness at the progress he has seen in his 20 years of patient care, particularly the shift from a paternalistic approach, through patient emancipation to a much more collaborative model of patient care with patients being empowered.



1. Nele Caeyers and Dieter Wiek launching the ReumaNet exhibition at the event in the Belgium Parliament. 2. Group including representatives from EULAR, PARE and ReumaNet attended the launch of the Don't Delay, Connect Today! national exhibition at the Belgium Parliament on Thursday, 15 February. 3. The exhibition featured plaster casts of the hands of adults and children with RMDs, as well as rheumatologists and health professionals in rheumatology.

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During his keynote presentation on behalf of EULAR, **Johannes W.J. Bijlsma** highlighted

the **Don't Delay, Connect Today!** campaign, stressing the importance of connecting with one another and combining efforts to share one united message. Studies demonstrate the progress that has been made in time to diagnosis, but also highlight that there is still room for further improvement in order to make the most of this window of opportunity: preventing joint damage, retaining mobility and reducing disability. The importance of primary, secondary and tertiary prevention was emphasised, with a focus on reducing the impact of diseases, reducing disability and limiting or delaying complications.

As in previous years the conference delegation, and people online, were active on social media. The **Twitter wall**, displayed just outside the plenary room, allowed delegates and the

external audience to engage via Twitter using the official conference hashtag **#pare2018**. Twitter engagement during the conference was high; 2,570 tweets were shared during the conference, from 303 users, reaching a potential audience of approximately 462,100 people with 4.8 million impressions.

"Arthritis does not care about your citizenship. Pain does not ask for your passport"
Marianne Thyssen

Panel discussion

Following the opening addresses and presentations on Friday morning, **Dieter Wiek**, moderated a lively interactive panel discussion with **Johannes W.J. Bijlsma**, **Bernard Lauwerys**, **Professor Tanja Stamm**, EULAR VP, representing health professionals in rheumatology (HPRs) and **Neil Betteridge**, EULAR International Liaison Officer, Public Affairs. The panel discussed the concept of preventing RMDs such as rheumatoid arthritis, the importance of a healthy lifestyle, the role politicians play in enabling early diagnosis and the role health professionals play in non-pharmacological interventions in secondary prevention.

Following presentations in the opening session, the conference programme consisted of eight interactive workshops, three of which were repeated allowing most delegates to attend three different



(From left to right) Nele Caeyers, Neil Betteridge, Johannes W.J. Bijlsma, Marianne Thyssen, Lilliane Ovaere, Gerd Jacobs and Bernard Lauwerys

workshops. The workshops covered a range of important and relevant topics including understanding the European policy landscape; how to influence policy; engaging national organisations with the **Don't Delay, Connect Today!** campaign; collaborating with HPRs to promote long-term healthy lifestyle changes; two skills training workshops – media interviews and how to make a video; and two Young PARE workshops – working with schools to ensure young people are supported and delivering campaigns to promote early diagnosis of children and young people with RMDs.

The opening addresses, presentations, panel discussions, a selection of the workshops and feedback sessions after Friday and Saturday's workshops, were all live streamed for those who were unable to attend the conference. The videos are now available on the **EULAR website**.

The 2018 Annual Conference welcomed European Commissioner Marianne Thyssen to open the conference dedicated to prevention, early diagnosis and access to care for people with RMDs.



Marianne Thyssen explaining why we need to tackle RMDs as a united Europe during her address, as Johannes W.J. Bijlsma listens



Delegates were given the exciting opportunity to visit and learn about the European Parliament while in Brussels



Pieter Geninazzi shared his personal story of the challenges he faced in education while growing up in Belgium

Workshops, feedback and voting statements

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

Simon Stones moderated the interactive workshop feedback session following the workshops on Friday. A similar session was held on Saturday, moderated by **Dr. Maarten de Wit**.

Young PARE

For the first time, in addition to their two workshops in the main programme, Young PARE officially merged their internal meetings with the conference, holding one closed Young PARE workshop and their working group meeting on Thursday.

On Thursday, the Young PARE group workshop, **'Learn, Lead, Inspire!'** led by **Silvia Ostuzzi**, with the support of the Young PARE working group members, aimed to bring together European youth

leaders in order to help them develop their leadership and advocacy skills. Attendees undertook a leadership practical activity and also worked on developing a short action plan for working with educational institutions and employers.

