Fit for the future

Prof. J.W.J. Bijlsma, EULAR President 2017–2019, provides an update on developments with the EULAR School of Rheumatology and exciting plans for EULAR’s new strategic plan

The EULAR School of Rheumatology (ESOR) was launched at the 2017 EULAR Congress and, from this year’s congress in Amsterdam, it will be possible to become a member of ESOR by registering and paying 30 Euro per individual. Members will receive the RheumaApp, a fee reduction for different courses and access to some content captured at the EULAR Congress. The ESOR section on the EULAR website (www.eular.org/school_of_rheumatology.cfm) offers freely-accessible materials to patients and patient organisations. A new group of volunteer patients, under the leadership of Dieter Wiek, has started working on the PARE Classroom. Present thinking includes ideas to develop various materials to support patient organisations on issues such as how to improve patient-doctor communication and how to fundraise successfully. It is a very dynamic start!

The EULAR Strategic Objectives 2018 - 2023

1. **ESOR**: By 2023, EULAR will be the leading provider of education in rheumatic and musculoskeletal diseases (RMDs).
2. **Congress**: By 2023, EULAR will provide the foremost RMD congress experience, building on the heritage of our outstanding annual meeting.
3. **QOC**: By 2023, EULAR will deliver pre-eminent comprehensive quality of care (QOC) frameworks for the management of people with RMDs.
4. **Research**: By 2023, EULAR will have established a European centre for RMD research to advance high quality collaborative research.
5. **Advocacy**: By 2023, EULAR’s activities and related advocacy will have increased participation in work by people with RMDs.
6. **Governance, Infrastructure, Financials**: By 2023, EULAR will have established governance, workflows and infrastructure to deliver the EULAR strategic objectives.

A formal announcement will be made at the EULAR Congress giving greater detail, but I would like to give some information specific to our PARE members here. Regarding quality of care, for many years we have had EULAR Recommendations on how to diagnose, treat and manage certain rheumatic and musculoskeletal diseases (RMDs). We would now like to go further and include suggestions on how to implement these recommendations, what outcomes we should look for and how we can evaluate the success of these recommendations. We will continue to heavily involve patients in these processes. EULAR will aim to establish a European Centre for RMD Research to advance the highest quality of integrated and collaborative science. EULAR will organise activities in the public affairs arena (for example, Brussels for the EU, as well as the national and regional levels) that will lead to an increase in the number of patients with RMDs that can participate in work (paid and non-paid). Many patients will be involved in this area. Some of these activities will be led by members of the PARE Board, who have proven to be of utmost value in the political arena. Work is an important theme for many politicians and many organisations. Focusing on this area will probably solicit many positive responses and also draw attention to RMDs.

The whole strategy can only be realised when our three pillars – doctors/scientists, health professionals and patients – work tightly together. I sincerely hope that you will join us in these efforts.
Dear Colleagues
By Nele Caeyers

Dear friends of PARE

Time flies – it is June already! And June in rheumatology means EULAR Congress time! Exciting days are awaiting us in Amsterdam, the host city for 2018, with loads of opportunities for networking and learning. We surely hope the PARE programme meets your expectations and that you will return home with a suitcase full of innovative ideas.

2018 has already been an exciting year. We had a wonderful PARE Conference in Brussels in February, filled with interesting workshops and enthusiastic participants. In March, we announced the Edgar Stene Prize winner from Poland. Congratulations to Magdalena Misuno for her inspirational story on her personal champions. You can read more about Magdalena in this issue of Breakthrough.

We are also thrilled to see so many organisations taking up the EULAR campaign Don’t Delay, Connect Today on a national level. Early diagnosis and access to care are relevant topics in all European countries today. Thank you for spreading the word. Please let us know if you are planning to use the campaign in your country too! If you need inspiration for World Arthritis Day on 12 October 2018, don’t forget to visit the www.worldarthritisday.org website.

This issue of Breakthrough also gives you an update on the developments around the EULAR School of Rheumatology, presents the PARE position paper on biosimilars and shows the intense collaboration of Young PARE with EMEUNET. Also, the health professionals focus on the well-established collaboration between our two pillars.

