EULAR launches “School of Rheumatology”

EULAR President Gerd-Rüdiger Burmester highlights teaching and education as key areas of current and future focus

EULAR continues to make tremendous efforts in teaching and education. These range from the EULAR main event, our EULAR Annual European Congress of Rheumatology, to smaller meetings such as the postgraduate course, and to newer means of education such as the online courses. Therefore, we believe it is time to put all these efforts under one roof and to launch the “EULAR School of Rheumatology”.

Here, we want to create a “corporate identity” for all EULAR members who are interested in education and are willing to bring in new ideas. All in all, there will be seven classrooms: for physicians/scientists in various stages of education, the non-physician health professionals (HPs) and, of course, PARE members.

Within these classrooms we will have online courses, physical meetings and information booklets. There may be new material that has not been developed – because it hasn’t even been thought about yet! – but may soon change our approaches to education.

In February, we had an inaugural meeting of many teachers to build up our school. It has been amazing to see the efforts everyone puts into these areas, especially since this is all voluntary work. EULAR, with the integral help of PARE members, HPs and doctors, can be the world’s primary provider of education in rheumatology, and this will be provided mostly for free or for only small charge so that the less affluent and developing countries can also afford to participate.

I am delighted that the launch of the “School of Rheumatology” falls into the period of my final year in office as I feel it will be of utmost benefit to PARE organisations. So far PARE has not explicitly offered any online educational material, but a survey among the PARE community showed great interest in accessing such tools. We are working hard to be able to offer something attractive in the PARE classroom very soon. It will strengthen the role and participation of the PARE community even further – something that has always been the aim of our work.

Looking back to when I started, we have made considerable progress in improving the quality of our activities. We have changed the format of our main event, the EULAR Annual European Conference of PARE – with the main targets being delegate education and the exchange of experiences and best practices.

The creation of a strong network of 40 people with rheumatic and musculoskeletal diseases (RMDs) trained as patient research partners is an important achievement of the EULAR Standing Committee of PARE. This network provides us with the opportunity to actively participate in research initiatives within EULAR as well as other research projects, and to integrate the views of patients in major projects and initiatives. EULAR’s decision to translate all new recommendations into easy to understand lay language will help their dissemination and implementation.

We have given particular support to young people within PARE and their training. We hope that Young PARE constitutes the future leaders of the PARE community.

There is much more to list, but most important for me now is that we ensure the steady growth and adaptation of our activities to the needs of our time and our members. I look forward to working towards these goals with a strong team in my final year as Vice President.

EULAR’s “Time Is Joint – Joints over Time” campaign

In rheumatic and musculoskeletal diseases, it is essential to identify and treat diseases as early and intensely as possible. However, it will not suffice simply to alert the general public and future patients to early signs of their potential disease – we must also offer them early and continuous access to care. This new campaign has been informed by cardiologists (“Time Is Muscle” – myocardial infarction) and neurologists (“Time Is Brain” – stroke). More will soon be announced via www.eular.org
Dear members of the PARE community and friends of PARE,

At this year’s EULAR Annual European Congress of Rheumatology, PARE will focus on various topics including challenges faced by young people with rheumatic diseases, digital applications, new approaches to pain management, optimising treatment, precision medicine, rare diseases, patient organisations, self-management and non-medical treatment.

PARE’s sessions deal with information and education, and foster capacity building for the individual patient as well as patient organisations. The abstracts and posters at the congress illustrate the great work of our member organisations and enable the exchange of information about activities that happen on the pan-European level.

This newsletter outlines the numerous PARE projects and activities as well: the magnificent Stene Prize entries proved how you can take action to live life to the full in spite of a rheumatic disease, the Knowledge Transfer Programme inspires organisations and shows what is possible if we share and support each other, and the Engagement Programme strengthens the ties between our member organisations and EULAR.

And, of course, there is World Arthritis Day – a global web-based campaign to raise awareness for people with RMDs and their needs.

My special thanks go to Diana Skingle, whose term as Past-Chair ends and who will leave the board. Di has done an exceptional job, has inspired us all and contributed to PARE’s progress. We hope she will remain active in some of PARE’s projects.

Simone Lüscher, Deputy Congress Manager since 2014, will now take over from Ernst and PARE would like to warmly welcome her! When asked what she likes about her work for EULAR and her thoughts about the future of the congress, Simone said: “People and organisation are my passion! My entire career has been based on these two pillars, combined and enhanced with work abroad and various advanced trainings. Working for a non-profit organisation was a dream of mine which has come true. And of course what makes this job so exciting? Knowing that tomorrow will be unlike today! I believe that today’s congress structure is a big advantage for EULAR and its independence.

