Therefore, apart from a new cycle regarding our strategy (for the years 2018–2023), I will not begin any major new initiatives during my presidency – let’s first develop and consolidate what we have started. I will put great effort into the EULAR School of Rheumatology, including ensuring interesting school activities for patients. In addition, we will be working with PARE and our Public Affairs Group on the large public awareness campaign *Don’t Delay, Connect Today!* "Remission is now a realistic option"

I have spoken to many people with rheumatic and musculoskeletal diseases (RMDs), including the much-appreciated leadership of Marios Kouloumas and Dieter Wiek, about what has been of most importance to them during the 70 years of EULAR. We all recognise that the evolution of research and scientific knowledge has enabled a new era of treatment for people with RMDs and that this evolution has made remission now a realistic option for many patients. Due to new drug treatments, significant and permanent joint damage is now prevented in most cases – especially in patients with rheumatoid arthritis, psoriatic arthritis and spondyloarthritis.

Doctors, as well as patients, are now much more aware that shared decision-making can lead to therapeutic advantages. Better patient information and applying the principles of self-management will help to achieve a better outcome for many.

I see great opportunities for what the School of Rheumatology will offer patients. We will create webinars for patients on relevant topics, such as biosimilars. These webinars can be developed as a discussion between patient and physician, rather than just a lecture by the physician. We will also create tools to help patients develop their self-management skills.

"Co-operation will take us further"

In short, a lot of work must be done in the coming two years. With the help of the people with RMDs and the EULAR PARE organisations, as well as the help of members from the other two EULAR pillars, I am confident that we will be able to take important steps forward.

We need people to join EULAR in these efforts. If you can help, or have good suggestions, please tell us. Working together is rewarding and only this co-operation will take us further.
Dear Colleagues

By Dieter Wiek

Dear members of the PARE community and friends of PARE

The past year has been an exciting time for PARE. Our Brussels Conference, on World Arthritis Day in October, focused on "How to reduce the burden of chronic diseases in the workplace" and was a great success. The PARE Annual Conference in Lisbon this year offered delegates skills training and workshops that will, hopefully, inspire delegates in their work with their organisations.

Our PARE programme for this year’s EULAR Congress in Madrid offers a wide range of topics such as co-morbidities, health equity, employment, psychological well-being and EULAR’s new campaign Don’t Delay, Connect Today! Early diagnosis is of utmost importance to patients. The Edgar Stene Prize stories – and this year’s winner’s story in particular – give a vivid account of how important a timely diagnosis is and what optimal treatment means for quality of life.

EULAR’s 70th anniversary illustrates the progress made in the treatment of people with rheumatic diseases. New therapies in the last 20 years have prevented most patients developing severe physical disabilities. However, I feel that, although a lot has been achieved across Europe, there is much still to be done so that all patients receive the standard of care available nowadays. Patient organisations can contribute to improving access to diagnosis and treatment, information and patients’ self-management.

It’s time for me to say goodbye as Chair of the Standing Committee of PARE. My thanks to the PARE Board and the EULAR Secretariat for their great support. I wish my successor Nele Caeyers much success for the endeavours to come.

Dieter Wiek, Chair of the EULAR Standing Committee of PARE

Celebrating 70 years of EULAR history

Breakthrough asked the current and past two EULAR PARE Vice Presidents for their views on advocacy and EU Affairs, patient involvement in research and what makes EULAR so successful. Here are some of their highlights

Marios Kouloumas, EULAR Vice President, representing PARE 2013–2017

“...rheumatology in EULAR through its 70-year history has been determinative and important in strengthening objectives relating to research, management and in raising awareness of the severity of these diseases to the individual as well as to society. Also, the participation of representatives of scientific and health professionals in the various PARE working groups and activities – and vice versa of PARE in the structures and most activities of EULAR – has helped greatly in improving the overall quality and outcomes. EULAR’s three pillar approach is a unique worldwide set-up which empowers EULAR to achieve its goals!”


“...Something which closely unites EULAR’s patient group network is a passion to change the world for people with rheumatic and musculoskeletal diseases (RMDs). During the 15 years I have been working for and with PARE, the advocacy work has become increasingly effective – to the point where European institutions, such as the Commission, now explicitly recognise RMDs as a major disease alongside established priorities such as cancer.

“Nothing about us without us’ is not just a slogan. It is a fundamental right to self-determination. This is what makes us strong.”

