In 2019, the 22nd EULAR Annual European Conference of PARE was held in Prague and was hosted by the Czech League Against Rheumatism.

The 22nd Annual European Conference of PARE saw the launch of a new focus for the Don’t Delay, Connect Today campaign, which is supported by the three pillars of EULAR. Time2Work will put the spotlight on work and rheumatic and musculoskeletal diseases (RMDs), whilst still embracing the campaign’s key principles of prevention, early diagnosis and treatment.

With the new focus on the ever important topic of work and RMDs, the conference opened with an inspiring address from guest of honour, the Czech Minister of Health, Adam Vojtěch. Welcomed by Professor Johannes W. J. Bijlsma, President of EULAR, Adam Vojtěch informed delegates about his collaborations with patient organisations and the measures he is taking to support people with RMDs in the Czech Republic, including providing forty centres offering biological treatments and his commitment to make these more widely available as costs come down.

Dr. Jakub Závada, from the Czech Institute of Rheumatology in Prague presented evidence of the effectiveness of anti-TNF therapy on work productivity and Sarah Copsey from EU-OSHA (The European Agency for Health and Safety at Work) introduced the new pan-European campaign on musculoskeletal disorders, which will be launched in 2020 and run for two years. The opening session also included addresses from Professor Jiří Vencovský, President of the Czech Society of Rheumatology and Edita Müllerová, President of the Czech League Against Rheumatism both of whom welcomed the growing collaboration between their organisations.

116 delegates from 35 countries attended the 22nd EULAR Annual European Conference of PARE in Prague, which embraced the new EULAR Don’t Delay, Connect Today campaign theme of Time2Work.

The Task Force responsible for planning the 2019 Conference of PARE

Johannes W. J. Bijlsma, EULAR President
Peter Boyd, Young PARE representative
Nele Caeyers, Chair Standing Committee of PARE
Claudine Goyens, Task Force member
Elsa Mateus, Chair Elect Standing Committee of PARE
Hana Šmucrová, representing the 2019 host country
Tanja Stamm, EULAR VP representing health professionals in rheumatology
Linda Van Nieuwkoop, Task Force member
Ugo Viora, Task Force member
Dieter Wiek, EULAR VP representing PARE

Adam Vojtěch, Czech Minister of Health sharing a moment with Professor Johannes W. J. Bijlsma, President of EULAR

Fostering EULAR’s relationship with the Czech Minister of Health Federico Torres, EULAR Brussels Office; Neil Betteridge, International Liaison Officer, Public Affairs; Dieter Wiek and Edita Müllerová

Edita Müllerová, President of the Czech League Against Rheumatism
Presentations

Following the welcome addresses Jakub Závada presented data from the Czech Biologics Registry (ATTRA) looking at the effect of anti-TNF therapy on work productivity and activity impairment in people with rheumatoid arthritis (RA), ankylosing spondylitis (AS) and psoriatic arthritis (PsA). Participation in social and work-related activities are important when considering treatment goals, but many people with rheumatic diseases have to take time off work (absenteeism) or struggle with work because they are feeling unwell (presenteeism). Questionnaires were used to assess the effectiveness of anti-TNF treatments in people with RA, AS and PsA over a year and found that treatment reduced both absenteeism and presenteeism.

This year’s Stene Prize theme is, My Ideal Employer – work without barriers for people with RMDs.

Francisco Carreira Roca described his journey from being a healthy, sporty, practicing architect to a sudden, unpredicted spinal collapse due to undiagnosed osteoarthritis exacerbated by years of poor posture whilst hunched over a desk.

Based on his professional and personal experience, Francisco’s key messages to employers included the importance of:

- Investing in occupational health and safety measures to protect worker’s health, whether they have a pre-existing medical condition, or they become ill due to their work.
- Being aware of employees’ needs and considering options such as flexible work hours, working from home and ensuring people take regular breaks during the working day - a happy employee is a good employee!
- Creating a climate of cooperation, collaboration and understanding of the needs of everyone and ensuring that adjustments, adaptations and modifications benefit all.

This was the perfect lead into the new EU-OSHA healthy workplace campaign on musculoskeletal disorders, which will be launched in October 2020 and run for two years.