“Of course, after all these years, the congress has reached a format, thanks to Ernst, which is outstanding. My intention is to maintain this high standard, recognise necessary adjustments, make changes where needed and lead it into the future. I will miss Ernst’s enormous know-how and experience. We have had a good transition period which gives me confidence in accepting the challenges to come.”

Dear colleagues,

By Dieter Wiek

EULAR Congress management handover over within EULAR Secretariat

“When I joined EULAR in September 2002, coming from a 27-year-long career with IBM, the EULAR office consisted of Fred Wyss, the Executive Director, and Elly Wyss, his wife, as Accountant and Education Co-ordinator. I jumped into the middle of the preparations for the 2003 EULAR Annual European Congress of Rheumatology in Lisbon. Without any knowledge about the medical or the conference world, I tried to get everything aligned for a timely opening in Lisbon on 18 June. Nobody will ever forget the hottest EULAR Congress ever!” said Ernst Isler, when asked about his early memories and start of his career as EULAR Congress Manager.

Since then 14 years have passed and a EULAR Congress without Ernst is difficult to imagine for all involved. From 8,500 participants, the congress has developed to an event with now around 14,000 delegates from all around the world – with an all-time high in London 2011 with more than 16,000 participants.

Ernst added: “What I will miss most is what I enjoyed most during these 14 years: the collaboration, co-operation and friendship with literally hundreds of people from all over the world. Each and every single one is a personality and a character to remember, without whom everything we achieved would not have been possible. Thanks to all of them. I wish Simone all the best on this road. She knows it’s not an easy one. And she deserves the support from all around her.”

PARE would like to thank Ernst very warmly for his dedicated support of the PARE delegates over the years and for the many times he made the impossible possible!

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Time to say goodbye and a warm welcome!

Dieter Wiek, Chair of the EULAR Standing Committee of PARE

Ernst Isler, in action at the EULAR Congress

Ernst Isler and Simone Lüscher: Congress Manager handover has been a smooth transition

Simone Lüscher

Inside EULAR
Education has been a key focus of EULAR Health Professionals (HPs) over the past two years. With the wide variety of HPs practicing across the EULAR member countries, it is essential to have a strong educational framework to make sure that the patient experience consistently meets expectations and that HPs' care reflects the best possible practices in rheumatology. At the centre of these efforts has been Prof. Thea Vliet Vlieland, a physiotherapist from the Netherlands and Chair of the HP's educational sub-committee.

In October 2014, Thea started a project to make an inventory of HPs' needs regarding education in the management of rheumatic and musculoskeletal diseases (RMDs). In the first phase, 19 telephone interviews were conducted with country presidents or their representatives from 17 different countries. This work then set the scope for the second phase – an online survey which targeted all HPs within EULAR and attracted over 1,000 responses. The feedback has been instrumental in helping us to shape the strategy for HP education from 2016-2020.

Communication difficulties
Among the highlights, one commonly voiced concern was the difficulties many HP members have communicating only through the English language, something we know the PARE community can relate to. We also gained valuable insights into what other models for providing access to education might really work in future. We are planning a follow-up survey in which we hope to partner with PARE to get a feel for what patients think their HPs should know. Watch this space!

Working with patients
One practical manifestation of the educational offering for HPs in EULAR was launched in autumn 2015, with more than 100 HPs subscribing to take the new EULAR online course for HPs. This is a two-year course developed by Dr. Els van den Ende from the Netherlands, along with Thea and a willing group of volunteer writers and developers. The course ends with a formal examination and accreditation, which is an important step in introducing an element of standardisation among HPs within EULAR. We hope that, in years to come, EULAR accreditation will be an important part of any HP's personal profile and will be useful for patients when choosing which HPs they might prefer to visit.

Finally, I wanted to highlight the really smart work going on in conjunction with patients and other stakeholders. Nurse researcher Dr. Mwidmi Ndosi has shown the way forward with some outstanding research on patient-oriented education (see Ann Rheum Dis doi:10.1136/annrheumdis-2014-207171). Dr. Ndosi's approach is to find out what patients say they need to know, rather than the more traditional approach of HPs telling patients what they think they should know. The final step in the process has been for the formation of an HP study group for patient oriented education. HPs and patients working together is clearly an important path for the future and it is great to see an HP leading the way.

There are numerous other activities going on in the HP section of course and I hope to touch on some of these in future editions of Breakthrough. If any of the projects outlined here are of interest, please contact any one of the HP officers or the EULAR Secretariat who would be happy to point you in the right direction for further information.
EULAR Congress 2016 – London calling!

The global city hosts EULAR Congress 8-11 June 2016

After a successful congress in 2011, London welcomes the Annual European Congress of Rheumatology for a second time from 8-11 June 2016. The “capital of the world” is ready to receive more than 14,000 expected participants to this unique arena for the exchange of scientific and clinical information.