Maarten de Wit, EULAR Vice President, representing PARE 2005–2009

“...Over the last decade, EULAR has shown a sincere interest in collaborative research. It has facilitated PARE to develop recommendations for patient participation in scientific projects and to establish a network of trained patient research partners (PRPs). PRPs are always involved in the developments of EULAR disease management recommendations. They take responsibility for making sure that important patient concerns are not neglected and are incorporated in the discussions. But PRPs are also involved in the review of lay summaries of recommendations and other scientific publications to make them understandable for patients.”

The reasons for this impact are manifold. Firstly, the vision of those people at the turn of the century who developed the PARE Manifesto, the first common ‘agenda for change’.

Secondly, the fantastic support of the EULAR Executive Committee and Secretariat when the former ‘Social Leagues’ became PARE and became truly integral to everything EULAR does. But, above all, the energy and commitment of the PARE members themselves, who just never give up!

‘Nothing about us without us’ is not just a slogan. It is a fundamental right to self-determination. This is what makes us strong.”
Changes in the EULAR PARE leadership – goodbyes and welcomes

After eight years in a leading EULAR position, Marios Kouloumas finishes his term of office as Vice President representing PARE in June. EULAR PARE would like to thank Marios for his tremendous achievements and outstanding commitment. At the same time, EULAR PARE warmly welcomes Nele Caeyers as the new Chairperson of the Standing Committee of PARE. Here they both share their personal thoughts, reflecting on the past while looking to the future.

“I will continue to participate in the collective effort to raise recognition of the impact of RMDs on individuals and society.”
Marios Kouloumas, EULAR Vice President representing PARE

“My first European involvement with PARE was in 2002 at a meeting of patient organisation representatives in Koenigswinter, Germany. This was crucial to my further involvement within EULAR as a patient representative. I was hugely excited and motivated by the opportunities given to us to co-operate at this level, as well as the openings for promotion of patients’ rights and the common cause of improving the quality of life for people with rheumatic and musculoskeletal diseases (RMDs). Despite being demanding and requiring a lot of personal time, my involvement in EULAR has given me great pleasure, working in co-operation for a common cause in an environment with a big family feeling. The response we have received, and the positive impact of our work on people with RMDs, has also been rewarding.

We have achieved much over the years but, for me, the fact that we managed to build a very strong network of co-operating patient organisations at the European level is very important. The EULAR PARE Annual Conference is now a high-quality conference providing education, inspiration and empowerment to patient representatives, as well as knowledge and skills to campaign at a national level for patients’ rights.

The training and participation of patients in research is a very important development as well, and the translation of the recommendations into lay language is improving patient access to healthcare. The creation of the working group of young people with RMDs is another important advancement – this way young people can acquire a voice and bring attention to the specific problems they face.

I will continue to volunteer and participate in the collective effort for recognition of the impact of RMDs on individuals and society, as well as for the need to implement policies for the effective care and management of RMDs.”

Marios Kouloumas, EULAR Vice President representing PARE

“Having been involved in EULAR PARE since 2005, I am now ready to face this new challenge of becoming the Chairperson of the EULAR Standing Committee of PARE. There are exciting years ahead!”
Nele Caeyers, ReumaNet, Belgium

“Being Chair will take a lot of my time. I am very grateful for all the support I get from within the PARE community, but also from my national organisations ReumaNet and the Belgian Society of Rheumatologists. And, of course, from my wonderful family – thank you Jorien, Tisse and Raf. I’m so proud of you!”

Nele Caeyers, Chair Elect Standing Committee of PARE

“Having been involved in EULAR PARE since 2005, I am now ready to face this new challenge of becoming the Chairperson of the EULAR Standing Committee of PARE. There are exciting years ahead!”
Nele Caeyers, ReumaNet, Belgium

“At the age of 22 my life was put on hold when I got the diagnosis of lupus nephritis and antiphospholipid syndrome (APS). It was 1997 and I had never heard of lupus before and did not know rheumatic and musculoskeletal diseases (RMDs) could strike at such young age. Twenty years later, I have learned a lot – not only about RMDs, but also about self-management, patient education, patient participation and about myself as a person. Saying I am ‘happy’ I got lupus is a bridge too far, but I can honestly say it has enriched my life. The EULAR community has given me many chances to grow as a person; it is now time to share my experiences.

My main focus will be on a new working mode for EULAR PARE. Tasks will be divided to guarantee maximum outcomes. We will attract more volunteers into the work of PARE and allow these people to grow gradually into the work of PARE. This way, we hope they will have time to get acquainted with the organisation and be inspired by the wonderful team we have in place today. The enthusiasm and willingness to always improve the work of PARE is great. We should all work together to achieve our goals and we need you for this as well! PARE would not exist without volunteers. I hope many will get infected with the PARE virus! There is no cure, but who cares?!”