Plenty of inspirational articles are waiting for you. I hope you enjoy reading them but, most of all, I hope they will function as a spark to get you going in your own country.

All the best

Nele Caeyers, Chair, EULAR Standing Committee of PARE

Musculoskeletal Imaging Standing Committee

Lene Terslev, Chair, explains the work of the EULAR Standing Committee for Musculoskeletal Imaging and its relevance to people with rheumatic and musculoskeletal diseases

The activities of the EULAR Standing Committee for Musculoskeletal Imaging are aimed at the improvement of patient care through the appropriate use of imaging in daily clinical practice.

The use of imaging modalities as part of daily clinical rheumatology practice has increased over the last 20 years, improving patient care and the understanding of rheumatic and musculoskeletal diseases (RMDs). The EULAR Standing Committee for Musculoskeletal Imaging was established in 2007 with the aim of promoting and disseminating the use of imaging in rheumatology through education and research in both the understanding and the application of imaging modalities for patient care.

“The committee endorses local ultrasound courses”

The committee participates via the organisation of practical skills sessions on MRI and ultrasound imaging during the annual EULAR Congress and has developed EULAR online courses on both ultrasound and other imaging modalities. To ensure standardised training in ultrasound, the committee has developed a competency assessment for ultrasound in rheumatology that includes successful participation in the EULAR ultrasound courses, conducted every year prior to the annual congress, and to the course educating upcoming ultrasound teachers. Since 2017, a EULAR ultrasound course on children has also been available. The committee also endorses local ultrasound courses and has created a EULAR network of imaging training and research centres.

“The guide was developed in collaboration with a PARE representative”

Several learning tools have been developed, such as the EULAR imaging library which demonstrates different pathological conditions for educational purposes and an ultrasound scanning guide to assist rheumatologists in optimising their scanning procedure. This guide was developed in collaboration with a PARE representative and has resulted in the updated guidelines for EULAR Standardised Procedures for Rheumatology Ultrasound Imaging. The guidelines propose the positioning of patients during ultrasound examinations, which was agreed by the PARE representative.

The committee’s research activity is focused on the clinical utility of the different imaging techniques and their use in clinical practice.

The committee has contributed to the development of a consensus-based EULAR-OMERACT ultrasound scoring system for rheumatoid arthritis and other research activities have resulted in several published recommendation papers in different diseases.
Developing a deeper collaboration

Tanja Stamm, EULAR Vice President representing Health Professionals in Rheumatology, highlights how collaboration between the pillars of EULAR is key to improving outcomes for people living with rheumatic and musculoskeletal diseases.

PARE and health professionals in rheumatology (HPRs) should work together more closely in the future – both on an individual basis and at an organisational level. I am convinced that this will drive the future of rheumatology care in Europe.

What can health professionals offer to patients with rheumatic and musculoskeletal diseases (RMDs)? Early referral and timely treatment are important examples within primary care: innovations and new models of care in many European countries will create excellent opportunities for health professionals to work in primary care settings. HPRs working in primary care, for example, refer patients with inflammatory rheumatic diseases as early as possible to the right medical specialists, and deliver evidence-based and timely treatment to people with degenerative joint diseases.

“Without HPRs, patients with osteoarthritis would have a lower quality of life”

Evidence-based treatment for patients with osteoarthritis is mainly delivered by physiotherapists, nurses and occupational therapists. It substantially improves functioning, health status and quality of life, while also reducing pain and fatigue, and increasing self-efficacy. Without HPRs, patients with osteoarthritis would have a lower quality of life, substantially decreased functioning in daily living activities and more joint damage. Pain in joints, loss of function and aesthetic changes related to hand osteoarthritis can be important targets of health professional interventions.

Prevention and health promotion are other important areas for health professionals, along with secondary prevention which occurs in the workplace. HPRs are specialists in physical activity, occupations, paid work, ergonomics, movement, and the planning and conducting of activities. The lives of many people would improve if there was better health promotion about – but not limited to – RMDs, and primary and secondary prevention for people with RMDs in the workplace.

