

e - BREAKTHROUGH

News from the Standing Committee of People with Arthritis/Rheumatism in Europe

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Dates for your diary:

- **24-26 April:** 18th EULAR Annual European Conference of PARE, Dublin
- **2 May:** World Ankylosing Spondylitis Day
- **10 May:** World Lupus Day
- **12 May:** Fibromyalgia Awareness Day
- **20 May:** World Auto-Immune Arthritis Day
- **10-13 June:** EULAR Annual European Congress of Rheumatology, Rome
- **12 October:** World Arthritis Day

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

Seize every opportunity

by Diana Skingle,
Chairperson of the EULAR Standing Committee of PARE



Dear Colleagues

The PARE agenda for 2015 is packed with exciting activities and events. Firstly, on 24-26 April, there is the 18th Annual European Conference of PARE in Dublin, Ireland. Read about what is in store for delegates on page 3. Once again the workshop format will allow participants to share best practice and learn new skills. Seize every opportunity to enrich your teams and organisations.

In June, we have organised a packed PARE programme at the EULAR Annual European Congress of Rheumatology in Rome (see below). Your activities and projects will be showcased through oral abstracts and posters. We hope that the range of topics and high quality speakers will make the Congress once again a not-to-be-missed and inspirational experience for all PARE delegates.

On 12 October, World Arthritis Day (WAD)

brings a new campaign "It's in your hands, take action", designed to encourage a wide range of stakeholders to be involved in raising awareness of rheumatic and musculoskeletal diseases. The campaign will be launched at the EULAR Congress. Make sure that you check the WAD website www.worldarthritisday.org regularly so that you are ready to take part.

This is my last editorial for e-Breakthrough as the Chair of the Standing Committee of PARE; I am happy to hand over to Dieter Wiek from Germany in June. It has been an absolute privilege to take on this role on your behalf. Thank you so much for all your wonderful support. I will continue to work with PARE as Past Chair, supporting Dieter and the whole PARE team. I wish them every success. I also look forward to meeting many of you at PARE events in the coming months.



Rome 2015

The Eternal City prepares to host the EULAR Congress

Just a few weeks to go until 10-13 June when the attention of the whole world of rheumatology will focus on Rome. Scientists, health professionals and people with rheumatic and musculoskeletal diseases (RMDs), and their respective organisations, will gather for the EULAR Annual European Congress of Rheumatology to discuss the latest advances in the field of RMDs through lectures, workshops, abstracts, poster presentations and symposia. "The 2015 PARE programme at the Congress has many hot topics on its agenda - we will discuss how to measure the success of campaigns, and hear more about our key topic 'taking control and empowerment'. Our Stene Prize Award and the PARE Abstract Award will also feature in the Congress Opening Plenary Session" says Marios Kouloumas, Chair of the PARE programme organising task force. The team of the PARE Booth in the EULAR Village also looks forward to welcoming delegates from all over the world, and to sharing the latest information and material about the projects and work of the Standing Committee of PARE.





Introducing the Standing Committee on Musculoskeletal Imaging by Dr Esperanza Naredo*

Imaging plays an increasingly important role in the diagnosis, assessment and monitoring of patients with rheumatic and musculoskeletal diseases. In the last decades, great technological developments have made education in imaging not only a necessity but also a challenge for rheumatology education, practice and research.

The EULAR Standing Committee on Musculoskeletal Imaging (ESCMDI) was established by the EULAR Executive in 2007. This committee oversees all imaging techniques relevant to musculoskeletal diseases. It works in collaboration with the other Standing Committees and the Radiology community. The principal objective of ESCMDI is to improve patient care through the appropriate use of imaging by the promotion and dissemination of education and research on imaging. The committee is composed of delegates nominated by the national scientific societies from countries which are members of EULAR, a representative of EUMENET (EULAR working group of young clinicians and researchers in rheumatology), and several co-opted members with a particular interest and expertise in imaging.

Since its birth in 2007, ESCMDI has been the umbrella for many educational activities such as numerous international courses on the principal musculoskeletal imaging procedures. The committee has developed guidelines for the content and conduct of 'European educational activities on Imaging' to ensure their high quality. Furthermore, a number of recommendations on the appropriate use of imaging techniques in rheumatic diseases such as rheumatoid arthritis, spondyloarthritis, osteoarthritis and juvenile idiopathic arthritis have been successfully conducted and disseminated under the auspices of ESCMDI. Recently, the committee has begun the development of the EULAR Imaging web database, which will enhance the educational offer provided by EULAR. In addition, a new study group focusing on anatomy as a tool for improving imaging performance and capability has been brought under the ESCMDI umbrella.

