A New Year message from the President of EULAR

At the beginning of a new year it is always important to look for possibilities ahead, but also to the experience of recent past. ‘Don’t Delay, Connect Today’ started in 2017 and had many impressive manifestations during 2018. Just to mention a few: a cycling tour over the Hebridean Islands of Scotland, a motor tour in Cyprus, presentations in different parliaments, such as in Belgium and Romania. I attended a few and saw beautiful videos of others, and I was truly impressed. At local and national level we created awareness of the public and decision makers; but we also created important cooperation between different groups within the pillars of EULAR, and with people outside EULAR. This made me, in my role as President of EULAR, very proud. In this sense ‘Don’t Delay, Connect Today’ has been a great success in 2018; and we are eager to continue.

Of course we need to be a little critical of our own campaign. Are we indeed reaching the right people, are we able to make a real change? These questions are difficult to answer. For sure we gained a lot by our campaign. But to influence the world, our activities are only small droplets, with less influence than a tweet from Donald Trump. Should we therefore limit our efforts? Absolutely not, the (fake) news nowadays consists of items that are temporarily important, but forgotten a few months later. Our message is a strong message, that will stay for years and years to come. Being consistent, being repetitive with a clear message will bring changes in the long run. We must continue our "small scale" activities with even more vigour in the new year. We will not only enjoy it, but we will actually see people coming together, we will see people changing their mind, we will see new initiatives. I’m very confident that ‘Don’t Delay, Connect Today’ will continue to be a success. I’m looking forward to all the new initiatives, and I am happy to assist where relevant.

For all those actively involved, but also for all readers of e-Breakthrough and for all PARE members, I wish you a very happy and fruitful 2019: ‘Don’t Delay, Connect Today’.

Dear friends of PARE,

It is with great pleasure I wish you a very happy 2019, on behalf of Elsa Mateus, Dieter Wiek and myself! We hope this new year will bring you inspiring moments, active partnerships, fruitful projects but most of all good health. We can’t help you with the last one, but we look forward to continue working with you all in 2019 to improve the lives of all people with rheumatic and musculoskeletal diseases.

In this issue of e-Breakthrough you can read the latest news about the EULAR School. Also there is a report from PARE’s newest Working Group that is developing the PARE Classroom of the EULAR School. It explains what the School can offer us and how organisations can benefit from the online courses that will be available.

Young PARE will soon say goodbye to Petra Balážová, the first chair of the team. In an interview, she looks back on the hard work, but also the lovely time she had with Young PARE. Thanks for everything, Petra!

There’s more in this issue, of course, so I wish you happy reading! And let us know if PARE can make a difference in 2019!

Nele Caeyers, Chair, Standing Committee of PARE

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The EULAR School: Introducing a new era in rheumatology education!

EULAR has traditionally been a pre-eminent provider and facilitator of high-quality educational offerings for physicians, health professionals in rheumatology, and people with rheumatic and musculoskeletal diseases. Launched at the Annual European Congress of Rheumatology in Amsterdam in June 2018, the EULAR School now offers our learners an integrated Learning Management System (LMS) with easy login, access to their profile and all educational offerings at a glance. This includes **2 different levels of entry** to the educational offers:

- **Learner Access** - purchases course/educational material at regular price, full registration and access to the LMS platform
- **Full Member Access** - buys a yearly package with specific features and discounts.

In 2019, we are again offering the School App, updated and with improved functions, as a helpful tool for learning. Watch out also for some new entries in our Highlights section such as new courses and new EULAR textbooks. For more information about EULAR School membership please see the EULAR website.

For people with rheumatic and musculoskeletal diseases, there is a special PARE classroom of the EULAR School in development. See below a report of the first meeting of the Working Group that is preparing the detailed programme of courses. Meanwhile, PARE learning material is already available including the latest information about biosimilars, the EULAR PARE Knowledge Transfer programme, and guides on how to make a video and how to conduct media interviews. There is much more to come. Keep checking the website!