The 2020 -2022 EU-OSHA campaign advocates that employers view diversity in the workforce as an asset and be committed to ensuring everyone’s health and safety, whilst taking account of disability and diversity in the design and planning stages when changes are proposed, or new purchases are planned. Adapting work to workers is a legal requirement, but coordination between safety and equalities amongst personnel is also important. Training on diversity should be provided for all – managers and workers – and outside expertise should be sought when necessary. Practical advice on ensuring the health and safety of a diverse workforce includes designing workplaces that are as accessible as possible for all workers – known as universal or inclusive design. Sarah Copsey emphasised that providing ergonomic furniture and equipment to make work easier and the workplace safer and more accessible will benefit all workers.

The umbrella message of the campaign is that work-related musculoskeletal disorders are preventable and manageable. Preventative measures can be simple and low cost to implement. Early intervention when problems first arise is a key factor to the successful management of RMDs, as well as providing rehabilitation for workers with RMDs. Other factors being promoted by the campaign included the importance of staying physically active, even in periods of musculoskeletal pain, tackling work-related stress, which can influence RMDs, and promoting good musculoskeletal health among the future generation of workers, for example through schools. For more information visit the EU-OSHA musculoskeletal disorders theme page: https://osha.europa.eu/en/themes/musculoskeletal-disorders
From the panel discussion following the presentations clear themes emerged; the importance of early diagnosis and treatment, the need for evidence-based advocacy with improved collaboration and communication amongst all stakeholders and the imperative for the three pillars of EULAR to collaborate and speak with one voice – together we are stronger!

**Workshops**

Interactive workshops are at the heart of the conference, providing delegates with the opportunity to learn from experts through presentations and case studies.

**Policy and campaigning**

Neil Betteridge, International Liaison Officer, Public Affairs and Federico Torres, from the EULAR Brussels office, ran a workshop on working with policy makers, employers and trades unions to support the advocacy activities of PARE organisations at national and European levels. Based on EULAR’s strategic goals of improving conditions for people with RMDs to obtain a job on equal terms and increasing people with RMDs participation in work, case studies were provided by Professor Anthony Woolf, Chair of the Arthritis and Musculoskeletal Alliance (ARMA) and Gráinne O’Leary, Chief Executive of Arthritis Ireland.

The first case study presented by Professor Woolf looked at musculoskeletal health in the workplace and initiatives being used to help drive the political agenda to help people with RMDs to access and remain in employment. His second case study provided examples of working directly with employers and trades unions.

The Arthritis Ireland case study featured the Fit for Work programme, which started with a report launched in 2009 and how this formed the basis for continuing policy engagement starting with the formation of a coalition and the development of a work position paper. Multi-stakeholder conferences aimed at employers, health and safety professionals and policy makers were held in 2011 and 2013 and resources were developed for engaging with employers and employees, which are available online.

In the feedback session delegates were asked to vote on whether they thought the better way to make use of limited resources when improving the position of people with RMDs in the workforce is to:

a) Focus only on RMDs and what is needed?

b) Collaborate with the wider chronic disease community to raise awareness of issues such as workplace adaptations, flexible working, etc?

The majority voted for collaboration with the wider chronic diseases community as providing the strongest case for change.

**Young PARE**

Young PARE held a successful closed meeting on Thursday afternoon with a focus on transitions in life and implications for young people with RMDs. Additionally, two of the Saturday workshops were devised and led by Young PARE representatives; Peter Boyd led a workshop on Finding the Right Job.
at the Right Time and Wendy Olsder led a workshop on Entitlements and knowing your rights at work.

Led by Peter Boyd, the workshop on Finding the Right Job at the Right Time looked at some of the challenges of working with an RMD and how psychological interventions can help individuals build resilience and reduce stress. Dr. Romualdo Ramos, an occupational psychologist, described salugenesis, a model that focuses on the factors that support health and well-being rather than disease and focus on the relationship between health, stress and coping in a meaningful way. Peter Boyd used his personal story as a case study for remaining in work with an RMD by adapting and retraining. The second half of the workshop looked at a suite of resource materials that were first developed by EULAR PARE in 2010. These comprised three modules with a series of factsheets, the first module is aimed at people with RMDs entering the workplace for the first time, the second is for people who develop an RMD whilst in work and the third for people returning to work. Boryana Boteva, PARE Board member from Bulgaria introduced the modules, which are currently being reviewed and rebranded by EULAR in connection with the Don’t Delay Connect Today campaign and its work focus. Delegates were invited to comment on selected fact sheets from each module and their comments will be fed into the review process.

Wendy Olsder led a workshop looking at Entitlements and Knowing Your Rights at Work. Federico Torres provided an overview of health and safety and disability rights at an EU level, explaining that the EU sets goals and minimum and maximum standards on health and safety at work and equal treatment, which are then transposed to national law. Wendy Olsder continued that whilst each country has different legislation in this area, there is no legislation to ensure that people with RMDs who live without recognised disability are safe in their workplace. Added complications are the misunderstanding of recurring symptoms that are often invisible when people with RMDs are being assessed, and the lack of harmonization among committees that recognise entitlements.