Nele Caeyers, Chair Elect Standing Committee of PARE
Working with people with RMDs – Health Professionals in Rheumatology

At a time of leadership change for the EULAR Health Professionals in Rheumatology (HPRs), thoughts are set towards past and future accomplishments. The relationship between HPRs and people with rheumatic and musculoskeletal diseases (RMDs) is at the core of our conversations with HPR leaders, Christina Opava, Annette de Thurah and Tanja Stamm

Educational strategy for HPRs will benefit people with RMDs in the future
By Dr. Annette de Thurah, Chair of EULAR’s Standing Committee of Health Professionals in Rheumatology

“Let me introduce myself: I am a 57-year-old nurse from Denmark with a Master’s degree in Public Health and a PhD in Medicine. I have been working in rheumatology for more than 25 years and am an associate professor at Aarhus University in Denmark.

It is well known to people with RMDs that, in coming years, we will find a general lack of rheumatologists in Europe. This will call for extended roles for HPRs and for compatibility in health professional training within European countries. That is why HPRs within EULAR have taken steps towards developing an educational strategy for HPRs, recently ratified by the EULAR Executive Committee.

The next phase will be the establishment of a EULAR Task Force on HPR Educational Competencies – starting in 2017 under the leadership of Prof. Thea Vliet Vlieland from the Netherlands. We are looking forward to following through the work of this important task force, and are very hopeful that it will benefit people with RMDs in the future.”

Close collaboration between people with RMDs and HPRs is essential for delivering optimal interventions
By Prof. Tanja Stamm, EULAR Vice President-elect, representing HPRs

“Throughout my experience in international organisations and European projects, I have always appreciated the challenge of working with international colleagues from my own profession and other disciplines. From 2008 – 2012, I was Chair-elect, Chair and past Chair of EULAR’s Standing Committee of Health Professionals in Rheumatology. I was a member of the Scientific Committee of the Foundation for Research in Rheumatology (FOREUM) until 2016.

In my future work with EULAR, I would like to facilitate and encourage EULAR’s networking, and the support and education of students and young researchers across disciplines. Rheumatology should become one of the most attractive areas for health professionals to work in – in clinical practice as well as in research. We need more clinical and research projects with HPRs as principal investigators. Future research areas should look at accurate measurements of patient-reported outcomes, state-of-the-art technological innovations and digital assistive devices, as well as studies on the effects of health professionals’ interventions in large samples sizes.

We need to increase our co-operation with rheumatologists and, specifically, with people with RMDs. Clinical and research projects should be conducted together with the strong involvement of patient research partners. A close collaboration between patients and health professionals is essential for HPRs to deliver the optimal interventions in a well-fitted way. Furthermore, patient-centred research will demonstrate how health professionals can best benefit people with RMDs.”

Time to say goodbye
By Prof. Christina Opava, EULAR Vice President, representing HPRs

“There is much focus on the lack of rheumatologists. If I could make a wish, it would be for the PARE community to better recognise the expertise of health professionals in rheumatology (HPRs) and to actively support our continued efforts to improve the health of people with RMDs and their ability to carry out daily activities.

If, as patients from all countries, you keep asking for access to HPRs who have adequate training in evidence-based care, eventually it will happen. I would suggest that you encourage HPRs in your country to take the EULAR Online HPR course. It is accessible, affordable and contains evidence-based information that could be used to improve the non-pharmacological treatment of people with RMDs – and even reduce some of the workload rheumatologists currently carry.

As much as I will appreciate having more time for family and friends after retiring from my four-year position as EULAR Vice President, I will also be sad to lose regular contact with my ‘EULAR family’. I will miss my PARE friends and would like to thank you all – in particular my fellow Vice President Marios, PARE Chairs Diana, Dieter and Nele, and the PARE staff Birte, Florian and Maria. Our collaboration has been my sincere pleasure and I am proud of our joint achievements!”

Dr. Annette de Thurah  Prof. Tanja Stamm  Prof. Christina Opava
EULAR Congress 2017 – Bienvenidos a Madrid!

The capital of Spain hosts the EULAR 2017 Congress

After a very successful congress in 2013, Madrid welcomes the EULAR Annual European Congress of Rheumatology for a second time from 14–17 June 2017. The IFEMA – Feria de Madrid 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 Marios Kouloumas, 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.

Marios said: “With the input of the Standing Committee of PARE and the expertise of the EULAR Scientific Committee members, I am confident that we have managed, once more, to put together a stimulating and diverse programme which will also be attractive for health professionals to attend. We are very excited as, for the first time, we will run a workshop in Madrid which will address the management of volunteers. We hope this new concept will be attractive to our audience.”

