

eular

fighting rheumatic & musculoskeletal
diseases together

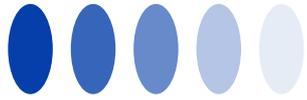


The therapeutic alliance of patients and physicians/health professionals in musculoskeletal rheumatic diseases within the European League Against Rheumatism (EULAR): Lessons learned and plans for the future

Marios Kouloumas

Former Vice President EULAR

9 Δεκεμβρίου 2018



An umbrella organisation encompassing 45 nations



Albania



Armenia



Austria



Belarus



Belgium



Bosnia &
Herzegovina



Bulgaria



Croatia



Cyprus



Czech Republic



Denmark



Estonia



Finland



France



Georgia



Germany



Greece



Hungary



Iceland



Ireland



Israel



Italy



Latvia



Lebanon



Lithuania



Macedonia FYR



Malta



Moldova



Montenegro



Netherlands



Norway



Poland



Portugal



Romania



Russian
Federation



San Marino



Serbia



Slovak Republic



Slovenia



Spain



Sweden



Switzerland



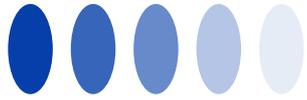
Turkey



Ukraine

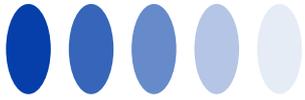


United Kingdom

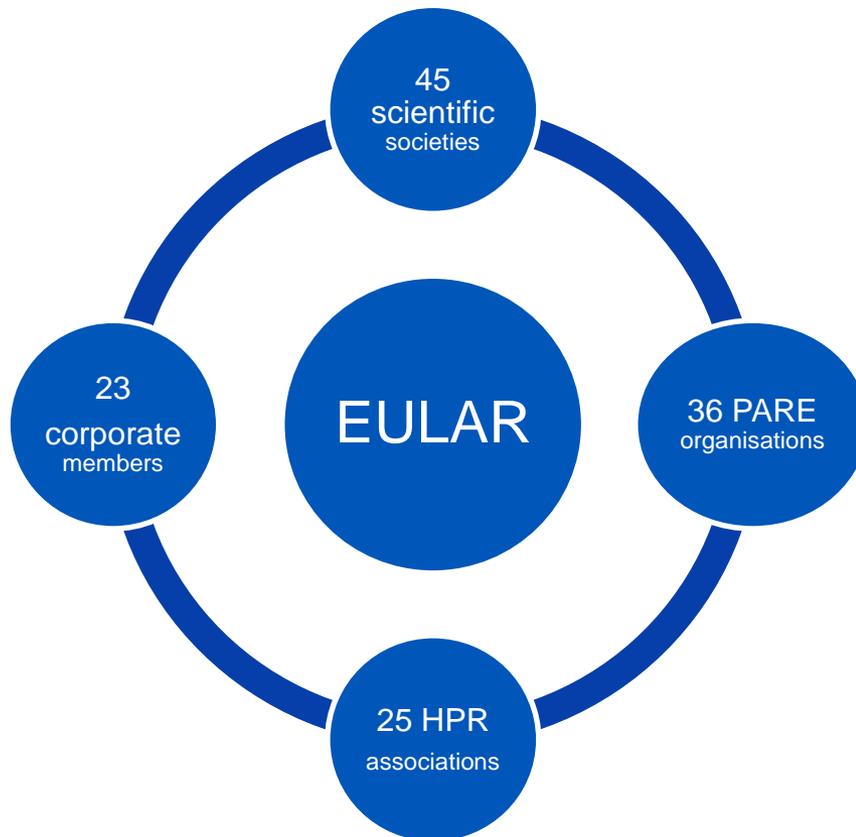


The three pillars of EULAR





EULAR institutional members 2016



**representing 120 million
people with rheumatic and
musculoskeletal diseases
(RMD) in Europe**

EULAR Standing Committees



Education and training

Clinical affairs

Investigative rheumatology

Epidemiology and
health services research

PARE (People with Arthritis and
Rheumatism)