Marios Kouloumas, EULAR Vice President representing PARE, and his team have prepared a PARE programme which specifically focuses on the point of view of people with rheumatic and musculoskeletal diseases (RMDs). Marios said: “With the input of the Standing Committee of PARE and the expertise of the members of the EULAR Scientific Committee, 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.”

He further informed: “Our topics this year cover a wide range where we will feature rare diseases and, if enough is done in this area, introduce the hot topic of precision medicine and discuss its opportunities for patients, show successful examples of patient organisations in action, demonstrate how digital applications can benefit the patient, and also focus on providing the latest information around the treatment and management of fibromyalgia and systemic sclerosis.

With our support, Young PARE has organised a session in which they will feature their Virtual Knowledge Centre, hear the perspectives of health professionals by Thijs Swinnen, Dr. Anna Moltó from EMEUNET, the young rheumatologist network, as well as the first feedback from PARE delegates.

Dieter Wiek, Chair of the Standing Committee of PARE, added: “We are delighted that PARE has again received a substantial number of abstracts – here we can also clearly say that not only is the number of abstracts rising steadily but that the quality has improved considerably. We would like to thank all the submitters and the organisations very warmly. However, there is still room for improvement and we would like to encourage the PARE community to take advantage of the new ‘abstract writing support system’.”

Between October and December, experienced volunteers from PARE organisations now offer concrete advice to those who would like to submit an abstract to the EULAR Congress with regard to topics, structure and set up of an abstract, and language. Please do not hesitate to contact Birte Glüsing at the EULAR Secretariat for more information.

The PARE Booth will be waiting for your visit and is meant to be the central meeting point for PARE delegates to receive the latest information on PARE activities and to meet their colleagues to exchange the latest news. Come and visit us in the EULAR Village and get your own copy of the 2016 EULAR Stene Prize booklet, as well as many other recent publications from patient organisations all over Europe.

Just next to the PARE Booth, the PARE Posters will be displayed from Thursday to Saturday. After great success in the last two years, we will again offer two official PARE Poster Tours at lunchtime on Thursday and 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. Here you will be given an overview of the learning taken from the congress and its outcomes from the perspective of health professionals by Thijs Swinnen, Dr. Anna Moltó from EMEUNET, the young rheumatologist network, as well as the first feedback from PARE delegates.

The PARE Programme

<table>
<thead>
<tr>
<th>Day / time</th>
<th>Session title</th>
<th>Session type</th>
<th>Room Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 June 13.00 – 14.30</td>
<td>PARE Standing Committee Meeting – by invitation only</td>
<td>Joint Session</td>
<td>Room S16</td>
</tr>
<tr>
<td>8 June 15.00 – 16.30</td>
<td>Optimising treatment and patient care through precision medicine: A threat or an opportunity for patients and patient organisations?</td>
<td>Joint Session</td>
<td>Room S19</td>
</tr>
<tr>
<td>8 June 17.00 – 18.30</td>
<td>Patient organisations in action</td>
<td>PARE Session</td>
<td>Room S19</td>
</tr>
<tr>
<td>9 June 10.15 – 11.45</td>
<td>Designing solutions to support young people to address the challenges of living with a rheumatic or musculoskeletal disease</td>
<td>PARE Session</td>
<td>Room S19</td>
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<tr>
<td>9 June 10.30 – 15.00</td>
<td>Digital applications for the benefit of the patient</td>
<td>PARE Session</td>
<td>Room S19</td>
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<tr>
<td>9 June 15.30 – 17.00</td>
<td>What is done for people with rare diseases? Can we do more?</td>
<td>PARE Session</td>
<td>Room S19</td>
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<tr>
<td>10 June 10.15 – 11.45</td>
<td>From abstract to concrete – the variety of activities of PARE organisations</td>
<td>PARE Abstract Session</td>
<td>Room S19</td>
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<tr>
<td>10 June 13.30 – 15.00</td>
<td>It’s in your hands</td>
<td>PARE Session</td>
<td>Room S19</td>
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<tr>
<td>10 June 15.30 – 17.00</td>
<td>What’s new: Latest advances in treatment and management of Systemic Sclerosis and Fibromyalgia</td>
<td>PARE Session</td>
<td>Room S19</td>
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<tr>
<td>11 June 10.15 – 11.45</td>
<td>New approaches to understanding and managing chronic musculoskeletal pain</td>
<td>PARE Session</td>
<td>Room S19</td>
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<tr>
<td>11 June 12.00 – 13.30</td>
<td>There is more than drugs</td>
<td>Joint Session</td>
<td>Room S19</td>
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<tr>
<td>11 June 13.45 – 14.45</td>
<td>Highlight session</td>
<td>PARE Session</td>
<td>Room S19</td>
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PARE welcomes FOREUM – the new rheumatology foundation for research

Florian is passionate about the opportunities for patient involvement in the FOREUM-funded projects and supports PRPs when they participate in individual studies. Over the past two years, 11 studies have been funded in programmes for osteoarthritis, systemic lupus erythematosus and spondyloarthritis. Several PRPs have provided the user perspective in a meaningful way by reviewing 85 Letters of Intents and 28 full Grant Proposals.