EULAR Edgar Steine 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! 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.

The PARE Programme

<table>
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<tr>
<th>Day / Time</th>
<th>Session title</th>
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<tr>
<td>14 June 15.00 – 16.30</td>
<td>EULAR Campaign: Don’t Delay, Connect Today!</td>
<td>Joint Session</td>
<td>Room N115/N116</td>
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<td>14 June 17.00 – 18.30</td>
<td>Co-morbidities: having one RMD is enough – we don’t need anything else</td>
<td>PARE Session</td>
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<td>15 June 10.15 – 11.45</td>
<td>Bringing rheumatology research to the next level: addressing the main challenges of patient partnerships in research and healthcare service design</td>
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<tr>
<td>15 June 13.30 – 15.00</td>
<td>To be and to become: transition from paediatric to adult care</td>
<td>Joint Session</td>
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<tr>
<td>15 June 13.30 – 15.00</td>
<td>Barrier free employment for young people with RMDs</td>
<td>PARE Session</td>
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<tr>
<td>15 June 15.30 – 17.00</td>
<td>Difficult to reach patient groups</td>
<td>PARE Session</td>
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<tr>
<td>16 June 10.15 – 11.45</td>
<td>From abstract to concrete – the variety of activities of PARE organisations</td>
<td>PARE Abstract Session</td>
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<tr>
<td>16 June 13.30 – 15.00</td>
<td>Health equity and economy – a vital relationship</td>
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<td>16 June 15.30 – 17.00</td>
<td>Latest advances in the treatment and management of psoriatic arthritis and the latest news on the use of biosimilars in RMDs</td>
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<td>17 June 10.15 – 11.45</td>
<td>Workshop: Strengthening your organisation – how to manage volunteers</td>
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<td>17 June 12.00 – 13.30</td>
<td>Suffering in silence: optimising the management of psychological well-being for people with RMDs</td>
<td>Joint Session</td>
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<tr>
<td>17 June 13.45 – 14.45</td>
<td>Highlight session</td>
<td>PARE Session</td>
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People with RMDs: At the heart of EULAR Public Affairs work

Neil Betteridge, EULAR’s Liaison Officer, Public Affairs, reports on activities through 2016–2017

The year 2016 was a remarkable year for Europe – and globally – in terms of the public affairs agenda. EULAR’s external focus has adapted to address this. For example, 2016 saw the European Commission evaluate EU legislation in the field of health and occupational safety (OSH), leading to several new policy and legislative proposals.

For the rheumatic and musculoskeletal disease (RMD) community, EU and national OSH policies are of utmost importance, since improving working conditions is crucial to prevent RMDs in the workplace, as well as to help people with these diseases to remain at work. EULAR’s aim here has been to develop recommendations and to discuss how to improve working conditions for people with RMDs with policy makers and stakeholders.

So, in its role as Secretariat of the European Parliament MEP Interest Group on RMDs, for example, EULAR organised a meeting of the Group on this topic, as well as to discuss how to improve working conditions for people with RMDs with policymakers and stakeholders.

The aim of the meeting was to discuss the current situation of RMDs in the workplace, as well as to help people with these diseases to remain in work. EULAR’s aim here has been to develop recommendations and to discuss how to improve working conditions for people with RMDs with policy makers and stakeholders.

Ms. Metsola reminded the audience about the underlying reasons justifying increased action – RMDs represent the most prevalent (38%) and burdensome occupational diseases, and are the largest cause of lost working time in Europe. On behalf of EULAR, former PARE Board member Alison Kent called on policymakers to develop a comprehensive and co-ordinated approach to RMDs in the workplace.

“Need to promote a preventive culture and promote workplace adaptations”

2) World Arthritis Day Conference: “Reducing the burden of chronic diseases in the workplace – new policies for better working conditions and the retention of ill people at work” (12 October 2016)

The purpose of the Conference was to develop recommendations to EU and national policymakers, as well as to key stakeholders on three main areas:

a) prevention of RMDs in the workplace
b) access to occupational therapists and other health professionals
c) retention of people with RMDs in the workplace.

Over 140 participants attended the event, including high-level representatives of the European Commission, the European Parliament and WHO. In her opening message, Commissioner Thyssen stressed that the European Commission has a vital contribution to make in improving the lives of people with RMDs. Following on from the Interest Group meeting, the conference further demonstrated the need for better legislation and policies to improve working conditions to an audience of high-level policymakers and stakeholders.