*Esperanza Naredo, Rheumatology Department, Hospital GU Gregorio Marañón, Madrid, Spain and Chair of ESCMDI



IT'S IN YOUR HANDS TAKE ACTION



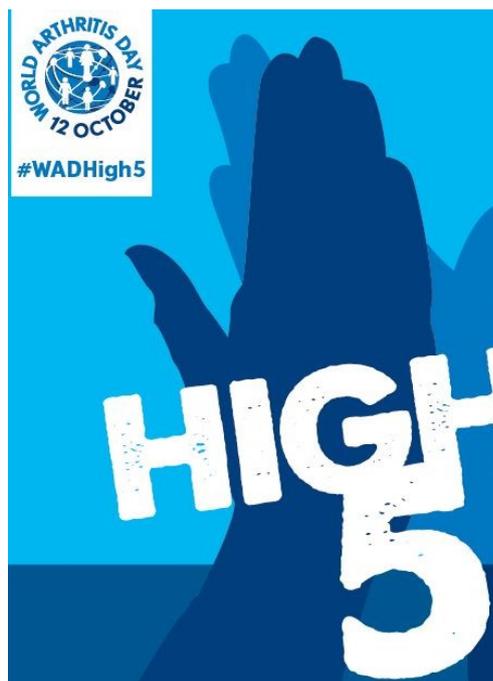
For World Arthritis Day this year, we are asking people to take action and share virtual High 5s on social media to raise awareness of rheumatic and musculoskeletal diseases (RMDs). The 'High 5 for World Arthritis Day' campaign will initially be launched at the EULAR Congress in June, with social media activity kicking off in July.

Our aim is to take social media by storm by owning High 5s across Twitter, Facebook, Instagram and all other channels with the hashtag **#WADHigh5**. Everyone can get involved in the #WADHigh5 campaign by High 5ing a friend to support them living with a RMD, a doctor for supporting you in managing your RMD, or even politicians to spur them to take action for people with RMDs.

We are launching a new website in June – make sure you take a look to find out more about World Arthritis Day: www.worldarthritisday.org

'High 5 for WAD' forms part of the wider 2015-2016 theme for World Arthritis Day: **'It's in your hands, take action'**. This simple but important statement has been developed to remind all stakeholders that we must seize every opportunity to take action and make a difference to the quality of life of people with RMDs.

We look forward to sharing another successful WAD with you...High 5!



Integrating the youth perspective into PARE

by Linda van Nieuwkoop and Petra Bednarova



Linda van Nieuwkoop (Netherlands)

After a successful meeting in Tallinn, Estonia, the PARE youth task force developed a youth strategy and wrote a plan of action for 2015 and 2016. The first step to enhance the integration of young people in PARE is the establishment of a permanent PARE youth working group. This working group will expand the Young PARE website by gathering best practices of national youth groups who organise appealing activities for their members. Young PARE will, in particular, promote the use of social media. Another challenge for the working group is the establishment of new youth groups in countries without activities for young people with rheumatic and musculoskeletal diseases (RMDs). Finally, the group will create opportunities for sharing knowledge and experiences between national youth leaders. To this end the new working group will organize the first Young PARE networking event, scheduled for August 2016.



Petra Bednarova (Slovakia)

Petra Bednarova (Slovakia) will be the first chair of the Young PARE working group and is full of ideas for the future. She hopes that the working group will bring young people with RMDs across Europe together. We hope to establish a working network that will contribute to a better quality of life for young people, and that their voice will be taken into account at national and European level.

Linda van Nieuwkoop (Netherlands) has energetically contributed to the strategy document as the chair of the PARE youth task force. She will stay active as a member of the working group, with a special interest in developing an online knowledge centre on the Young PARE website. She hopes to inspire countries, which do not yet have a youth group, to start one. She hopes that existing youth groups will exchange their knowledge and experience to learn from each other, and to improve services for young people with RMDs across Europe.

PARE Conference 2015 - Live streaming from Dublin

In just a few days more than 100 delegates from PARE organisations all over Europe will head to Dublin to attend the 18th EULAR Annual European Conference of PARE on 24 - 26 April in the beautiful Malahide seaside resort. 25 volunteers and staff members of Arthritis Ireland, the host organisation of this year's Conference, are getting ready to give a very warm welcome to their fellow European colleagues.