“People spend a considerable amount of their lifetime at work”

People commonly spend a considerable amount of their lifetime at work. Furthermore, people work at home – for example in home offices, when doing housework, taking care of children and/or grandchildren or do voluntary work. Likewise, leisure activities also benefit from an ergonomic, physiological and health-promoting approach. Health promotion and early prevention should start early in life. I believe kindergartens and schools should be important targets for future activities in this area.

Patients do not only benefit on an individual basis from interventions by HPRs. On an organisational level, patient organisations work closely with health professionals. This collaboration was the topic of a workshop at the 21st PARE Conference held in February in Brussels. In this workshop, we focused on behavioural changes.

“We hardly implement this knowledge and change our behaviour”

Despite that we all – or most of us – know what is healthy, we hardly implement all this knowledge in our daily life and change our behaviour. We stop exercising, we buy and eat unhealthy food, and we conduct stressful jobs. Health professionals can offer strategies to help. In addition, national PARE organisations may be ideal partners for starting campaigns and large-scale activities at the organisational level that can reach more people, more regularly as we know that motivation for a healthy life style decreases over time.

The results of a survey carried out by EULAR among health professionals in rheumatology and PARE organisations showed that 36% of all PARE organisations have already run a healthy lifestyle or health promotion activity or campaign involving health professionals in rheumatology. Furthermore, 50% of all PARE organisations are planning a healthy lifestyle or health promotion activity or campaign to help prevent or reduce damage from RMDs. The most commonly collaborated with HPRs are physiotherapists, specialist nurses, occupational therapists and psychologists.

I am delighted that a lot is already happening, but there is still room for more and deeper collaboration between PARE and health professionals.

Visit www.eular.org/health_professionals_member_orgs.cfm to find the EULAR HPR member organisation in your country.
EULAR recommendations: Lay summaries

Today, more patients are becoming actively involved in the management of their own disease and healthcare decisions. This is called shared decision making, whereby decisions about potential treatments are made on the basis of information given by the health professional and on the preferences of the patient. To make a well-informed decision, it is necessary for patients to be provided with understandable, accurate and up-to-date information about the treatment options for their diseases. This includes the benefits and risks of taking or rejecting a particular treatment.

EULAR develops specific disease management recommendations primarily to inform practicing health professionals and to improve their daily treatment routines. However, parallel information for patients is often not available. EULAR, and in particular the EULAR Standing Committee of PARE, considers it important that these recommendations also reach patients – without proper information, patients may not fully understand the implications of their treatment options.

The traditional, scientific wording of the EULAR Recommendations is often difficult for lay people to understand. Lay summaries have, therefore, been developed. They are written in English and have been adapted to use words and phrases patients will easily recognise.

“It is important that these recommendations reach patients”

For non-English speaking countries, the summaries should be translated into the national language, with the help of a local rheumatologist, taking account of the information needs of patients locally. This is important to make the recommendations accessible to a wide audience. To assist in this, PARE initiated the development of a practical guide to the dissemination and translation of recommendations to patients. It contains easy to understand guidelines, checklists, tools and tips. In many cases patient organisations and health professionals may choose to work together to promote patient education in their country.

Mitchell Silva of ReumaNet vzw said: “We want to ensure all Flemish patients have access to the high quality EULAR recommendations. Translating the lay versions is not too difficult and results in a wide implementation of the recommendations.”

Additionally, the Annals of Rheumatic Diseases (ARD) now also publishes short research summaries of selected key research papers published in the journal in lay language for patients and non-clinicians. These aim to explain clearly the results of the research studies as well as any implications for treatment of the specific condition.

Visit www.eular.org/lay_recommendations.cfm for more information.

Biosimilar developments

Dieter Wiek, EULAR Vice President representing PARE, provides an update on PARE’s position on biosimilars

Following the publication of EULAR PARE’s position paper Biosimilars – what do patients need to consider? in November 2015, more biosimilars for rheumatic and musculoskeletal diseases (RMDs) have entered the market in different European countries after approval by the European Medicine Agency (EMA). New studies and data about the use of biosimilars, as well as feedback from patient organisations – in particular PARE organisations – indicated a need to update PARE’s position.