3) Meeting with Member of Cabinet of Commissioner Marianne Thyssen

Following the Conference, a EULAR delegation met with Inge Bernaerts, Member of Cabinet of Commissioner Thyssen. The aim was to provide and discuss the recommendations developed during the Conference and explore possible collaborations between EULAR and the Commission in this policy area.

Ms. Bernaerts stressed the important contribution organisations like EULAR could make in the development and implementation of EU OSH policies.
Other relevant activities in 2016

Meeting with Commissioner for Health and Food Safety, Dr Vytenis Andriukaitis

The day after the Conference, a EULAR delegation met Commissioner Andriukaitis and members of his cabinet. The aim of the meeting was to discuss ongoing policy initiatives in the field of EU public health and explore the involvement and collaboration of the RMD community. Commissioner Andriukaitis encouraged EULAR to work closely with the Commission.

MEP Interest Group meeting: “Policy issues and challenges in the treatment and care of rare diseases” (December 2016)

As part of the focus on rare RMDs, particular attention was given to the establishment of European Reference Networks (ERN). MEPs and the European Commission presented at the event, as well as Prof. Marta Mosca on behalf of the RMD community. She presented ReCONNECT, an ERN proposal aiming to improve early diagnosis, patient management and care delivery within the network and with affiliated centres. The good news is that, during 2016, ReCONNECT was chosen as one of the ERNs to receive support from the European Commission.

Working for people with RMDs in 2017

EULAR Public Affairs priorities in 2017 focus on two main policy areas: more on the development of the occupational health and safety agenda; and research and innovation.

1) Occupational safety and health

Following the launch of the above-mentioned initiative from the European Commission aiming to improve the health and safety of workers in Europe, 2017 again sees EULAR advocating for EU and national policy initiatives to better prevent RMDs in the workplace and retain people with these conditions at work.

“Existing legislation needs to be updated”

In its communication “Safer and Healthier Work for All”, the European Commission concludes that the overall structure of the current occupational safety and health legislation is generally fit for purpose. Nevertheless, a number of areas were identified where existing legislation needs to be updated and it also identified variation in terms of implementation across Europe – an aspect EULAR members underlined during the 2016 World Arthritis Day conference. The European Commission also highlighted the need to help small and medium sized businesses to improve their workplaces to the benefit of people with RMDs.

“How to improve working conditions for people with RMDs?”

For EULAR and the RMD community, this marks an exciting opportunity to work with the European Commission, to ensure it takes strong and concerted action on RMDs in the workplace. EULAR will, therefore, closely cooperate with the Commission and EU-OSHA to ensure that any proposed actions have the right target and ensure that the views of people with RMDs are adequately reflected.

In addition, EULAR will support member organisations which are active on this issue to advocate at the national level, particularly with regard to the implementation of existing EU legislation, with the goal of ensuring full compliance of companies of all sizes with OSH legislation.

2) Research and innovation in RMDs

The aim of EULAR advocacy activities here is to promote further EU support towards research and innovation in the field of RMDs. Following the ongoing mid-term evaluation of Horizon 2020, EULAR also aims to contribute to the development of the next Research Framework Programme (2021-2027).

To this end, three main activities have been planned for this year.

i) In May, the Roadmap for Research in RMDs (RheumaMap) was launched in the European Parliament during the meeting of the Interest Group on RMDs. Prof. Iain McInnes, who led the group of experts in charge of the development of RheumaMap, presented the landmark document at the event. RheumaMap identifies a number of unmet needs and priorities in research and innovation in RMDs which have to be addressed in the coming years in order to reduce the enormous burden of these conditions.

ii) On 17 June, a session on Horizon 2020 will take place during the EULAR Congress in Madrid. The aim is to discuss the research needs of the RMD community and highlight ways in which the European Commission can support research and innovation in this area.

iii) On 17 October, EULAR will hold its annual WAD Conference. This year’s conference will focus on the future of health research and innovation after Horizon 2020. The aim of the conference is to develop recommendations for the new EU Research Framework Programme. Once more, the views of PARE organisations will be crucial to this event.

The views, wishes and needs of people with RMDs are at the heart of all EULAR’s Public Affairs activities, whether this be dialogue with the EU institutions or more broadly, such as with the WHO.

So, a big “thank you” to all PARE organisations for your invaluable input towards our collective efforts to make the world a better place for people with RMDs.
Starting this year, EULAR is launching *Don’t Delay, Connect Today!* – a campaign which aims to bring awareness and understanding of rheumatic and musculoskeletal diseases (RMDs) to society at large.