FOREUM values the involvement of patients in the same way that EULAR does in recommending the inclusion of patient representatives in its governing bodies. Maarten de Wit is currently member of the FOREUM Executive Committee which is responsible for managing the foundation's operations. Marios Kouloumas is member of the Scientific Committee which is responsible for evaluating research applications and developing texts for new calls for research proposals. The Board of Trustees is led by Prof. Josef Smolen.

Marios Kouloumas expects that the involvement of PARE organisations in scientific initiatives will increase over the coming years. If you are interested to know more, please seek information on current calls for research proposals on www.foreum.org.

PARE promotes dissemination of EULAR recommendations

Since PARE initiated the development of a dissemination guide for patient organisations, the project has rapidly progressed. With the help of members of the EULAR Network of Patient Research Partners, the first lay summaries have been written and published on the EULAR website. Some national patient organisations have started translating the lay summaries into their own language and introduced new ways to distribute them among their members and other interested people.

Patient research partners

After the publication of its guide for the dissemination of EULAR recommendations to patients, PARE developed a procedure for the production of lay summaries. Patient research partners (PRP) play a vital role in this process. Using tips from the guide for writing text in a language that is understandable for lay people, PRPs review draft summaries written by a medical writer. These summaries are written in English and are expected to be translated into other languages by EULAR member organisations.

Translation into other languages

On its website, the Deutsche Rheuma-Liga (the German League against Rheumatism) has an international section where you find the lay versions of the EULAR recommendations translated into German. Together with other information material and recommendations, this gives patients the opportunity to increase their knowledge and competences regarding their disease.

Juergen Clausen, staff member of Deutsche Rheuma-Liga, supports patient participation in research and ensures that dissemination of research results to patients is taken seriously. “The most striking feature of the lay summaries is their condensed form highlighting only those results that are most relevant to patients,” says Juergen.

ReumaNet, the Flemish platform for patient organisations in rheumatology, has started translating the lay versions of the EULAR recommendations as well as the lay versions of the Annals of Rheumatic Diseases. Flemish Patient Research Partners are involved in the translation process. Claudine Goyens, PRP from ReumaNet, says: “It is great to get this high quality information about our conditions in an understandable language. It empowers us and gives us a lot of background information to take with us to consultations with specialists. I look forward to more recommendations!”

Co-ordinator Nele Caeyers adds: “It is quite a task to get a good translation, and a lot of people are involved in the process. But I am always happy when I can put the final version on the website, knowing that we help so many patients controlling their disease.”
Two prominent events guided EULAR’s Brussels activities in 2015, namely the annual EULAR Brussels Conference that takes places around World Arthritis Day and the re-establishment of the European Parliament Interest Group on Rheumatic and Musculoskeletal Diseases (RMDs). Both these events received considerable attention from policy-makers and other stakeholders, demonstrating the increased recognition of RMDs at EU level.

EULAR Conference 2015

Last year’s conference focused on the increasing interconnection of healthcare systems, which is a key trend in the provision and use of healthcare services in Europe.

Representatives of the European Commission, the EU Presidency, the European Parliament, and key stakeholder organisations agreed that the use of cross-border care is still very limited in the EU. Among other factors, lack of awareness and adequate information, as well as the extra costs to be covered by patients were mentioned as the most important barriers for patients looking for cross-border care. Based on the information provided by the EULAR member organisations of PARE, Dieter Wiek, Chair of the EULAR Standing Committee of PARE, confirmed that people with RMDs do not have enough information on cross-border legislation, procedures and treatment possibilities abroad.

The use of cross-border care is still very limited in the EU

Recommendations to EU, national and regional policy-makers developed during the conference focused on policy initiatives aiming to ensure that EU citizens are aware of – and have access to – adequate information on cross-border mechanisms and opportunities, while ensuring that cross-border treatments are unbureaucratic and straightforward for individuals. In addition, participants also called on policy-makers to further develop the use of eHealth technologies in cross-border care by addressing some of the main challenges for health professionals but also for patients. Additionally, issues such as the lack of core standards of education, the recognition of qualifications in other Member States, the lack of (harmonised) standards of care, and the potential impact of health professional’s mobility on patient safety were addressed.