On Friday, the Young PARE workshop, **'Working with schools to ensure young people with RMDs in education up to the age of 18 are supported'** was led by **Peter Boyd**, an elected patient representative on Arthritis Ireland's board of directors and member of the EULAR Young PARE working group, supported by **Wendy Costello, Pieter Geninazzi, Tanita Wilhelmer** and **Betka Göhmann**.

Pieter shared a compelling personal case study, focusing on some of the challenges he has faced during his education in Belgium, as well as some of the tools and people that have supported him.

The delegates brainstormed the potential barriers that school aged children with RMDs may face. Each of the subgroups then took one overarching

barrier, such as lack of information, or bullying and difficulties socialising, and then considered how this issue could be addressed. Subgroups were tasked with considering the key stakeholders and audiences, and considering what kind of activities or campaigns could be undertaken by both smaller and larger more developed organisations.

@lalez88: Thank you for preparing and facilitating the wonderful workshop and also thank you to @GeninazziJ for sharing his story #strongertogether #connecttoday #pare2018

Wendy, a founding member of the Irish Children's Arthritis Network (iCAN) and chair of the European Network of Children with Arthritis (ENCA), shared her personal case study, including both the positive and negative experiences she has encountered as a mother of a child with an RMD, as well as the role that a patient organisation can play in offering support and being an information provider.



Delegates in the workshop feedback session voted on whether they agreed (green card) or disagreed (red card), or were unsure how they felt (white card) about each statement



Maarten de Wit moderated the workshop feedback and panel discussion session on Saturday, with (R-L) Neil Betteridge, Wendy Olsder, Elena Nikiphorou and Esmé Newton-Dunn



Wendy Olsder led one of the Young PARE workshops, focusing on delivering campaigns to improve the early diagnosis of young people with RMDs



Elena Nikiphorou, supporting workshop 4 and representing EMEUNET

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

- The Knowledge Transfer Programme should be used solely for overcoming barriers facing children with RMDs in schools for one year (*approximately 60% agreed*)
- Reducing isolation needs patient educators not HCPs (*approximately 90% agreed*)

The second Young PARE workshop, held twice on Saturday, **‘Knowledge is power – delivering campaigns to promote early diagnosis of children and young people with RMDs’** was led by **Wendy Olsder**, Young PARE Member and the Chair of Youth-R-Well.com, supported by **Dr. Alessia Alunno**, **Professor Berent Prakken**, **Madeleine Beerman** and **Betka Göhmann**.

The workshop began by asking delegates to brainstorm and note down barriers to early diagnosis and treatment of young people with RMDs. Wendy then introduced the workshop, and shared an

overview of her personal story. Alessia moved on to illustrate some of the potential barriers to early diagnosis and treatment in paediatric rheumatology, using the case study of a dancer to demonstrate the delays in diagnosis that can occur.

Madeleine shared a powerful case study from the Swedish National Organisation for Young Rheumatics, explaining how their photography and social media campaign highlighting the hidden effects of RMDs has achieved great success.

@alessia_alunno: Delighted to have represented @EMEUNET at #PARE2018 and to have met many people whose enthusiasm is inspiring! “We all go home with a luggage full of ideas” (cit. @Kouloumasm) and also with the heart full of emotions! Thanks @eular_org @EULARYoungPARE

In their subgroups the delegates were tasked with outlining a potential campaign that could be implemented in order to overcome one of the barriers (identified in

the icebreaker) to the early diagnosis and treatment of RMDs in young people.

The voting statements that were presented to the plenary were:

- You will always need support from other organisations (pharmaceutical companies, government) in order to have a successful campaign (*approximately half agreed and half disagreed*)
- We should prioritise informing other specialists with campaigns, such as orthopaedists and infectious disease specialists, instead of GPs (*majority disagreed*)
- A photo campaign is more effective than written media when promoting early diagnosis of children and young people with RMDs (*almost unanimous agreement*)

Policy and campaigning

Given the location of the conference, a key focus for the conference was European Public Affairs and campaigning.

On Friday, **Neil Betteridge**, a long-standing member of the EULAR Executive Committee and EULAR’s Liaison Officer for Public Affairs, led a workshop entitled **‘Understanding the European policy landscape from an RMD perspective’**. The workshop was run with the support and experience of **Federico Torres** and **Philip Easthill**, from the EULAR Public Affairs Office in Brussels, and featured a case study from **Camille Bullot**, from the European Patients’ Forum.