The window of opportunity

*Don’t Delay, Connect Today!* has its focus on the urgent need to develop the concept of what EULAR President Prof. Gerd R Burmester refers to as the “window of opportunity” – the important timings of early diagnosis and early referral of patients affected by RMDs to specialists. Some 120 million people in the EU are affected by an RMD, and there are possibly many more people living with an undetected or inadequately treated RMD.

“120 million people in the EU are affected by an RMD”

Further challenges lie in the severe lack of specialists in rheumatology, and in general rheumatology teaching at the general practitioner level. In Portugal alone, there are only 107 rheumatologists to serve a population of over 10 million people who are geographically dispersed throughout the country’s mainland and its island municipalities. A similar situation can be found in many other EU countries such as Ireland and Germany.

Political action in Portugal

Speaking at a roundtable event held at the Portuguese Parliament in Lisbon on 23 February, Prof. Burmester told members of Parliament and national media that “there is strong evidence that patients treated within the window of opportunity stand a better chance of achieving remission, or a low disease activity state”.

Introducing the campaign concept to the audience, he went on to explain that preventing damage to joints and organs through early intervention is key – and leads to a significant improvement in patient quality of life. Mortality rates are also shown to be significantly lower for those diagnosed and treated within this first, key period.

**Ready, steady, go!**

EULAR member organisations from the three pillars in Spain – the Spanish Society for Rheumatology (SER), the Spanish organisation for health professionals in rheumatology, Openreuma, and the Spanish patient organisation, LIRE – have joined forces to officially launch *Don’t Delay, Connect Today!* through events held in June in Madrid.

The EULAR 2017 Congress and a dedicated publicity stunt at the capital’s main station, Atocha, will kick off the campaign and emphasise the importance of making connections with everyone working in RMDs – from patient groups to physician and health professional associations. Connecting together, and communicating one united message at a European and local level, will provide a strong platform to press for change.

The campaign has been designed to run over the long-term, stretching into 2018 and beyond – with World Arthritis Day in October scheduled to push the campaign pan-Europe.

**Taking it local – with a toolkit**

In order to reach national-level audiences, events, such as the political roundtable in Portugal, are being held to raise awareness. Further events are supported using a toolkit designed by EULAR. This provides members and national associations with a set of recommended guidelines and tools required to roll-out the campaign nationally and according to local language requirements.

For the Portuguese roundtable event, President of the Portuguese League Against Rheumatic Diseases, Dr. Elsa Mateus, told the Parliament: “RMDs are the costliest of all disease categories, representing an enormous burden on the healthcare and social security systems of all EU Member States. This campaign is crucial as early diagnosis will help to save costs at all levels. When appropriate treatment is started early, medical costs, disability and work limitations can be reduced.”

**“Early diagnosis will help to save costs at all levels”**

The first workshop to launch the toolkit and inform national organisations about this important campaign took place in February at the 2017 EULAR PARE Annual Conference in Lisbon, Portugal. Webinars to inspire national action will follow from June to October.

*Don’t Delay, Connect Today!* www.eular.org
Edgar Stene Prize shines light on benefits of early diagnosis

The topic of this year’s Edgar Stene Prize competition “Early diagnosis and access to care in rheumatic and musculoskeletal diseases – the ideal world and the reality” relates to the EULAR-initiated campaign Don’t Delay, Connect Today! The campaign is designed to stress how early diagnosis, and access to treatment and care of rheumatic and musculoskeletal diseases (RMDs) can prevent damage and reduce the burden on the individual and society.

“I was delighted to lead the 2017 Edgar Stene Prize Jury this year,” said Polina Pchelnikova, PARE Board member and member of N.A.D.E.G.D.A. – the Russian Federation’s EULAR PARE member organisation. “The Stene Prize is important because it helps drive public attention to the crucial issues that people with RMDs face. It also allows people with RMDs to feel that they are not alone – that many other people around the world deal with similar problems. The personal stories show the dramatic consequences of a delayed diagnosis and the impact on the individual.”

“The stories show the consequences of a delayed diagnosis”

The contest was a success with a total of 17 contributions. This year’s winner is 28-year-old Stefanie Hulst from The Netherlands. Stefanie, who has fibromyalgia, will be presenting her essay “Diagnosis from the perspective of a child” at the EULAR Congress in Madrid during the PARE Abstract Session on Friday 16 June, 10.15–11.45 in Room N115/N116. Please come along!

Second place was awarded to Nanna Hanquist Johnson from Denmark and third place went to Eszter Rozán from Hungary.

A 2017 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) after the congress.

The 2017 EULAR PARE Annual Conference was hosted by LPCDR, the Portuguese League Against Rheumatic Diseases. 120 delegates from 33 countries came together and enjoyed the great hospitality of the Portuguese team. It was a particular honour to welcome Mr. Manuel Delgado, Secretary of State of Health, who gave the welcome speech on behalf of the Portuguese Ministry of Health.