Overall, the conference clearly showed the need to further develop the single market in the healthcare sector, remove existing obstacles to patients’ cross-border healthcare and to the mobility of health professionals. The barriers and corresponding recommendations, which were discussed at the conference, will form the basis for discussions with policy-makers in the time ahead.
Together with several MEPs and with EULAR as the secretariat, the Interest Group (IG) on RMDs was successfully relaunched in the European Parliament on 19 November 2015. During the previous legislative term (2009-2014), the IG on RMDs was instrumental in raising awareness about these conditions in the EU, as well as in promoting relevant policy initiatives for the RMDs community.

The IG already enjoys the support of several MEPs from across the EU and throughout the political spectrum, and continues to gather momentum. The group is expected to meet three times per year and will promote parliamentary actions in the EU that aim to improve the prevention and management of RMDs, as well as the social and economic inclusion of people with these conditions. Among other topics, it will discuss and promote actions in policy areas such as public health, health and safety at work, disability and medical research.

The initial meeting of the IG was led by the Chair Roberta Metsola (MEP from Malta) and Vice-Chair Takis Hadjigeorgiou (MEP from Cyprus). EULAR President-Elect Prof. Johannes Bijlsma presented the views of the RMD community, providing data on the burden of RMDs in Europe. He emphasised the increased recognition of RMDs as a public health priority and underlined the continued need for action. Sören Haar, Head of the EULAR Brussels Office, presented the activities, results and achievements of the IG between 2009 and 2014, and gave an overview of good practices and successful stories of similar groups which could inspire the work of the IG.

Ms. Metsola and Mr. Hadjigeorgiou voiced their strong support for policy improvement in the field of RMDs. Ms. Metsola also emphasised her results – and substance-driven – approach for the IG. This approach and the support of more than 15 MEPs who have already joined is a considerable accomplishment for the RMD community, and is expected to result in relevant political achievements.

**Upcoming events – EULAR Conference 2016**

This year the EULAR Brussels Conference will take place on World Arthritis Day itself – 12 October. The focus of the event will lie on health and safety at work, one of the health-related priorities of EU institutions where new policy developments are expected to be developed in the coming months.

"RMDs are the main work-related health problem"

RMDs are the main work-related health problem, accounting for more than 38% of all occupational diseases. Existing working conditions can not only cause the development or worsening of RMDs, but can also prevent people with these conditions from remaining at work, or returning to work after treatment.

Achieving adequate working conditions for people with RMDs has been a key priority for EULAR, with different activities taking place in the past years. In 2009 for instance, the EULAR Charter for Work was launched. Among other issues, the charter highlighted the role that policy-makers, employers, healthcare providers and other stakeholders can play in creating a legal framework for a working environment that is inclusive of people with RMDs.

"Achieving adequate working conditions for people with RMDs has been a key priority for EULAR"

Following the evaluation of existing EU legislation on health and safety at work, the European Commission is expected to adopt new measures in the coming months, which will certainly cover relevant aspects for people with RMDs. Furthermore, the European Parliament has recently acknowledged the work-related burden of RMDs, and has called on the Commission to implement a comprehensive legal instrument against RMDs in the workplace.

The EULAR Conference on World Arthritis Day 2016 aims to feed into the debates around the new EU legislation and policy initiatives on health and safety at work by bringing in the views and expectations of the RMDs community. With the support of EULAR member organisations and the collaboration of different stakeholders, the event is expected to develop recommendations to policy-makers to ensure that new policy developments in this area better help to prevent RMDs in the workplace, while promoting adequate working conditions for people with RMDs to stay at work or return to work.
This year, people with rheumatic and musculoskeletal diseases (RMDs) were invited to write about their personal experiences and their individual coping strategies to live life to the full despite being affected by an RMD. What are the top tips from people with RMDs to live as independently as possible, achieve important personal goals, and to take active control of their life?

Dieter Wiek, Chair of the Standing Committee of PARE and ex officio jury member said: “It was very meaningful to read the contributions to this year’s competition as they offer a wealth of wisdom and inspiration. They show what people with RMDs are able to achieve despite the many challenges they face, and that it is possible to live your dreams. I very much hope that these essays will be widely distributed, not only among patients but also their families, healthcare providers and politicians. These essays are wonderful testimonies that living life to the full can be a reality. Early diagnosis, and the appropriate management and treatment of the disease are of utmost importance. With the right support at the right time, society can enable people with RMDs to be independent and fully integrated.”

The winner of the 2016 Edgar Stene Prize competition is Simon Stones from the United Kingdom. His essay moved and inspired all five jury members – although it was a difficult choice to make as, this year, 20 entries competed for the prize. For the first time EULAR also awarded prizes to 2nd and 3rd places which went to Triin Pobbol from Estonia and Daniela Berga from Latvia.

Simon Stones will present his winning essay during the PARE Session “It’s in your hands” at the EULAR Congress in London on Friday 10 June between 13.30-15.00 in Room S19.