Health professionals

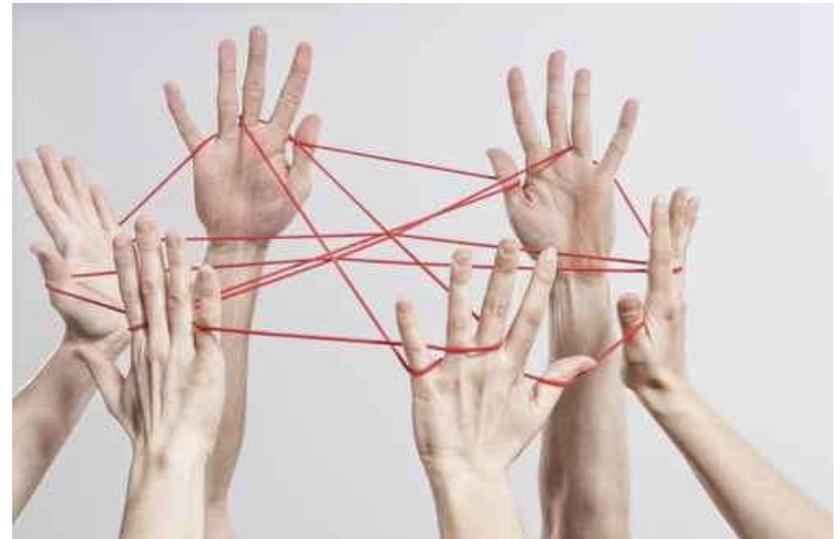
Paediatric rheumatology

Musculoskeletal imaging

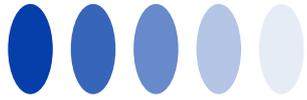


EULAR mission

- Reduce the burden of rheumatic diseases on the individual and society
- Improve the treatment, prevention and rehabilitation of musculoskeletal diseases
- Foster excellence in education and research in the field of rheumatology
- Promote translation of research advances into daily care
- Fight for the recognition of the needs of people with rheumatic diseases
- Represent the interests of the entire rheumatic disease community on the EU level

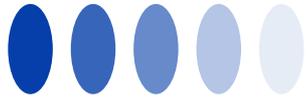


For more information visit
www.eular.org



Don't Delay, Connect Today

- The EULAR Campaign, **Don't Delay, Connect Today**, was **launched in 2017** and continues to enjoy an ever-increasing audience in Europe in 2018. Designed to raise and promote awareness of the symptoms connected to rheumatic and musculoskeletal diseases (RMDs) and the **importance of gaining early diagnosis and access to care**, the campaign embraces all three pillars of the European League Against Rheumatism (EULAR): People against rheumatism in Europe (PARE), health professionals and scientific societies.



World Arthritis Day 12 October

World Arthritis Day (WAD) is a global awareness-raising day. EULAR participates by promoting international activities for and on this day

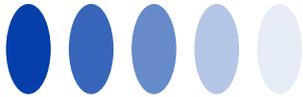


With your support and input, we can work together towards earlier diagnosis and access to treatment.

2019



Time 2work

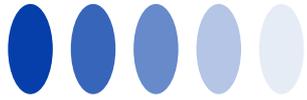


European League Against Rheumatism recommendations for the inclusion of patient representatives in scientific projects

M P T de Wit, S E Berlo, G J Aanerud, et al.

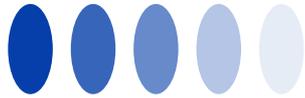
Ann Rheum Dis published online January 20, 2011
doi: 10.1136/ard.2010.135129

The aim is to guarantee that the perspective of people with rheumatic and musculoskeletal diseases is structurally facilitated and incorporated in every EULAR scientific initiative and every EULAR recommendation.



EULAR PARE Patient Research Partners





Patient Research Partners involved in scientific projects

EULAR

EULAR Recommendations

Health Professionals Projects

Review of lay summaries for Annals of Rheumatic diseases

EULAR Study Groups

Review of grant proposals:

- Patient reported Outcomes
- Pain
- Osteoarthritis

FOREUM Research Foundation

- Executive / Scientific Committee members
- Review of research applications
- Involvement in research projects

Secretariat

- Coordination of the PARE PRP network
- Implementation of recommendation for inclusion of PRPs in scientific initiatives
- Advice to researchers

National networks of patient research partners

EU RESEARCH PROGRAMS

Framework Program FP7

- AutoCure
- Eumusc.Net

Horizon 2020

- HarmonicSS
- GLORIA
- APPROACH

Innovative Medicine Initiative

- BTCure
- EUPATI
- EUROteam

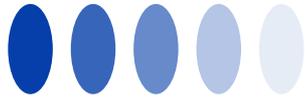
European Medicines Agency requests

Plus many involved in →



EULAR Management Recommendations

- EULAR considers it essential that recommendations reach all audiences – from rheumatologists, patients and patient organisations to healthcare professionals – in order to support all in understanding how to best manage an RMD. EULAR provides lay summaries of some of the recommendations, in English, and calls on all interested organisations to disseminate and translate them into their own language.