“The presentations, workshops and discussions highlighted that there is still much to be done to improve the early diagnosis of rheumatic and musculoskeletal diseases (RMDs), as well as access to specialists and the appropriate treatments. With EULAR’s support, LPCDR had the chance to raise this important topic at a very successful political round table discussion with key high-level stakeholders in the Portuguese Parliament prior to the conference.”

“We have learned so much”

Elsa Mateus, President of LPCDR, stated: “Hosting the PARE Conference was a great experience and we have learned so much. We are very satisfied as we feel that our objectives have been achieved. We provided rheumatologists and health professionals with an insight into what patient organisations can do and how we can support each other. We raised awareness of the importance of early referral to rheumatology specialists and we empowered our 20 delegates who otherwise would not have had the chance to participate in this kind of educational event. We would like to thank EULAR, in particular EULAR President Prof. Gerd R. Burmester, and all those who supported us on-site and who were involved in making this conference happen in Portugal.”

2017 marks a special year for EULAR – not only is the organisation celebrating its 70th anniversary, but it is also the 20th anniversary of the PARE Conference. This was marked throughout the event with a poster, speeches and a dedicated video workshop which will result in a film to highlight the benefits of this educational event for supporting the development of activities at national level.
At the beginning of 2017, EULAR Young PARE worked hard to plan for the next two years. Our aim is to expand on our strategic objectives (see www.youngpare.org/wp-content/uploads/2015/05/PAR021Youth-strategy.pdf), while focusing on two key objectives prioritised by young people with rheumatic and musculoskeletal diseases (RMDs).

In line with EULAR’s efforts to raise awareness amongst employers and other stakeholders, in 2017 EULAR Young PARE is highlighting the education and employment needs of young people with RMDs. How we do this will be influenced by EULAR’s campaign Don’t Delay, Connect Today! In 2018, supporting high quality, inclusive education for young people with RMDs will be one core focus. We anticipate that the PARE classroom in the EULAR School of Rheumatology will support us in achieving this.

Virtual Knowledge Centre
Moreover, we will continue working on all EULAR Young PARE’s strategic objectives. By doing so, EULAR Young PARE will continue to promote better care and support for young people with RMDs, with the aim of ensuring that each EULAR PARE organisation has a youth liaison person, a youth group or community, and at least 80% of organisations should have at least one specific service aimed at young people with RMDs.

One of the challenges over the past year has been to increase the use of our Virtual Knowledge Centre. We would like it to become the place to go to when looking for information on – and inspiration for – European youth groups and organisations. To make it more popular, we need to promote it within our network and start using it on a more regular basis. Only together are we stronger!

If you are interested in knowing more about Young PARE, please visit www.youngpare.org or the EULAR webpage www.eular.org/pare_young_pare.cfm. We look forward to hearing from you!

Our future plans are focused on helping and supporting the development of new ankylosing spondylitis (AS) organisations in countries where they don’t exist. We also plan to encourage the development of research programmes to discover the causes, and improve methods, of treating, diagnosing, curing and preventing AS. Additionally, we aim to bring together representatives of patient organisations, government and statutory authorities, and individuals for exhibitions, meetings, lectures, classes, seminars and training courses.

Growing together through co-operation
By Zhivko Yankov, President of the Ankylosing Spondylitis International Federation (ASIF)

As a global organisation, ASIF is happy to announce that we accepted Antardhwani, the spondylitis association of India, as a member during our last Council Meeting in Moscow in October 2016. We now have 38 spondylitis society members from 36 countries.

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“The EULAR PARE Annual Conference is a must-attend event”

Our ties with partners like EULAR PARE are very important in achieving an exchange of information and experience. The EULAR PARE Annual Conference is a must-attend event for everybody involved in promoting awareness of rheumatic and musculoskeletal diseases (RMDs), their social burden and the emotional life-changing impact on people with RMDs. Despite all the efforts of so many advocates and experts, the general public and policy makers still know little about the economic impact of AS and other RMDs. There is much to do in the future – one of the key tools in spreading public awareness is successful co-operation between EULAR PARE and ASIF. We are interested in spreading the message of World Arthritis Day, a great initiative promoted by EULAR and a good example of unity in upholding the rights of people with RMDs. It puts social considerations associated with RMDs on the map and encourages discussion at national and international levels.