Comments about the content and context of the new position statement were invited from the PARE community in particular. The more detailed and comprehensive statement is now on EULAR PARE’s website. Some of these key points are:

- no patient should be switched from an original product to a biosimilar because of cost-effectiveness against the patient’s decision – a switch should always be based on a shared decision between patient and doctor.
- if so-called naïve patients (patients who have not taken a biologic so far) should take a biologic, the less expensive biosimilar can be used, as long as there are no contraindications, the patient has been informed and the decision is based on a shared decision between rheumatologist and patient.
- as long as no studies exist, a switch between different biosimilars is not recommended.
- because of concerns about the immunogenicity of the biologics, multiple, medically unnecessary therapy changes should not be performed unless study data are available.

EULAR PARE has produced a video on biosimilars which gives people with RMDs an overview of what they should know about biologics and biosimilars – in particular about efficacy, safety and switching.

Visit www.eular.org/pare_training_modules.cfm to access the video and the position paper.

A EULAR video explains biosimilar drugs
EULAR Congress 2018 – Welcome to Amsterdam!

The Netherlands hosts the EULAR 2018 Congress

After 12 years, Amsterdam welcomes back the Annual European Congress of Rheumatology for a second time. From 13–16 June 2018, the RAI Amsterdam is ready to receive around 14,000 participants to this unique arena for the exchange of scientific and clinical information.

An exciting and stimulating PARE programme has been prepared over the past year by Dieter Wiek, EULAR Vice President, representing PARE, and his team. The PARE programme specifically focuses on the perspective of people with rheumatic and musculoskeletal diseases (RMDs) and their respective organisations. Please see the overview of the PARE programme below and we hope to see you there!

Come and visit our joint EULAR booth in the EULAR Village to receive the latest information on PARE activities and meet your colleagues to exchange the latest news. The PARE team will be waiting to welcome you. Get your own copy of the 2018 EULAR Edgar Stene Prize booklet, as well as many other recent publications from patient organisations all over Europe.

The PARE Posters will be displayed from Thursday to Saturday. We will again offer two official PARE Poster Tours at lunchtime on Thursday and on Friday. If you would like to join one of the tours, please register officially on the day – places are limited so don’t be disappointed! If, at the end of the congress, you find you were not able to cover all you had wished to, you can always attend the PARE Highlight session to get an overview of the PARE programme.

We look forward to seeing you in Amsterdam!

The PARE Programme

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<td>16 June 09.00 – 10.30</td>
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News from the heart of Europe

EULAR Public Affairs: Past, present and future

Neil Betteridge, EULAR Liaison Officer, Public Affairs reports on activities through 2017–2018

It is my experience that to get the future right, we need to understand our past. So as EULAR nears the end of its current 5-year strategy, it is worth reflecting on what has been achieved under the Strategic Objective relating to public affairs.

EULAR has been committed to:

✓ increasing its influence in policymaking processes
✓ increasing the recognition of RMDs as major diseases
✓ developing a long term, co-ordinated public affairs strategy
✓ collaborating internationally on relevant policy issues.

Like all ambitious objectives, some have been more concretely achieved than others. Recent evaluation, however, indicates that, overall, EULAR has achieved positive results. For example:

• RMDs have been recognised as a major chronic condition by EU institutions, as reflected in several key policy documents e.g. the Horizon 2020 Research Framework Programme. This means that the views and recommendations of the RMD community are more likely to be considered in policy development
• WHO has recognised RMDs explicitly, for the first time, in its action plan on non-communicable diseases
• annually, EULAR organised a public affairs conference around World Arthritis Day, involving EU and national policymakers, stakeholder organisations and the RMD community to discuss key policy issues
• out of these conferences, EULAR has contributed to the development of EU and WHO policies by developing position papers and recommendations on topics such as the prevention / retention of RMDs in the workplace; access to healthcare; cross-border health care; and the future of EU support to medical research
• these recommendations were taken by EULAR delegations to policymakers such as the Commissioner for Health and Food Safety, Dr Vytenis Andriukaitis; and the Cabinet of Commissioner for Employment, Social Affairs, Skills and Labour Mobility, Marianne Thyssen
• the European Parliament Interest Group on RMDs was re-established. It meets three times per year to discuss topics such as those highlighted above, often taking actions in support of our causes
• EULAR leaders now sit on the Scientific Panel for Health, the main advisory body on EU health research issues; and on the Alliance for Biomedical Research in Europe, representing the main medical scientific societies
• EULAR developed RheumaMap, the first ever roadmap for research in RMDs, which addresses the main challenges in rheumatology research in the next years and is being used to communicate EULAR’s needs and recommendations to policy makers.

So, some real progress in raising the profile of EULAR and, most importantly, RMDs. But, challenges remain, and others will arise. These include the debate on the role of the EU in areas such as public health, social affairs and research; and how the EU can still provide direction in health policy when some member states are increasingly sensitive to issues around self-determination, as witnessed most concretely of late by Brexit.

New approaches will be needed in the next public affairs strategy – and the voice of PARE will be central to this.

Round-up of recent events

World Arthritis Day Conference 2017

Horizon 2020, the current EU Research Framework Programme, will come to an end in 2020. Following the mid-term evaluation of the programme, last year the European Commission started to discuss the new Research Framework Programme (FP9), which will run from 2021 until 2027. The Commission is expected to publish its proposal by the middle of 2018.

To contribute to the development of FP9 and to developments in research policies more widely, EULAR’s conference theme for 2017 was “The future of health research and innovation after Horizon 2020: Do we need a novel approach?.” The event took place in Brussels in October as part of EULAR’s World Arthritis Day activities.

The goal was to identify key challenges in research and innovation in RMDs and other conditions, so as to develop policy recommendations. To this end, EULAR co-organised parallel workshops with well-known stakeholder organisations:

Workshop participants discuss future policy recommendations at the Brussels Conference
Accessibility Act, seeking to facilitate access to products and services for disabled people. The Directive proposes the establishment of minimum accessibility standards for the production and delivery of goods and services (e.g. computers, smartphones, services related to public transport) as well as the removal of existing barriers for the commercialisation of these products.

Other initiatives include the anti-discrimination Directive, which proposes specific provisions to prevent discrimination of different kinds, including discrimination against disabled people; the revision of the legislation on the rights of railway passengers; and the European Pillar of Social Rights.

To assess these developments and explore possible parliamentary initiatives, the Interest Group on RMDs organised a meeting in the European Parliament, with the support of EULAR as Secretariat to the group. The event took place on 26 February 2018, with over 30 delegates participating.

Speakers included representatives from the European Parliament, the European Commission, the European Disability Forum, the European Social Insurance Platform, the Belgian National Institute for Health Care and Disability Insurance, and the European Regional and Local Health Authorities.

Additionally to the presentation of RheumaMap by EULAR President Prof. J.W.J. Bijlsma, two keynote speeches were among the highlights of the day. Prof. A. Radstake, from Utrecht University, presented on the topic “What can the health community learn from successful stories in research and innovation?” and Prof. T. Radbruch (from Deutsches Rheuma-Forschungszentrum Berlin) focused on the “Challenges in health research and innovation in the next decade: how to establish priorities.” Each illustrated in different ways how much has been achieved, but also how much more could be done given appropriate support.

We were also pleased to have high level representatives from the European Commission, the European Parliament, the Permanent Representation of Bulgaria, and WHO, as well as EULAR representatives from PARE, health professionals and clinicians.

The video of plenary sessions, the agenda and the report are available on the EULAR website.