The 2016 Edgar Stene Prize 2016 goes to the United Kingdom

How I take action to live life to the full

Delegates discuss the hot topic of patient-centred care in Bulgaria
There is no message more powerful than your personal story

The World Arthritis Day team encourages you to get involved with the 2016 campaign

The Future In Your Hands World Arthritis Day (WAD) 2016 campaign asks people with rheumatic and musculoskeletal diseases (RMDs) to share their personal stories on how they have taken action to live their lives to the fullest.

The aim of the campaign is to inspire others living with RMDs to not give up, to live their dreams and to take action! The stories will also encourage others to improve the quality of life for people with RMDs by seizing every opportunity to take action.

We ask people to submit their stories in many different ways, including:

- through our website www.worldarthritisday.org
- via social media (YouTube, Twitter, Instagram and Facebook).

For more information please consult the website at http://worldarthritisday.org/get-involved#organisation.

Also, if you happen to be in London for the EULAR Annual Congress of Rheumatology, come and meet us at the PARE Booth in order to learn more about the WAD 2016 campaign.

Some of these stories will then be selected for inclusion in a montage video which will be launched on 12 October 2016. The stories will be selected by a jury panel which will review the submissions against the judging criteria.

The biggest news of 2016 is the launch of our Virtual Knowledge Center. This is an online toolbox exclusively for the Young PARE network of liaison persons, so that they can share best practices, knowledge and experiences. It is a lively environment and we welcome feedback and constructive suggestions from liaison persons on what more to include. This tool can be found on our website www.youngpare.org

EULAR Young PARE is taking huge steps forward as we work to improve the lives of young people with rheumatic and musculoskeletal diseases (RMDs) across Europe.

One of EULAR Young PARE’s strategic objectives is to be involved in all aspects of work in EULAR PARE. We have managed to recruit and embed youth members of EULAR Young PARE into each of the working groups and task forces. The youth members bring a different perspective into each of these working groups. They share their knowledge, innovative ideas and also learn from more experienced colleagues to help make a difference.

Another objective of EULAR Young PARE is to be more actively involved in planning and attending the EULAR Annual European Conference of PARE and EULAR Annual European Congress of Rheumatology. EULAR Young PARE successfully held two youth workshops at the 2016 PARE Conference in Sofia, Bulgaria and has a separate session planned at the 2016 EULAR Congress in London, UK. The team is honoured to have been included in the preparations for the conference and congress, and we hope that young people, patient organisations, and other attendees at the conference and congress find our input useful. We hope that the popularity of our sessions will increase over the coming years as a greater emphasis is placed on supporting young people with RMDs.

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EULAR Young PARE also has lots of plans for the coming months. We are organising a networking event for liaison persons in the winter of 2016. This will provide delegates with the opportunity to participate in a number of workshops. The event will be interactive, enabling individuals to actively participate in solving issues that occur at a national and international level.

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One of EULAR Young PARE’s strategic objectives is to be involved in all aspects of work in EULAR PARE. We have managed to recruit and embed youth members of EULAR Young PARE into each of the working groups and task forces. The youth members bring a different perspective into each of these working groups. They share their knowledge, innovative ideas and also learn from more experienced colleagues to help make a difference.

Another objective of EULAR Young PARE is to be more actively involved in planning and attending the EULAR Annual European Conference of PARE and EULAR Annual European Congress of Rheumatology. EULAR Young PARE successfully held two youth workshops at the 2016 PARE Conference in Sofia, Bulgaria and has a separate session planned at the 2016 EULAR Congress in London, UK. The team is honoured to have been included in the preparations for the conference and congress, and we hope that young people, patient organisations, and other attendees at the conference and congress find our input useful. We hope that the popularity of our sessions will increase over the coming years as a greater emphasis is placed on supporting young people with RMDs.

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EULAR Young PARE also has lots of plans for the coming months. We are organising a networking event for liaison persons in the winter of 2016. This will provide delegates with the opportunity to participate in a number of workshops. The event will be interactive, enabling individuals to actively participate in solving issues that occur at a national and international level.

The Future In Your Hands World Arthritis Day (WAD) 2016 campaign asks people with rheumatic and musculoskeletal diseases (RMDs) to share their personal stories on how they have taken action to live their lives to the fullest.

The aim of the campaign is to inspire others living with RMDs to not give up, to live their dreams and to take action! The stories will also encourage others to improve the quality of life for people with RMDs by seizing every opportunity to take action.

We ask people to submit their stories in many different ways, including:

- through our website www.worldarthritisday.org
- via social media (YouTube, Twitter, Instagram and Facebook).

For more information please consult the website at http://worldarthritisday.org/get-involved#organisation.