EULAR Management Recommendations

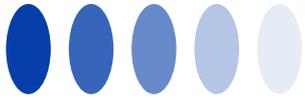
Lay versions available online:

- Patient education for people with inflammatory arthritis (Zangi et al. 2015)
- Management of medium to high-dose glucocorticoid therapy in RMDs (Duru et al 2013)
- Vaccination in adult patients with autoimmune inflammatory rheumatic diseases (van Assen et al 2010)
- Management of SLE (Bertsias et al. 2008)



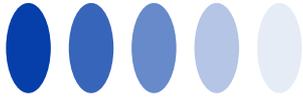
More lay versions are being produced

- **aim is to have all EULAR recommendations in lay language available**



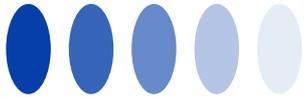
EULAR and the European Union

- EULAR has made considerable efforts to develop its European presence through a great variety of activities and actions at the EU level. The aim has been to make the voice of the RMD community heard in the EU arena. EULAR has collaborated with EU institutions and stakeholders in shaping EU policy initiatives, while advocating for concrete measures in areas such as public health, medical research, and employment and social affairs.
- EULAR has collaborated with the European Parliament in the elaboration of two Written Declarations on Rheumatic Diseases (2005 & 2008)



EULAR and the European Union

- Eular Brussels Conference 'Bringing chronic diseases to the forefront of health innovation: From the lab to individualised health care' (Brussels, 9 October 2018)
- Lobbying for inclusion of RMDs as major disease area in H2020 and new research framework programme (Eular Brussels Conference 12 October 2017)
- EULAR WAD Conference (12 October 2016) "Reducing the burden of chronic diseases in the workplace. New policies for better working conditions and the retention of ill people at work"
- Conference 'Belgian EU Presidency conference on rheumatic and musculoskeletal diseases' (Brussels, 19-20 October 2010)



EU Parliament Interest Group on RMDs

- The European Parliament Interest Group on Rheumatic and Musculoskeletal Diseases (RMDs) was created in 2009 and was re-established during the current parliamentary term (2014-2019)
- The Interest Group (IG) is currently comprised of 22 MEPs from different political groups and nationalities
- Last meeting 19 November 2018: Future of health and social policy in the EU: Post-election and post-Brexit challenges

New campaign for the EUP elections for 2019



EULAR RheumaMap

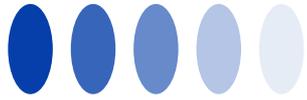
- “*Research Roadmap to transform the lives of people with Rheumatic and Musculoskeletal Diseases*”
- EULAR calls for increased support for research excellence in rheumatology
- Launch at the European Parliament in 2017 to highlight importance of RMD
- The RheumaMap, was researched and put together by EULAR drawing on the expertise of the European RMD community, from scientific societies to health professional and patient organisations.



International relations – working together

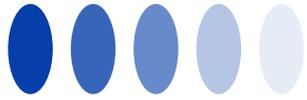
- WHO International and Regional Office for Europe
- Bone and Joint Decade
- European Federation of National Associations of Orthopedics and Traumatology (EFORT)
- Other major Leagues against Rheumatism (ACR, ILAR, APLAR, PANLAR)
- Co-opted organisations to Standing committee PARE: AGORA; ASIF; ENFA; FESCA; Lupus Europe
- European Patients Forum (EPF)





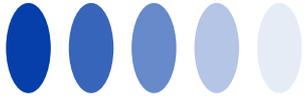
Lessons Learned

- Globally is a unique organization representing the whole RMDs community in Europe
- The profile and importance of rheumatic and musculoskeletal diseases have been greatly raised, being now recognized as one of the major chronic diseases.
- EULAR is now seen as an active, engaged and trustworthy European health organization



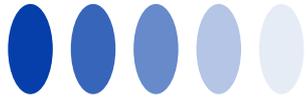
Lessons Learned

- Eular views are incorporated into the EU policy agenda and other initiatives (horizon 2020)
- Increasing the EU funding opportunities for public health oriented projects. Researchers, patients and health professionals are target groups for these support mechanisms.
- WHO recognize RMDs as major disease and call for actions



Plans for the future

- European Centre for RMD research
- Increasing participation in work by people with RMDs
- Enchasing the work of Eular
- Provide education in rheumatic and musculoskeletal diseases
- Deliver quality of care frameworks for the management of people with RMDs



let's continue to work together

- Involve in the campaign Don't Delay, Connect Today!
- Participate in World Arthritis Day!
- Find to us on Facebook
 - <https://www.facebook.com/EULARYoungPARE/>
 - <https://www.facebook.com/EMEUNET/>
- Talk to us on Twitter
 - @eular_org
 - @eular_press
 - @eularyoungpare
 - @emeunet