**Meeting of the European Parliament Interest Group on RMDs**

Several policy initiatives on disability issues are currently being discussed in Brussels. One of the most important is the
Following the award of a EULAR facilitation grant, the three Romanian EULAR member organisations – the Romanian League Against Rheumatism, the Romanian Society for Rheumatology and the Romanian Association of Medical Partners for Rheumatology – launched their national Don’t Delay, Connect Today campaign. Starting from April, a series of events have been planned, targeted at the general public, to raise awareness about the need to see their GP and/or rheumatologist for early diagnosis and treatment. This supports the aims of EULAR’s campaign to increase the chances of people with rheumatic and musculoskeletal diseases (RMDs) receiving early treatment of symptoms to manage their disease effectively.

On 19 April, a press conference and roundtable discussion took place in the Central University Library, Bucharest. It presented a great opportunity for guests and invited speakers to interact with representatives from the press and media, and to increase the visibility of the event and EULAR campaign in Romania. The event was targeted at policymakers, patients, rheumatologists, nurses and physiotherapists. Speakers included Dieter Wiek, EULAR Vice President representing PARE, on the role of patient organisations in supporting early diagnosis / early referral and minimising the health, social and economic impacts of RMDs; and Codruta Zabalan, a patient from the Romanian League Against Rheumatism, on living with a rheumatic disease in Romania – what should be done?

“42% of Romanian workers say they experience back pain because of their workplace – one of the highest percentages within Europe. Early treatment has a major role in reducing the direct, indirect and intangible costs of RMDs and in maintaining a healthy workforce,” said Dr. Cătălin Codreanu, President of The Romanian League Against Rheumatism.

This important, high-level event follows similar national campaign launches at the Belgian national parliament in February 2018 and at the Portuguese parliament in Lisbon, Portugal in February 2017.

Co-ordinated media plan
In Romania, a series of actions and public events have taken place, following a co-ordinated media plan. A public education event was organised which saw educational flyers and other educational materials distributed in shopping centres, metro stations and other crowded places.

An awareness raising video has been produced with the message “Don’t Delay, Connect Today”. It has been posted on Youtube, on the www.reumatism.ro website and is mentioned in all materials which contain the hashtag #ConnectToday. A dedicated Facebook page will be created using teaser social media posts designed to stimulate communication and mutual support among patients.

Will you #ConnectToday?

Events in shopping centres were organised in Bucharest

Dieter Wiek and Marios Kouloumas supporting the Romanian national launch

Marios Kouloumas, on behalf of the EULAR Campaign Task Force, provides an update on national events promoting the Don’t Delay, Connect Today campaign and highlights the support EULAR can provide through its Engagement Programme

EULAR’s Engagement Programme aims to engage with and support national organisations by providing a EULAR representative or speaker at their events. It is a means of assisting national organisations to become stronger at the national level and to become more effective contributors to the work of EULAR at the European level.

The aims of the EULAR Engagement Programme are to:
• improve the quality of life of people with RMDs in a specific country by working or engaging with national organisations
• raise the profile of RMDs and the organisations involved
• facilitate a mechanism for national organisations and EULAR to collaborate nationally
• foster collaboration between EULAR member organisations and other stakeholders at national level
• share detailed knowledge about EULAR organisations’ programmes and capacities.

A review of these visits has now allowed EULAR to develop the programme even further, with the aim of making the visits more effective and visible. The programme has been renamed as the EULAR PARE Engagement Programme.

Edgar Stene Prize celebrates personal champions

Magdalena Misuno from Gdańsk in Poland has won the 2018 Edgar Stene Prize competition. 37-year-old Magdalena, who has systemic lupus erythematosus, was voted the best essayist writing on the theme of “My personal champion – supporting my everyday life with a rheumatic and musculoskeletal disease (RMD)”. Magdalena will be presented with her prize at the Annual European Congress of Rheumatology in Amsterdam in June. She will present her essay in the PARE Abstract Session on Friday 15 June in the PARE Room at 10.15am. This year’s 2nd prize winner is Per Clausen from Denmark, with 3rd place being awarded to Maiken Brathe from Germany.

A 2018 Edgar Stene Prize booklet with an anthology of entries will be ready for the EULAR Congress and available at the PARE Booth in the EULAR Village. It can also be downloaded from the EULAR website (www.eular.org/pare_stene_prize.cfm) after the congress.