The workshop offered an overview of EU decision making processes, who is advocating in Brussels and moved on



Madeleine Beerman leading a subgroup in the campaign planning session as part of one of the Young PARE workshop



Neil Betteridge provided a summary of the policy workshop he ran during the plenary feedback session, delivering statements for the delegates to vote on



Dieter Wiek leading delegates through an energising and enjoyable set of stretches



Tanja Stamm at the plenary feedback session

to cover the relevant topics in key policy areas in upcoming years, including public health, employment and social affairs and research and innovation. The EULAR EU Public Affairs working lines were outlined, including meeting with policy makers and the annual October World Arthritis Day conference in Brussels.

Camille gave an overview of the EU legislative procedures, explained where patient organisations can fit into the legislative process and how they can have a positive influence. The differences in knowledge and influence between European umbrella organisations and national patient organisations were discussed, and a case study example relating to clinical trials legislation was presented.

In three subgroups the delegates were asked to consider which policy areas need more collaboration between national organisations and national or EU institutions, what support do national organisations need from

EULAR, and what support could national organisations offer EULAR.

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

- The three most important policy areas for collaboration are:
 - Equal access to health care
 - Early diagnosis (rare diseases)
 - Research promotion (99% agree)
- Support from EULAR to national organisations
 - Generic information (how to lobby) and specific advocacy support to national organisations (all agree)
- Support from member organisations
 - Sharing of best practices (hot topics, data, learning, audiences) (all agree)

Neil Betteridge also ran a policy workshop on Saturday, ‘**How to influence policy to make a better world for people with RMDs**’.

Supporting this workshop were **Federico Torres, Philip Easthill** and **Sören Haar** from the EULAR Public Affairs Office in Brussels. The workshop aimed to identify opportunities for engagement, as well as how to build relationships with those involved in the policy making process.

Neil and Sören role played a scenario between a policy maker and a EULAR public affairs representative, demonstrating how to capitalise on an opportunity to capture the attention of a policy maker and make an effective pitch to interest them in the key issues for an organisation.

Federico shared an overview of the EULAR advocacy activities and tips for successful engagement. Sören then shared a case study of the EULAR campaign run at the last EU election, sharing insight into how organisations can be involved in the 2019 election.

@BoryanaBoteva: “How to influence policy to make a better world for people with RMDs”, an interesting workshop facilitated by Neil Betteridge and Federico Tores #PARE2018

The subgroups were given a scenario – that their organisation would like policy makers to improve early referral to specialists for people with RMDs – and tasked with developing objectives, audiences, desired actions and key messages for their advocacy work.

Neil summarised the workshop outputs during the plenary session, and asked the delegates to make a choice on which statement they most agreed with from the perspective of a policy maker:

- Early intervention in RMDs is essential because...
 - It will produce enormous cost savings (approximately 55%)
 - It will prevent long-term suffering for millions of people (approximately 45%)
- The approach that would promote early intervention in RMDs most effectively is...
 - Awareness raising targeted at the general public (approximately 15%)
 - Developing more comprehensive medical training for GPs (approximately 85%)



The case study presenters, here Catherine Bailleux, each shared their experiences and plans to one table each, moving around after ten minutes so that each group learned about each of the case studies



Peter Boyd leading discussion in the Young PARE workshop on working with schools to ensure young people with RMDs in education are supported

Johannes W.J. Bijlsma led a workshop focused on the future of the current campaign, **'Don't Delay, Connect Today in 2018 and beyond'** supported by **Dieter Wiek** and **Dr. Elena Nikiphorou**. **Marious Kouloumas, Professor Victoria Romero Pazos** and **Catherine Bailleux**, all provided case studies based on the campaigns run, or being planned by their national organisations.

Johannes gave an overview of the **'Don't Delay, Connect Today!'** campaign, the toolkits and the webinars, as well as the social media successes and the 2017 'Missed Connections' local launch in Madrid, supported by Dieter. Also showcased were Belgium activities around the **'Don't Delay, Connect Today!'** campaign, which included the launch event at Brussels Midi Station in October 2017, which was similar to the activity in Madrid, and the launch of the plaster hands exhibition at the Federal Parliament on Thursday, 15 February.