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The PARE Classroom by Elsa Mateus and Dieter Wiek

Members of PARE’s newly formed EULAR School Working Group (see right) had their first meeting in Amsterdam at the beginning of November 2018. After inviting PARE members to participate in the EULAR School project, we were delighted to have 10 people join us. We provided 2 webinars to introduce EULAR’s School and PARE’s role, and soon we formed 3 subgroups, for different topics. Their members had the opportunity to work together and present their first results to the whole working group in very lively discussions, which brought new insights.

Our overall aim is to develop courses for individual patients and members of patients’ organisations. All courses are written in lay language, offer basic, in-depth and visual material and final assessment questions, so that you really know what you have learnt; and you have a certificate.

What our subgroups are working on:

- **a course for rheumatoid arthritis (RA) patients** covering topics from diagnosis to self-management. People diagnosed with RA (and their carers) should be educated and empowered to become knowledgeable and live an active life with their disease

- **Patient Education Partners programme** where patients use their own medical history in role-play interviews as a part of the training of medical professionals

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- **Patient Research Partners (PRP)** A course for patients interested in becoming involved in research, leading to accreditation as a PRP after a final assessment. There will also be an option available to subscribe to particular modules only, depending on own interests and the need for specific training.

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Members of PARE’s EULAR School Working Group (left to right): Kristijonas Mazuras, Alain Cornet, Stacey Grealis, Michael Bernardy, Dr. Maarten de Wit, Souzi Makri, Dr. Alessia Alunno, Marija Kosanovic, Prof. Thea Vliet-Vlieland, Dr. Elsa Mateus, Katerina Tsekoura, Gabriela Kluge, Prof. Victoria Romero Pazos, Dieter Wiek, Birte Gluesing, and (not pictured) Dr. Elena Nikiphorou
Health innovation is crucial to reduce the burden of chronic diseases in Europe. This is particularly important for the most prevalent and burdensome conditions such as rheumatic and musculoskeletal diseases (RMDs). Furthering innovation in health research and health care in Europe will not only help to improve the diagnosis, prevention and management of chronic conditions but will also help to reduce the impact of chronic diseases on health and social security systems.

In the light of on-going debates on the next EU Research Framework Programme (Horizon Europe), as well as on different policy developments aiming to boost health care innovation, EULAR organised its 2018 Brussels World Arthritis Day conference on the topic of “Bringing chronic diseases to the forefront of health innovation: from the lab to individualised healthcare”. The event took place on 9 October 2018, with the participation of 150 delegates and more than 4,500 people viewing at least part of the conference online.

The aims of the event were to explore the main challenges in health research and healthcare innovation in Europe; and develop policy recommendations on these topics. Lieve Wierinck MEP and Pierre Meulien (Executive Director, Innovative Medicines Initiative) provided the views of EU institutions, whilst three keynote speakers presented on associated topics.

Based on recent studies from the Health Economics Research Group, Prof. Stephen Hanney (Brunel University) presented an analysis of the return on investment from research and innovation in RMDs and other chronic conditions. Prof. Tim Radstake (Utrecht University) presented the main challenges and trends in innovation in health research, and Barbara Kerstiëns (European Commission) presented on how the Commission’s work has fostered biomedical research in Europe.

Representatives of the RMD scientific community, patient organisations, private companies working on eHealth solutions and the European Commission provided a panel to discuss key issues such as patient involvement, the transformation of health care systems and the need for adequate funding.

How to promote innovation was discussed by representatives from the private sector, health care providers, the RMD community and the European Commission. The event also showcased relevant innovative solutions in research and health care in RMDs.

To develop policy recommendations, delegates engaged in workshops addressing the following issues:

- Can citizens have a leading role in health care innovation?
- Organisational and human challenges in the introduction of digital solutions in health care services
- Policy issues in the use of big data in health care and research
- How to foster innovation through Horizon Europe (Ninth EU Framework Programme - FP9)?