21st EULAR Annual European Conference of PARE 2018

From 16–18 February 2018, ReumaNet hosted the 21st EULAR Annual European Conference of PARE in Brussels. The topic “Don’t Delay, Connect Today – working together towards prevention, early diagnosis and access to care in rheumatic and musculoskeletal diseases (RMDs)” brought together more than 120 representatives of RMD patient organisations from all over Europe, Canada and the US, including 27 Belgium representatives.

“A key focus was European Public Affairs”

A packed programme engaged the delegates in plenary sessions, different workshops ranging from learning how to make a video and insights into the EU to enhancing the collaboration with health professionals in rheumatology at national level and introducing the latest activities of EULAR’s Don’t Delay, Connect Today campaign. Given the location of the conference, a key focus was European Public Affairs and campaigning, so a visit to the European Parliament was a must for the attendees.

“ReumaNet is very happy with the impact of the conference – it was an inspiration for our national delegates to connect with their counterparts in Europe, and to finally understand the work of EULAR and its importance for each individual European wide,” said Nele Caeyers, Chair of the EULAR Standing Committee of PARE and ReumaNet’s Liaison Officer. “After all the years I have attended the PARE Conference in other countries as a delegate, I felt very proud that ReumaNet could now be the host for my friends and colleagues from the PARE community.”

“The event was full of energy and inspiration”

The attendance of Marianne Thyssen, EU Commissioner for Employment, Social Affairs, Skills and Labour Mobility, at 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. She implored delegates to continue to raise awareness of RMDs on a national and EU level.

For the first time, Young PARE officially merged their bi-annual meeting with the conference. With more than 25 delegates under 25, they were well represented and contributed to an event full of energy and inspiration.

“It was great to see Young PARE so active and visible at the PARE Conference. The introduction of the Young PARE award for the best campaign targeting or involving young people with RMDs was greatly appreciated this year, and I hope this continues to nurture interest in this topic in the future,” said Simon Stones, representative of Young PARE on the 2018 conference planning team.

The Twitter wall allowed delegates and the external audience to engage 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.


The next PARE Conference will be held from 5–7 April 2019 in Prague, Czech Republic.
Young PARE and EMEUNET – collaborating closely

Alessia Alunno and Elena Nikaphorou from EMEUNET, and Wendy Olser and Simon Stones from Young PARE discuss how the two EULAR groups have forged a strong working relationship

One of the key drivers for our brilliant working relationship is the fading hierarchical power that once existed between healthcare professionals, researchers and patients. With a generation of youth in both professional practice and patient advocacy, we look beyond our respective backgrounds, recognise each other’s unique talents and abilities, and work together as true equals to address the challenges we all face and want to overcome.

EMEUNET: We had very close and pleasant communication prior to, during and post conference – with lots of fun too! Aside from the “live” contact, we also interact and support each other on social media. EMEUNET is always willing and ready to help with dissemination of information, providing a rheumatology perspective and integrating our two perspectives working together towards common goals.

What do you see as the greatest assets EMEUNET can bring to Young PARE?

EMEUNET: Enthusiasm, support, ideas.

What are the future plans for EMEUNET / Young PARE?

EMEUNET: We very much hope to continue to work together on collaborative projects, developing scientific sessions at EULAR, working directly together to support each other’s activities which share common goals and objectives.

Young PARE: The way in which Young PARE and EMEUNET work together is a shining example of how research should be done – for, by, and with those living with RMDs. We will certainly continue to work directly to support each other’s activities, co-developing content for the PARE Conference and EULAR Congress, as well as on current and future joint projects. We hope to see an increasing number of opportunities for young people to get involved in research and advocacy opportunities, ranging from co-developing grants to co-authoring manuscripts, co-delivering presentations and everything in-between, which we feel is achievable with the faultless support and guidance of our EMEUNET friends!
Participants told us that they:

- want to continue working
- need their working environment adapted to their needs
- want understanding from their employers and co-workers
- need established working rights that permit them to be absent from work for health reasons
- want to feel safe to talk about their disease without being afraid of dismissal
- need to be able to reintegrate into the workforce after long-term absence due to illness.