Victoria shared an update on activities in Spain, the event at Atocha railway station at the EULAR Congress, followed by two events in A Coruña, and now four events planned across Spain for 2018. Catherine discussed the public stunt that took place in Brussels South railway station for World Arthritis Day 2017, and how the campaign would be supported in 2018 with the Plaster Hands exhibition, launched in the Federal parliament and then going on tour across Belgium. Marios shared insights into the spectrum of activities planned in Cyprus for 2018, including a social media campaign, media outreach and public events during the Annual Awareness Week (5 – 13 May).

Each of the subgroups brainstormed topics including whether the current campaign

should continue with a different focus, or whether there should be a new theme, what support materials are most useful at a local level, whether organisations would be interested in joining a centrally organised event on World Arthritis Day, and if so what support the organisations might need.

The statements brought back to the plenary were:

- The campaign focus/theme should:
 - Change every year to ensure all important RMD topics are covered over time (*approximately 75% disagreed*)
 - Stay the same to get the message across (*approximately 85% agreed*)
- A simultaneous event by various organisations across Europe on WAD is a good idea, but not feasible and costly. Efforts & energy should be invested elsewhere (*approximately 45% agreed*)
- EULAR should co-ordinate a one-day pan-European digital event from the North to the South to promote the campaign (*unanimously agree*)

Collaboration and empowerment

Tanja Stamm led a workshop on Friday focusing on improving collaboration between national organisations and health professionals. **Dr. Li Alemo Munters, Souzi Makri** and **Dr. Els van den Ende** supported this engaging workshop, **'Maintaining a healthy lifestyle can help prevent or reduce damage from RMDs: How can organisations and HPRs collaborate to promote long-term change?'**

The workshop began by asking delegates to share a healthy lifestyle change they would like to make, what was stopping

them from making this change, a positive change they have made and what motivated them to make this change.

Tanja reiterated the importance of healthy lifestyles for people with RMDs and identified types of HPRs who can support with making positive and sustainable lifestyle changes. Souzi shared a best practice case study illustrating the positive impact brought about by organising an aqua-aerobics class for people with RMDs in Cyprus that encourage activity with socialising. Li, an HPR working in collaboration with the Swedish national organisation, shared three examples of successful collaborations in Sweden, one in e-health, one in health care and one regarding patient education.

Els shared insight into some potential barriers for patients, including physical, economic, social and psychological, and some potential barriers for health professionals. She then continued, to share some key factors for success.

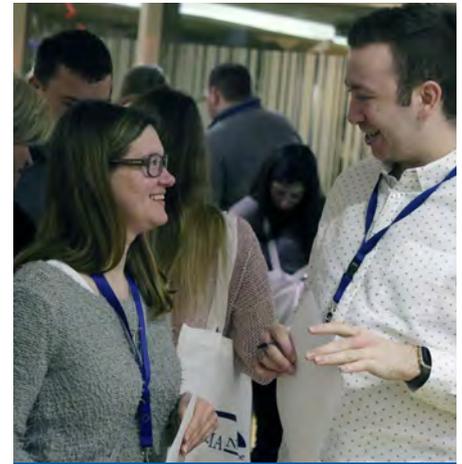
Delegates then split into subgroups in order to develop a plan for how organisations could approach future sustainable healthy lifestyle activities or projects in collaboration with HPRs.

The voting statements presented back in the plenary were:

- One size fits all – exercises programmes should be the same regardless of age and disease (*everyone disagreed*)
- Depression is a major barrier for lifestyle change: every RMD patient should be offered a consultation with a psychologist in exchange of a consultation with a rheumatologist (*approximately 70% disagreed*)



In the practical skills session on media interviews, delegates took it in turns to be interviewed on camera, while the rest of the group got involved and took on supporting roles



As in previous years, the delegates had the opportunity to meet each other in an informal environment during the Icebreaker

- All health professionals should have a fun-training to offer humour and fun in all consultations (*approximately 80% agreed*)

Skills training

For the second year running, **Esmé Newton-Dunn** led a personalised training workshop to help organisations prepare for engagement with the media, including developing a media protocol and tips for proactive and reactive communications with the media. The **‘Media interview skills’** workshop was held on Friday and included an opportunity for the delegates to role play a journalist and to practice being interviewed individually on camera.

A guide to conducting media interviews is available on the PARE section of the [EULAR School of Rheumatology](#).