EULAR Annual European Conference of PARE
24-26 April 2015, Dublin, Ireland

The overall Conference topic will be 'Patient centred-care - taking control'. As in previous years, the PARE Conference will offer a variety of workshops from campaigning to e-health, plus plenty of time for networking and exchanging experiences. After successfully streaming part of the 2014 event in Zagreb, PARE has decided to go a step further for Dublin. There will be live streaming from the Conference covering most of the sessions, including

some of the workshops. Please see the itinerary below and be part of the event - you can find and access the stream via the following link:

http://www.eular.org/social_media.cfm

Friday 25 April am

***09.10 - 10.00 CET** Opening of the 2015 Conference by Prof Hans Bijlsma, EULAR Treasurer, John Church, CEO Arthritis Ireland and Dr. Leo Varadkar, Irish Minister for Health

10.00 - 10.30 CET Presentation by Claire Kinneavy, Arthritis Ireland

10.50 - 11.35 CET Patient centred-care: Presentation by Hans Bijlsma, and panel discussion

Friday 25 April pm

14.30 - 17.15 CET Workshops and feedback session, panel discussion

Saturday 26 April am

09.00 - 13.45 CET Workshops and feedback, panel discussion and closure of event

Don't forget, you can have your say too. Let us have your comments and feedback during the Conference using the hashtag **#pare2015**

***All times are Irish Standard Time (GMT+1)**

The International Charter of Principles for Sharing Bio-specimens and Data

A new Charter for sharing bio-specimens and data was published recently by an international group of researchers in the *European Journal of Human Genetics*. The document was shared with patient research partners participating in the BeTheCure project and may be of wider interest to PARE member organisations. A lay version by the Centre for Research Ethics & Bioethics (CRB) Uppsala is below:

‘The value of collections of data and bio-specimens is rising. But that doesn’t mean there is more sharing of samples or data. One reason is the different ethical and legal frameworks that are making it difficult for researchers in different countries to collaborate. Deborah Mascalonzi, philosopher at CRB at Uppsala University is one of the authors of the Charter. According to her, another reason has to do with the investment it takes to build a sample collection: “Sometimes researchers are not that keen on sharing. There is a fear that the valuable work they have put into their sample collection will not be recognised. To try to solve that problem, we have provided a framework for recognition in the Charter.” Sharing stimulates research, making the process less burdensome. At least in theory. But the ethical and legal frameworks in different countries sometimes contradict each other, making collaboration difficult. The Charter conforms with relevant regulation, both legal and ethical, and provides a comprehensive tool for researchers. It deals with consent, data quality, criteria for acknowledgement and much more. It also provides a very hands-on tool: data and material sharing agreements are often written in a legal language that can be difficult to understand for the scientists and administrators that use them. To help solve this, the Charter provides a clear and simplified template. The same principles can be used for other access agreements.

A wide variety of stakeholders with different interests were involved in drawing up the Charter, which builds on existing consensus documents and position statements. There was also a stakeholder workshop with rare disease patient representatives, lawyers, ethicists, industry representatives and scientists.’

International Charter of Principles for Sharing Bio-specimens and Data, *EJHG*; 2014, DOI [EJHG.2014.197](https://doi.org/10.1038/ejhg.2014.197).
For the full version of the Charter: <http://www.nature.com/ejhg/journal/vaop/ncurrent/full/ejhg2014197a>.

“It is important for patients who donate their data and bio-specimens to be aware of the ethical and legal frameworks that cover their use.” Marios Koulomas, EULAR Vice President representing PARE and a member of BeTheCure’s Patient Advisory Board

EU Data Protection Regulation by EULAR EU Office Brussels



EULAR is concerned about the possible outcomes of the ongoing negotiations between the main EU institutions about the new Data Protection Regulation. The proposed legislation will establish new conditions for the storage and use of personal data by third parties in commercial and non-commercial activities (including research). Should the European Parliament position prevail, medical research would be severely hindered in Europe, as it would impose very strict conditions for the use of patients’ data in scientific activities. Together with a number of scientific organisations, EULAR has signed a position statement calling on the EU to ensure the introduction of specific provisions for the use of personal data in scientific activities. In addition, EULAR is inviting its member organisations to join a campaign aiming to express their support for these specific provisions. As the negotiations between the three main EU institutions are expected to start soon, it is a good time to raise our voice and call on the European Commission and the EU Council to oppose the Parliament’s amendments.

We would very much like to ask you to support a social media campaign which was recently launched by several stakeholder organisations such as the Wellcome Trust, the European Patients’ Forum, Science Europe, and the European Public Health Alliance. The campaign aims to show policy makers that both scientists and patients are united in their concern about the possible negative consequences of the negotiations around the EU Data Protection Regulation. The voice of patients is crucial in this campaign.

You can get involved by writing one of the statements below on a piece of plain paper or card, hold it in front of you and take a photo, before posting it on social media with the hashtag #datamattersEU

“I want to share my data to benefit health research”

“I trust health researchers to use my data for society’s benefit”



Re-branding the Finnish Rheumatism Association

by Maria Ekroth, Managing Director



Since patients with rheumatic and musculoskeletal diseases (RMDs) are generally in better condition today, thanks to modern medical treatments, the nature of the operations of the Finnish Rheumatism Association has also changed. The association brand image had become dusty, and the commendable and valuable activities had outgrown the brand.