ASIF is very focused on being an essential partner for those who promote awareness of RMDs.
Swedish Rheumatism Association meets e-health challenge

By Tidiane Diao, Project Manager, International Relations, Swedish Rheumatism Association

As with many member-based non-governmental organisations, the Swedish Rheumatism Association (SRA) has experienced a steady decline in membership over past decades. Today, the younger generation gets involved in different ways – via social media, rallying around single-issue causes. The idea of joining a large, established organisation that works for a number of causes in a more formalised way is less appealing than before. Meanwhile, the nature of healthcare is rapidly changing, with a myriad of digital solutions challenging the traditional relationship between patient and care provider.

In an effort to remain relevant to new members – as well as educating our older members to take advantage of the opportunities presented by e-health solutions – we have formulated an e-health strategy that involves creating our own solutions, aimed at solving the specific challenges of people with rheumatic and musculoskeletal diseases (RMDs). So far, we have created two applications/services, helped create a third and are planning a fourth for 2018.

Hälsoportalen (The Health Portal)

Hälsoportalen was created by the Swedish Rheumatism Association as a member-only coaching service. We hired nurses to help patients create individual programmes centred on a number of health-related issues – such as exercise/physical activity, diet, weight loss, sleep, stress, and alcohol and nicotine consumption.

Nurses and people with RMDs communicated regularly on the phone or through emails over time. They could also log into our web application, where they could design their own health plans, set goals for themselves, log their daily activities and see the results of previously-logged activities in the form of graphs.

Hälsoportalen helped more than 500 people with RMDs to get a qualified coaching programme. In our evaluation surveys, 80% of participants claimed the programme had led to lasting lifestyle changes.

Reumatiker (Rheumatics)

Reumatiker is our first true app, created for Apple and Android devices. Reumatiker lets the user access his or her prescriptions, stored on the Swedish eHealth Agency databanks. The app also contains a market place for pharmacies, so that the user can order prescription drugs from their device, as well as keep track of their prescriptions or the prescriptions of family members (the app enables having yourself set-up as a proxy).

The app also includes links to other e-health services given by care providers, such as the national quality registry for rheumatic diseases and a service for viewing your test results. Naturally, the app also subscribes to a stream of news and information from our web page.

The new health portal

The above-mentioned projects have been exciting new ground for us and filled us with the confidence and experience needed for our most ambitious project yet – the new health portal. This time we plan to deliver a mix of coaching services and e-health services on a massive scale, within the framework of a true portal. The first version of this project should launch internally (members only) in the autumn of 2017, with a public release planned for next year.

We firmly believe such projects are the future for patient organisations. Digital platforms allow us to provide value for all members – regardless of where they live – and help connect thousands of people with services that improve their lives and help them to manage their conditions more effectively.
Boryana Boteva, Bulgarian organisation for people with rheumatic diseases (BOPRD)

“BOPRD has been a member of EULAR PARE since 2011. For us this means that we can learn from the best and more experienced organisations, share best practices and establish a lot of valuable contacts with others – people with rheumatic and musculoskeletal diseases (RMDs), doctors and health professionals (HPRs). Over the years, EULAR has grown and become more professional and a lot has been done to strengthen our network.”

Codrula Zabalan, Romanian League Against Rheumatism

“The most valuable lessons EULAR PARE has taught me are about people and the strength we gain when joining forces. What is best about EULAR? The recommendations and best practice, lay language articles, highly educational conferences and congresses, www.worldarthritisday.org, European World Arthritis Day campaigns, the Knowledge Transfer Programme, courses for Patient Research Partners, encouraging research in RMDs by funding the best proposals within FOREUM, PARE’s voice in the Brussels Parliament becoming stronger and stronger, Horizon 2020, MEP campaigns, Fit for Work Charter, Edgar Stene Prize, a common road map etc… And all the people who make these possible!”

Marija Kosanovic, The Association of Rheumatic Diseases Patients of the Republic of Serbia (ORS)

“EULAR jump started our development, shaped our thinking, provided focus, financially supported us to join networks and to understand how things are done across Europe. EULAR provided standards to strive towards, taught us how to develop programmes and how to communicate with our stakeholders. Thanks to EULAR, we are today a strong, confident, expanding organisation.”

Ursula Faubel, Deutsche Rheuma-Liga, Germany

“EULAR ensures the interests of people with different forms of rheumatic and musculoskeletal diseases are represented at European level. To campaign for better funding, for research or better access to treatment at the EU Commission and at the European Parliament is a very important task EULAR has undertaken. We very much value that EULAR provides a platform for exchange with other patient organisations and has adapted projects from other countries. We have provided our know-how to other organisations as well.”

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EULAR supports the BJD: www.boneandjointdecade.org

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