EULAR will now develop policy proposals based on the outputs of the conference. These will be used to inform EULAR’s public affairs and advocacy work throughout 2019 and beyond.

The videos, pictures, presentations and the conference report are available on the EULAR website.

Dates for your diary

- **20 January 2019**: Deadline for Stene Prize national essays to reach EULAR Secretariat
- **31 January 2019** 23.59 CET: Abstract submission and bursary applications for EULAR Congress 2019, Madrid
- **28 February**: Rare Disease Day
- **15 March**: Stene Prize winner announced
- **5 - 7 April**: PARE Conference, Prague
How did you become chair of EULAR Young PARE?

I applied to be part of the then PARE Youth task force back in 2014. PARE has actively tried to become more inclusive of young people with rheumatic and musculoskeletal diseases (RMDs), incorporating their perspectives into many different events and activities. They have been part of several working groups, extra bursaries have facilitated increasing numbers of young people at the PARE conference, dedicated youth sessions and workshops have been organised (including at the EULAR Congress), and opportunities created for meeting and exchanging knowledge and experiences. The Youth task force developed robust strategic action plans for its future work and, as a result, was accepted as a formal EULAR working group - Young PARE. I was elected its chair in 2015.

What is the most important message you will take with you?

We need to be consistent in our work if we want to achieve great things. It is a continuous process that needs to be developed and it is only possible with motivated and responsible people around us.

What message will you give to the next chair?

Being Young PARE chair is a position with great responsibility but you are surrounded by like-minded people and it makes the job so much easier. Every one is very supportive and it is an opportunity to grow — as a leader but also as a person.

My successor, Tanita Wilhelmer, the new chair-elect of Young PARE, has always worked hard to improve the lives of young people with RMDs. Her heart in the right place; she is very responsible; very attentive to others and amazingly creative. She is the right person for the job!

EULAR PARE Engagement programme: Visit to Turkey

As part of the EULAR PARE Engagement programme, Dieter Wiek, EULAR Vice President representing PARE, and I had the opportunity to visit Turkish patient organisation Romaturka in October 2018. Romaturka is a regional society supporting people with rheumatic and musculoskeletal diseases (RMDs) and their relatives. The aim of the visit was to get to know the organisation better, to present EULAR PARE work to their Board members and at the national patient day event ‘Artrit Günü’, and also to explore possibilities for them to be actively involved in PARE activities.

Romaturka was established in 2006 and today it has 60 members. The main activities of the organisation are carried out under the slogan ‘Action is valuable. Take action!’ Romaturka has participated in World Arthritis Day every year, and last year they had an awareness activity at the Ankara railway station, where they used EULAR’s ‘Don’t Delay, Connect Today’ campaign branding. The organisation is also involved in a number of other projects like public discussions in Ankara and nearby cities, adaptive design for people with RMDs and the provision of educational materials. Another ongoing project is ‘Nova Code’ where scientists and graphic artists put scientific information into everyday language and share the resulting illustrations on social media platforms.

During our two-day visit we saw that Romaturka is doing a great job. They have very competent members and their social media reach extends nationwide. However, although they are still a regional organisation, I do believe that there is great potential for them to grow into a nationwide organisation over the coming years.
2018 was certainly another fruitful year for EULAR, with several important sets of recommendations published.

The emergence of new treatments in the management of hand osteoarthritis (OA) in recent years has been appraised in new recommendations (updated from 2007) for this condition. The recommendations place emphasis on the individualized management of hand OA and the need for keeping the patient at the centre of therapeutic decisions. Both pharmacological and non-pharmacological treatments, including surgery are covered, with a focus on hand function optimization and quality of life improvement.