The focus of the organisation was therefore changed from being an umbrella organisation into 1) **a network** providing those who suffer from RMDs with important information, assistance and peer support; 2) **an expert source** of up-to-date and reliable information for those with RMDs, and for health care professionals; 3) **a major player** defending the position and everyday life of people suffering from RMDs, and promoting good medical treatment and rehabilitation. The goal of the overhaul is to inspire and encourage even wider age groups – from children to retirees – to participate in our activities.

The same services for everyone

It is often believed that the focus of the Finnish Rheumatism Association is on common rheumatic

diseases, but the association also offers activities aimed specifically at people with rare musculoskeletal diseases. Those with rare diseases are as much in need of information and peer support as those suffering from more common diseases. However, the provision of services to them requires a more aware and systematic approach.

The number of people taking part in activities concerning rare diseases arranged by the association amounts to about 2,100, and they represent a total of 40 diagnostic groups. For these, thematic web pages have been constructed and placed on the association's website. No more than one mouse click is required in order for the visitor to find: information about his or her disease; contact information for trained peer supporters; and information about other services such as rehabilitation and weekend meetings. The activities are developed in cooperation with representatives of different diagnostic groups, in particular with member organisations - the Finnish Scleroderma Association, Lupus Finland, and Suomen Vaskuliittiyhdistys (the Finnish Vasculitis Association).



News from the Spanish League Against Rheumatism

by Juan José Díaz, Secretary



This has been a good and a bad year for LIRE, the Spanish League Against Rheumatology. The economic crisis turbulence keeps shaking the house, and money has been very scarce. Yet, that might have been the exact drive that has boosted our creativity, leading over the past year to record projects. Some of the projects we are involved in deal with exercise, like "Tú También Puedes" ["You can too"], by which people with rheumatic and musculoskeletal diseases (RMDs), who have reached high levels in sport, go



LIRE receiving the prize for the map of resources

around Spain sharing their dreams and achievements. Together with doctors and patient associations they help to promote the benefits of exercise.

One of the projects we are very proud of is the RMD resources map (ReuMappa), a tool that was considered as critical in the National Strategy for RMDs, launched by the Ministry of Health in 2014. We received a prize from the Spanish Society of

Rheumatology to launch it. Together with dozens of volunteers, LIRE is developing an 'app' that helps to locate nearby resources for those with RMDs in Spain, ranging from how to contact professionals to places to practice therapeutic exercise. To be honest, the creation of the map has resulted in a lot of good days for the association!



Discussing items to include in the map of resources with people with different RMDs at LIRE (and having some fun).



Santos Yuste Zazo and Gonzalo Aldenueva showcasing LIRE

Introducing ENFA



The European Network of Fibromyalgia Associations by Souzi Makri, Vice-President



The European Network of Fibromyalgia Associations (ENFA) is a registered charity that is dedicated to raising awareness about fibromyalgia in the general public, people with fibromyalgia, the medical profession and decision makers.

Fibromyalgia is a chronic condition of widespread pain and profound fatigue. The pain tends to be felt as diffuse aching or burning, often from head to toe. It may be worse at some times than others, and change location on the body. The fatigue ranges from feeling tired, to the exhaustion of a flu-like illness. It may come and go, and people can suddenly feel drained of all energy – as if someone just ‘pulled the plug’.

Fibromyalgia often develops after some sort of trauma that seems to act as a trigger. Diagnosis depends on having pain in all four quadrants of the body for at least three months, and on the patient’s history.

Treatment varies widely within EU countries with no internationally recognised pathway and no approved drugs, leaving millions of people suffering with the symptoms.

ENFA was delighted when, after much lobbying,

Members of the European Parliament adopted the Written Declaration 69/2008 on Fibromyalgia calling for the European Union to recognise fibromyalgia in Europe as a disease. However, since then there has been little progress in implementing the points made and we need to ensure they are kept in the minds of the European policy makers by attending events and by further lobbying.

We are hopeful that our recent Pan European survey of people with fibromyalgia will provide evidence of the treatment differences and inadequacies that exist.

On 12 May 2015, Fibromyalgia Awareness Day, our members will focus on spreading the message that fibromyalgia is a real and debilitating (although not ‘visible’) disease and that it needs to be recognised as such. Campaigns will be organised in cities and towns across Europe with patients and doctors distributing informative material and answering questions from the general public. Some countries will also be organising interactive workshops with the objective of informing and empowering patients.

For more information please visit www.enfa-europe.eu

The European League Against Rheumatism (EULAR) is the organisation which represents people with 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



Follow EULAR and World Arthritis Day on Facebook and Twitter

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EULAR supports the BJD: www.boneandjointdecade.org