Also, if you happen to be in London for the EULAR Annual Congress of Rheumatology, come and meet us at the PARE Booth in order to learn more about the WAD 2016 campaign.

Some of these stories will then be selected for inclusion in a montage video which will be launched on 12 October 2016. The stories will be selected by a jury panel which will review the submissions against the judging criteria.

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News from European Patients’ Academy (EUPATI)

By Elsa Mateus, EUPATI Fellow and PARE Board Member

As a member of the EULAR Patient Research Partners network, in March 2014 I was given the opportunity to apply for the EUPATI Patient Experts in Medicines Research & Development training course. I was accepted to the first group of 50 participants. After having successfully completed the six end-of-module exams, I am now a EUPATI Fellow.

The European Patients’ Academy (EUPATI) is a pan-European Innovative Medicines Initiative project of 33 organisations. It is led by the European Patients’ Forum, with partners from patient organisations, universities and not-for-profit organisations, along with a number of European pharmaceutical companies.

Building competencies
EUPATI’s key aims are to develop and disseminate objective, credible, correct and up-to-date public knowledge about medicines research and development (R&D), to build competencies and expert capacity among patients and public, and to facilitate patient involvement in R&D to collaborate in academic research, industry research, authorities and ethics committees.

The training course is a mixture of independent e-learning coursework (150-175 hours) and face-to-face training events (eight days) over a 14-month period. It covers six areas: Discovery of Medicines and Planning of Medicine Development; Non-Clinical Testing and Pharmaceutical Development; Exploratory and Confirmatory Clinical Development; Clinical Trials; Regulatory Affairs, Medicinal Product Safety, Pharmacovigilance and Pharmaco-epidemiology; Health Technology Assessment (HTA) principles and practices. The course will train 100 patients experts by the end of 2016.

By the end of 2016, there will be 12 EUPATI National Platforms (ENP) in Germany, Belgium, France, Austria, Malta, Poland, Spain, Switzerland, UK, Luxembourg, Ireland and Italy. Looking beyond 2016, EUPATI is developing guidance on patient involvement in R&D with different stakeholder groups and established best practice procedures.

Toolbox
The EUPATI Toolbox on Medicines R&D is already available in seven languages – English, French, Spanish, Italian, German, Polish and Russian. It provides articles, factsheets, slides, infographics, webinars and videos on over 50 topics around the A to Z of medicines research and development, including how to involve patients in this process.

Take a look at http://www.eupati.eu! Discover! Adapt! Share!

NRAS “Rheum2Talk” workshops

By Clare Jacklin, NRAS Director of External Affairs

The National Rheumatoid Arthritis Society (NRAS) is the only UK charity focusing specifically on supporting people living with rheumatoid arthritis (RA), their families and their healthcare professionals. In 2011 NRAS conducted “Family Matters”, a survey of family members of those living with RA, and this was followed in 2012 by a survey of people with a diagnosis of RA on the impact of family members of those living with RA, and this was followed by another survey of people with a diagnosis of RA on the impact of family members of those living with RA, and this was followed.

Nurses are often the healthcare professionals who are approached by patients to discuss sensitive subjects. However, nurses do not receive formal training about how to manage these types of issues, and there is evidence that they would like to.

“Rheum2Talk” is a free, one-day interactive, educational workshop for allied healthcare professionals (AHPs) and nursing staff that aims to improve the ability of healthcare professionals to discuss intimate and personal issues with patients that are impacted by RA, but that patients or healthcare professionals may find difficult to discuss. In particular, it aims to improve the ability of HCPs to communicate empathetically with patients.

“Rheum2Talk” was developed by NRAS in collaboration with Sarah Collins, an experienced psychotherapeutic counsellor, and Rose Whiteley, a psychotherapist/sex counsellor (both who also have RA), consultant rheumatologist Dr. Rod Hughes and Kate Gadsby, a nurse consultant from Royal Derby Hospital. The workshop is structured as a mixture of presentations, role plays and discussions, and is interactive.

Topics covered in the workshop include:

• the impact of rheumatology drugs on libido, fertility, contraception and sexual function
• scenario role plays taking turns at being the patient and the HCP
• presentations and video clips about empathy and “wearing other’s shoes”
• understanding sexual anatomy, sexual problems arising from having RA
• suggested ways to open discussion on these issues.
How to change your organisation to become user led

By Elsa Mateus, President of LPCDR

January 2015 was a historic moment for the Portuguese League against Rheumatic Diseases (LPCDR) – for the first time in its 33-year existence, a patient became President of the Board. LPCDR’s governing bodies will consist of eight patient organisations, two rheumatologists and one health professional for the 2015-2018 term.