There was agreement that people with RMDs should have a better understanding of their entitlements. Gráinne O’Leary, Chief Executive of Arthritis Ireland, provided a case study on how Arthritis Ireland has gone about engaging with employers and developed booklets for employees and employers. The booklet for employees provides information on how RMDs affect employment and how to manage an RMD in the workplace, including whether to disclose and what to do if it is no longer possible to sustain a job. The booklet also covers legal rights and how to access benefits. The booklet for employers provides information about RMDs, how these affect employment and employers’ legal obligations, as well as how to keep employees healthy at work, including prevention and early intervention and supporting employees with RMDs.

The value of work and role of occupational rehabilitation

Dieter Wiek led a workshop that explored the Value of Work and Asking the Right Questions. Paul Studenic, a young rheumatologist from Austria and member of EMEUNET presented studies relating to work and RMDs and in particular the challenges faced by young adults with RMDs. Management programmes like FAME-W can help improve productivity, impact of disease, fatigue, pain anxiety and self-efficacy after 12 weeks.
Dr. Yeliz Prior, a senior research fellow at the University of Salford who also runs a weekly rheumatology clinic as an advanced practitioner occupational therapist, provided evidence on the importance of work, the role of health professionals in rehabilitation and the results of a piloted study demonstrating that people with RMDs valued work rehabilitation and highlighted the benefits of receiving occupational therapy, whilst a control group, who were only given written materials, reported no benefits in relation to the written work advice pack, and lacked future aspirations to stay employed.

Delegates then broke into groups to discuss questions for people with RMDs; questions for health professionals in rheumatology (HPRs) and questions for doctors. All groups agreed that questions about the ability to work should be included in consultations. Whilst doctors tend to focus on medical care, people with RMDs would like to address wider issues such as psychosocial factors and should be offered access to self-management courses. Whilst patient care varies across Europe, it was suggested that HPRs could investigate the effect of health on work and work on health and offer sign-posting to rights and disability rights.

Professor Tanja Stamm led a workshop on Occupational Rehabilitation and how organisations of PARE can support people with RMDs to work.

Having presented the evidence for the use of non-pharmacological interventions in rheumatoid arthritis (RA), which included physical activity, psychological interventions, hand exercises, smoking cessation, nutrition and diet, three country case studies were presented.

Anja Marchal, is a coach and the coordinator of ReumaNet Belgium’s ReumaWerkt project, which provides peer-to-peer mentoring and education to people with RMDs. The project was launched in 2015 and is currently being evaluated (2018 – December 2019).

Hana Šmucrová presented a case study on vocational rehabilitation in the Czech Republic, which involves ongoing support including career counselling, training, employment mediation and ergodiagnostic – examination involving a multidisciplinary team. Vocational rehabilitation aims to help people with disabilities gain and maintain suitable employment. The Czech Labour Office provides and finances vocational rehabilitation to successful applicants.

Romualdo Ramos, an occupational health psychologist from Austria presented Fit2Work, the Austrian return to work approach that provides a service to people with disabilities at risk of losing their job or who are having problems finding a job. Fit2Work also provides consultation to companies fostering a healthy work environment.

Informal carers provide 80% of all care in Europe. They often bear the cost of their contribution and many have to reduce their working hours or stop working to provide full time care. Milena Gobbo, a psychologist from Spain provided insights into the psychological challenges of carers, who often neglect their own needs, and emphasised the need to support carers. Erika Mosor, a researcher with an occupational health background from Austria looked at the physical challenges faced by carers and how occupational therapists could provide support.

Insights into the experience of being a carer were provided by personal case studies from three different perspectives; Victoria Romero Pazos cares for her partner with an RMD, Elsa Mateus, who has an RMD, cares for her elderly mother, whilst Mia Prior, a young adult, spoke about being a child caring for a parent with an RMD.

With support from the workshop contributors and Linda van Nieuwkoop, a member of the conference taskforce, delegates worked in groups to develop ways in which organisations could support carers, which included providing printed and online information and education, respite weekends and a self-management toolkit.

Skills Workshops

Two of the eight workshops on offer were skills based; how to effectively design and present a poster, and how to work with pharmaceutical companies.