The project revealed that people with RMDs want to stay active in the workforce. They consider that being able to work is a key factor in enhancing their quality of life physically, mentally, economically and societally.

Impact of work on quality of life

By Katerina Tsekoura from ELEANA, the Hellenic League Against Rheumatism

ELEANA wanted people with rheumatic and musculoskeletal diseases (RMDs) to come forward and raise their voice about work related issues. The project’s aim was to see beyond statistics and yes/no answers. Participants included people who have worked but can’t work anymore, people who continue to work and people who have never worked. They were aged between 30-48, with a diagnosis of between 1-43 years.

81% said they prefer working to getting state benefits
50% said they face problems with their employer
30% said the employer was friendly at first but not supportive when they needed it
20% said they never talk to their employer for fear of getting fired
Although 70% claim they are aware of their working rights, only 40% of them have made use of health leave rights out of fear this could hurt their professional image
70% of the buildings are not accessible and 90% of working environments don’t have proper equipment.

Society has to be an active partner in ensuring that people’s rights are respected and that all required adjustments are carried out to enable people with RMDs to keep advancing their professional lives.

The results of this project will be used to raise awareness among policymakers in my country, as well as educating both patients and employers. The goal is to create a better working environment for people with RMDs.
Country news

Love Your Heart

Ailsa Bosworth, CEO of the National Rheumatoid Arthritis Society (NRAS), highlights a new programme aimed at heart health

Cardiovascular disease (CVD) accounts for just over a quarter of deaths in Britain and costs the economy billions in healthcare. The prevalence of CVD mortality in people with rheumatoid arthritis (RA) – and lack of awareness by people with the disease – has always been of concern to NRAS. Inspired by a face-to-face group programme educating people with RA about their increased risk of heart disease (developed by Dr. Holly John, consultant rheumatologist at Dudley NHS Foundation Trust), NRAS obtained permission to develop the programme into an online video and to make it widely available to people with RA across the UK.

The Love Your Heart programme is an engaging online, interactive educational video that will help those with RA understand why they are at increased risk of CVD and the impact RA can have on one of the most important organs – the heart.

This was one of the most ambitious projects we have taken on. After successfully securing the funding, it took 18 months to create, write, film, animate, edit and develop the interactivity and embedded evaluation within the video programme.

Participants will be able to:
- understand the reasons why RA increases CVD risk
- calculate a QRISK®2 score (a GP recognised prediction algorithm for CVD)
- learn how to reduce the risk of CVD
- log progress through a series of behavioural goals.

Baseline evaluation to determine “intended” behaviour change has been built into the video, and a 6-month evaluation will be automatically emailed to gauge “actual” behaviour change. It will also be possible to use the programme to train health professionals. GP Dr. Ruth Williams, who appears in the video, said: “This video will be a great resource to help train my GP colleagues.”

The increased risk of CVD for people with RA has the same level of severity as those who suffer with type 2 diabetes. Dr. John said: “It’s astonishing how many people with RA don’t know that their condition could be detrimental to their heart. It’s very easy to manage risk factors that are within an individual’s control from home with a healthier lifestyle, so Love Your Heart will be able to significantly raise awareness of this and help to address this major co-morbidity which can shorten the lives of those with RA.”

We hope the Love Your Heart programme will have real impact helping to reduce the risk of CVD in people with RA (and other forms of inflammatory arthritis). We were delighted that nearly 200 people completed the programme during the launch week.

NRAS is the first charity in our field to offer such a ground-breaking, interactive video. Posters and heart-shaped cards have been sent to all rheumatology units across the UK to encourage health professionals to refer their patients to this free video programme and we are promoting it through our social media channels.

Visit www.nras.org.uk/love-your-heart

Breakthrough

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Publisher
EULAR Standing Committee of People with Arthritis/Rheumatism in Europe

Number of copies: 700
All pictures supplied by EULAR and contributors unless indicated otherwise.

The Standing Committee of PARE would like to thank all those who have contributed to this newsletter