The knowledge and experience I have gained from EULAR PARE allowed me to present a plan of action for LPCDR, providing credibility for the user-led principle and facilitating the engagement of patients. Six of us had been variously involved with PARE activities. Like me, three of them had submitted essays to the national Edgar Stene Prize competition and two of them had attended the Annual European Conference of PARE. Participating in World Arthritis Day campaigns or in the Patient Research Partners training was also a common factor. Experiencing the empowerment that PARE provides has really made a difference to our active participation in our organisation.

Together we are stronger. If you feel confident enough to assume the responsibility, you may be surprised to find that other patients are willing to support you and join your team.

Make your change happen!

First meeting with representatives of RMD patient organisations: ANDAI, APOROS, MYOS, LPCDR and ANEA

Professionalising ReumaNet: the way forward

By Nele Caeyers, Communications Officer of ReumaNet

ReumaNet is celebrating its 10th anniversary this year! In these 10 years, the organisation has grown into a professional organisation with an enthusiastic bunch of volunteers and three staff members.

In Flanders, Belgium, there are a number of patient organisations active in the field of rheumatology. Each of them focuses on a rheumatic musculoskeletal disease, such as rheumatoid arthritis, ankylosing spondylitis or fibromyalgia. In 2006 these individual organisations decided to join forces, while keeping their own identity. ReumaNet would represent the voice of all people with a rheumatic condition in Flanders. The first steps were not easy, but gradually the impact of the group on rheumatology in Belgium grew.

In 2010, the Board decided to professionalise. An organisation working purely with volunteers can do well, but with so many dreams and ideas, a professional team would be welcome. ReumaNet started working with partners. Within our Partner Platform are different stakeholders: the scientific rheumatology association, pharmacists, physiotherapists and industry. We sit together every three months and discuss common goals and projects. In return, each partner pays a fixed amount so that ReumaNet can continue its work and pay the staff members.

The Partner Platform is mainly a brainstorm body and the Board of ReumaNet makes the final decisions. This way of working provides the organisation with a part of the necessary financial resources, but also makes sure the input of patients is heard. After five years working like this, all parties are still happy with this approach.

In 2015, ReumaNet took a next big step: we opened the doors of our first office.

The opening of Reuma Expertise Huis

With the support of the physiotherapists, we have a lively office where we have meetings, invite people, organise events and have a documentation centre.

It is our dream to have the rheumatologists, the health professionals and CLAIR, the French-speaking patients, in one Reuma Expertise Huis soon. Because, yes, patients can be experts, but only by putting ALL expertise together, can we move forward.

For more information visit [www.reumanet.be](http://www.reumanet.be) or email info@reumanet.be

Nele Caeyers, Ilse De Keyser and Anja Marchal are thankful to the full team – in particular all volunteers – for their great support
Towards personalised treatment

By Henriette Thorseng, the Danish Rheumatism Association

A national Danish rheumatological biobank was realised in spring 2015 after support from Gigltforeningen, the Danish Rheumatism Association. The biobank is a highly promising initiative which can, hopefully, ensure that more people with rheumatic and musculoskeletal diseases (RMDs) get the best treatment available.

Today, it can be difficult to find the right medicine for people with RMDs. Unfortunately it is not uncommon for people to try several medicines before the right treatment is found. Two patients with the same disease will not necessarily find the same effect from the same medicine. One medicine might not work for one individual, even if it works for others. Or it might cause severe side effects, but not for others.

The biobank

Samples of blood from people with RMDs – mainly people with rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis and other inflammatory rheumatic diseases – will be collected at routine blood tests with the patient’s acceptance.

Analysis of the biological material in the biobank will be linked to a national clinical database, DANBIO, with information about who experiences good effects of certain treatments, who needs to change medicine, side effects, lifestyle etc.

The researchers hope that, in just 5–10 years, the biobank will make it possible to identify genes or other biomarkers that can predict which is the best medicine on the market through a simple blood test.

This new approach is called personalised medicine and refers to treatments that can be tailored to each individual on the basis of identified sub-populations with the same disease that differ in their response to a specific treatment.

The role of the Danish Rheumatism Association

The great outlook for people with RMDs became clear to us after leading rheumatologists presented the biobank to us in 2012. (We supported the rheumatologists with a small amount of money to prepare a protocol which they presented for the Danish Health Authorities, together with supportive letters from us.)

By the end of 2013 we had managed to raise almost 0.5 million Euros, which would cover the establishment of the biobank. Our donation was conditional on the Danish Health Authorities taking responsibility for the future running of the biobank.

In 2014 we got the good news that the Danish Health Authorities had decided to run the biobank and, on 4 May 2015, the national Danish rheumatological biobank collected the first blood samples. So far more than 1,000 samples have already been collected and provide a basis for some newly-started research projects.

Blood samples are routinely collected from people with RMDs. Analysis of the biological material in the biobank will be linked to a national clinical database, DANBIO.