Led by Simon Stones and Diederik De Cock, this workshop looked at how to effectively design and present a poster. By combining practical...
information and an opportunity to design a poster based on real abstracts, delegates learned the skills needed to raise the standard of their poster entries and presentations at the EULAR Congress and other conferences. Takeaway from this workshop included:

- It’s not as easy as it looks
- Planning is key
- Having a clear brief is helpful, as is knowing your audience
- Teamwork is vital
- There is no right or wrong way to design a poster

As providers of medicines to treat RMDS, pharmaceutical companies and patient organisations have a number of mutual goals. Whilst many organisations have developed successful relationships with pharmaceutical companies, these are underpinned by a clear understanding of, and adherence to ethical codes and regulations. Organisations were also encouraged to develop their own guidelines for working with industry, if they do not already have them. Dieter Wiek kicked off this workshop on how to work with pharmaceutical companies with some real-life scenarios involving various interactions with pharmaceutical companies to challenge delegates understanding of what would be appropriate and what would not.

Ugo Viora, works for ANMAR, the Italian organisation and Esmé Newton-Dunn, healthcare communications consultant from the UK provided some general insights into working with pharmaceutical companies and Marios Kouloumas, President of the Cyprus League Against Rheumatism (CYPLAR), shared a case study on the highly successful CYPLAR 2018 Don’t Delay, Connect Today campaign, which was funded by a number of pharmaceutical companies among a range of other sponsors. This provided some practical examples of good practice, leading to further discussions and considerations on how to develop appropriate and successful interactions with pharmaceutical companies.

Special awards

In recognition of long service and their contributions to the conference special awards were awarded to Johannes W. J. Bijlsma, Neil Betteridge and Esmé Newton-Dunn.

Johannes W. J. Bijlsma has attended the conference of PARE for six years giving presentations and supporting workshops, as well as being a very motivated member of the Task Force helping to shape and develop conference programmes.

Dieter Wiek, who presented the award, thanked Professor Bijlsma for all his valuable contributions to PARE including his support for the engagement programme and helping foster the collaboration between the three pillars of EULAR PARE, the EULAR scientific and health professionals in rheumatology.

Neil Betteridge has been involved with PARE from its origins as the PARE Manifesto in 2000 through to the integration of PARE into EULAR in 2008. Since the integration of PARE into
EULAR, Neil has taken many active roles as a PARE representative within EULAR and as leader of the EULAR public affairs team. Neil is currently a member of the Executive Committee as liaison officer for international organisations.

The end of another inspiring event from PARE, the network of organisations representing people with #rheumatic & #msk diseases in Europe. Thank you for the privilege of being involved. And for the award, which belongs to us all. #pare2019

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Esmé Newton-Dunn, who works for an agency, Ruder Finn, has also been involved with PARE since 2000 providing support to Birte Glüsing, who ran the Manifesto Secretariat and who is now project manager for PARE within the EULAR Secretariat and coordinates the development and running of the conference. Esmé has continued to provide support on the development of the conference programme and workshops, as well as running some training workshops at the conference over the years.

Networking and sharing best practice

Best Practice Fair

The Best Practice Fair was held on Thursday evening providing an opportunity for an informal welcome and networking as delegates shared their organisations’ campaigns and activities through posters, videos and oral presentations.

Campaigns and activities entered into the Best Practice Fair were segregated into two categories; those aimed at people with rheumatic and musculoskeletal diseases (RMDs) and those aimed at the public, policy makers and healthcare professionals. Delegates voted for the best in category and the winners were announced on Saturday morning. Two additional awards were made; the Young PARE award for the best campaign or activity aimed young people with RMDs and an award for the best Don’t Delay, Connect Today campaign or activity. Both of these special awards were judged by juries.

Wendy Olsder (L) with Meike Voeten won the prize in the category aimed at people with RMDs for her poster on Droogbrood - a comic book about living with Juvenile Arthritis

Scotland Versus Arthritis

Today we won the @EULARYoungPARE award at the best practice fair during #pare2019 for our work with @NHSGrampian #rheumatology unit! Thank you for recognising the impact of our Joint Potential Plus programme! #partnerships #SelfManagement #transition #youngpeople #integration

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Green lanyards were used to identify first timers at the conference. Delegates who had attended previous conferences wore blue lanyards, whilst those with knowledge of the conference, including PARE Board members, member of the conference taskforce and support team could be identified by their grey lanyards and provided information and support where needed.

Networking Dinner
The networking dinner was held at the Zoffin Garden Restaurant on the banks of the Vltava River providing an opportunity to continue discussions and enjoy some relaxation after the hard work of the conference.