EULAR recommendations for the health professionals’ approach to pain management in inflammatory arthritis (IA) and OA were also published in 2018 and highlight that besides pain severity, physical and psychological functioning are major outcomes of any management intervention. Also, special emphasis is given to the pivotal role of the patient in therapeutic decisions.

Along similar lines, the 2018 recommendations for physical activity in people with IA and OA provide evidence for its effectiveness, feasibility and safety and advocate it as an integral part of standard care throughout the course of these clinical conditions (taking always into account general and disease-specific contraindications).

An update to the 2008 recommendations for Bechet’s disease has also been published, adding five overarching principles and one new recommendation. The term “syndrome” has replaced the word “disease” to reflect that Bechet’s is a constellation of symptoms. The management approach for the multi-organ system involvement seen with Bechet’s syndrome, is covered by the 9 recommendations produced. The newly added recommendation focuses on the surgical management of vascular complications.

Imaging techniques have a fundamental role in the diagnosis and follow-up of large vessel vasculitis, particularly of Takayasu arteritis (TAK) and Giant Cell Arteritis (GCA). In 2018, for the first time, 12 recommendations addressing this issue were produced. They focus on the role of ultrasound and magnetic resonance imaging (MRI) for diagnosis and management of GCA and TAK, respectively.

It is with great admiration that we observe the dedicated work of colleagues, supported by EULAR, to provide important sets of recommendations that focus on a multidisciplinary and patient-centred approach to care.

For further information, please see the EULAR website.

PARE’s position on biosimilars
by Dieter Wiek, EULAR Vice President representing PARE

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

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

Developments are in a constant flux: new biosimilars arrive on the market after patents expire; new research results are published; decision makers in healthcare systems exert pressure for cost savings. So we will have to review and update our position again and again in the future.

For more information please see the EULAR website.
É-Saúde: Interactive and personalized health services
by Prof. Victoria Romero Pazos, President of LIRE - Liga Reumatológica Española

É-Saúde is a digital platform that serves as a meeting point between citizens, health professionals and the Galician Public Healthcare System (Sergas). It provides interactive and personalized health services, via any device connected to the internet. Managed by Sergas, it offers the maximum level of confidentiality and safety. Patients had an active role in the development of the platform, so it is really user-friendly.

É-Saúde provides digital tools that help users manage information about their health: clinical history (from the moment the data is digitalized plus all new data as it is generated), medical reports, prescribed medication, etc. Users can set training goals to keep track of their health, and even share their achievements with other users or their doctors. They can also find reliable information about diseases, treatments, health advice, etc, from different sources. All information is reviewed by professionals of the Galician Public Healthcare Service and is accompanied by a warning that any recommendations contained in the documents are no substitute for professional medical advice.

Users of É-Saúde and health professionals can start or join communities of people with the same health issues. Patients' organisations can also be reached via the platform. Courses of the Health School for Citizens can be accessed so that people learn how to manage their health conditions more effectively; health appointments can be made; and information about healthcare centres and pharmacies is available.

Every user has a personal profile with two levels of security protection: (1) high security protocols like digital signature, or specific login details and password authorised by the Galician Government, and (2) basic security for universal access through a registered email and password. É-Saúde is therefore an important channel for support and secure communication between citizens and their health professionals, so that they can feel confident about their health services.

Would you like to read about your national organisation’s activities in one of the next issues? Please send your article (300 words max and photographs) to birte.gluesing@eular.org

The European League Against Rheumatism (EULAR) is the organisation which represents people with rheumatic and musculoskeletal diseases (RMDs), health professionals and scientific societies of rheumatology of all the European nations. EULAR endeavours to stimulate, promote, and support the research, prevention, treatment and rehabilitation of rheumatic diseases. Within EULAR, the national organisations of People with Arthritis/Rheumatism in Europe (PARE) work together and develop activities through the Standing Committee of PARE. For more information please visit www.eular.org

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EULAR supports the Global Alliance for Musculoskeletal Health http://bjdonline.org