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

- The media is a good way of reaching many people, but journalist often change what you say! (*approximately 95% agree*)
- If you are confident and have a good story, you do not need to prepare before you talk to the media... (*approximately 95% disagree*)

On Saturday, **Esmé Newton-Dunn** ran a two-part training workshop on **‘How to make a video’**, which covered planning, filming and editing a video. To make the workshop as practical as possible, delegates were paired up and each pair given a different location around the hotel in which to film a short video on an aspect of staying healthy at a conference. **Karlo Dzeverlija** provided his expertise on filming techniques and tips before the pairs were lent cameras on which

to make their short films. In the second half of the workshop **Marko Zovko** taught delegates how to download their films and edit them, adding captions and soundtracks. The resulting films were shown at the Best Practice Fair.

A guide to how to make a video is available on the PARE section of the [EULAR School of Rheumatology](#).

The voting statements presented back to the plenary session were:

- Making videos is very expensive – too expensive for most organisations (*approximately 95% disagree*)
- #SoMe is so last year! It’s better to meet face-to-face than to use video... (*approximately half agree and half disagree*)

Closing the official conference programme

At the close of the first conference combined with the Young PARE conference, **Simon Stones** delivered the closing remarks on behalf of Young PARE, based around the key themes, ‘Learn, Lead, Inspire’. Simon explained that young people should be enabled to have a voice and should be given ownership of activities and projects, cooperation is fundamental at all levels.

Nele Caeyers and **Dieter Wiek** presented the conference closing remarks, reiterating the theme of the conference, **‘Don’t Delay, Connect Today!’** and the importance of the three pillars of EULAR (scientific, patients and healthcare professionals) collaborating to make a positive change. As part of this Nele and Dieter mentioned the importance of making connections with the wider community, on a local,

national, European and global level, as well as continuing to prioritise the sharing of resources and knowledge.

Networking and best practice sharing

As in previous years, an **icebreaker** was held on Thursday evening. This provided an informal way to get talking with new people and find out more about their role and organisations. This year’s networking session was EU themed to reflect the Brussels location and was well attended and enjoyed.

On Saturday 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 on display were sorted into two categories, those campaigns that targeted people with RMDs or those that targeted the general public (including policy makers).

There were 30 campaigns presented, and delegates were encouraged to take their time visiting all the exhibits and asking presenters questions about their campaigns. They were also invited to vote for their favourite campaign in both of the categories and the presenter of the highest voted campaign from each category, was invited to join an interactive discussion, moderated by **Marios Kouloumas**, during the plenary session. **Chloe Haines** with JIA at NRAS was the winner in the category for people with RMDs and **Katerina Tsekoura** from ELEANA was the winner in the category of campaigns for the general public.



Jakob Ochmanski (on the right) accepting his Young PARE award from Simon Stones for a campaign specifically targeting young people with RMDs, this year the award was dedicated to Dora Papastavrou



Chloe Haines accepting her prize from Marios Kouloumas for the best campaign targeting people with RMDs in the Best Practice Fair



Katerina Tsekoura with her prize for winning the best campaign targeting the general public

@romeropazosvic: Congratulations to @KatTsekoura and Eleana for the prize of the best project to improve the employability of people with RMDs in Greece. Targeting both the employees and employers. 81% of people with RMDs prefer working than getting benefits #PARE2018

For the first time, there was also an award – judged by a panel of Young PARE representatives – for the best campaign targeting or involving young people with RMDs. This year the award was dedicated to Dora (Theodora) Papastavrou who was an active member of Young PARE, who won an award in the Best Practice Fair at the Lisbon 2017 conference and who very sadly passed away last year. **Jakub Ochmanski** from National Ankylosing Spondylitis Society was awarded the Young PARE award this year and also joined the panel discussion.

After all their hard work delegates attended a **gala dinner** on Saturday evening and continued future project planning and networking in an inspiring venue.

An informal networking session was held for delegates on Sunday morning and moderated by Maarten de Wit, Claudine Goyens and Souzi Makri, giving another great opportunity to share knowledge

and experiences, make connections and exchange contact details to stay in touch.

@SimonRStones: Huge congratulations to Jakob and all the @NASS_ASone @NASSexercise team - thoroughly deserved recipient of the 1st Youth Award. I'm so excited to see ASone grow in the coming months and years! #pare2018



Gala Dinner

The next **EULAR Annual European Conference of PARE** will be held in Prague, Czech Republic from 5th - 7th April 2019.



Photograph by Xuan Hoa Le @ pexels.com

EULAR Annual European Conference of PARE 2018 report

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