

EULAR PARE and Lupus Europe

Lupus Europe Convention

28 November 2020

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- Welcome and introduction to PARE team
- Introduction to EULAR PARE and our activities
- Enhancing collaboration between EULAR PARE and Lupus Europe
- Next steps



PARE Leadership:

Dieter Wiek, EULAR Vice President,
representing PARE

Elsa Mateus, Chair, EULAR Standing
Committee of PARE

Souzi Makri, Chair elect, EULAR Standing
Committee of PARE

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PARE Board:

Jeanette Andersen – Editorial Board

Boryana Boteva – Knowledge Transfer Programme

Katy Antonopoulou / Kristijonas Mazuras – CEO Exchange Platform

Polina Pchelnikova – Internal and external affairs

Marios Kouloumas – co-opted to PARE Board and current leader of the EULAR Campaign TF

Tanita Wilhelmer – Young PARE Chair



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EULAR Secretariat, PARE Department:

Birte Glüsing, PARE Manager

Alzbeta Göhmman, PARE Co-Ordinator

Diana Rodrigues, PARE Scientific Co-ordinator

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EULAR

- 3 EULAR pillars – scientific, HPR and PARE
- PARE stands for «People with Arthritis/Rheumatism in Europe» and represents the patient organisations / patient view within EULAR
- EULAR founded as scientific organisation but EULAR Statutes were changed in 1973 since then «Social Leagues» officially part of EULAR

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National organisations of people with arthritis/rheumatism

EULAR supports the development of user-led organisations on all levels, whereas its members support people with RMDs on a national level. The organisations differ across Europe in terms of size, structure and activities, but work with and for people with RMDs in that country.



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EULAR PARE Members

The vision of the EULAR Standing Committee of PARE is to empower people with rheumatic and musculoskeletal diseases in Europe to lead full and independent lives.



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PARE's primary aims

- Develop strong networks of effective, user-led organisations of people with RMDs;
- Ensure the voice of people with RMDs is heard and has influence among decision makers within Europe;
- Create powerful alliances that will make a difference to the lives of people with RMDs.



Standing Committee

The EULAR Standing Committee of PARE gathers representatives of rheumatic and musculoskeletal user groups around Europe to work together towards improving the quality of life for the more than 120 million people in Europe living with these conditions.



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Standing Committee

The national organisations of people with RMDs across Europe work together via the EULAR Standing Committee of PARE. Each member country is represented with one delegate in the committee.



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Standing Committee – co-opted members

PARE can co-opt representatives of external organisations to the Standing Committee – currently 6 organisations are having this special status:

- Agora
- FESCA
- ENFA
- ASIF
- **Lupus Europe**
- Sjogren Europe

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PARE
Community is
like a big
family



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Annual European Conference

The EULAR Annual European Conference of PARE is a EULAR-only network event and takes place once a year in or near a European city location. Each year, the conference is dedicated to a different topic, with keynote speakers, debates and workshops spanning the three days.



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Annual EULAR Congress

- PARE has its own programme – 12 sessions
- PARE has joined sessions together with the scientific representatives and HPRs
- Usually about 250 people with RMDs attend the Congress
- The PARE Standing Committee meets during the Congress
- PARE is part of the EULAR village and informs about its activities and its members



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Travel bursaries to the annual EULAR Congress

Every year EULAR awards a number of travel bursaries to the first/presenting author of an abstract that has been accepted for oral or poster presentation at the annual EULAR congress.



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Engagement Programme

EULAR aims to engage with and support national organisations by providing a EULAR representative or speaker at their events. This has assisted national organisations not only to become stronger at national level but also to become more effective contributors to the work of EULAR at European level.



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Knowledge transfer programme

Every year EULAR grants a set amount to its knowledge transfer programme. The programme is designed to support patient organisations that wish to further develop their skillset through applying lessons learned from other organisations in the EULAR network.

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fighting rheumatic & musculoskeletal
diseases together

edgar
stene
prize

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World Arthritis Day (WAD)

World Arthritis Day (WAD) is a global awareness-raising day. EULAR participates by promoting activities and material through the EULAR Campaign Don't Delay Connect Today and invites the RMD community to share these widely.



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PARE Newsletter



PARE E-Breakthrough



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Patient Research Partners (PRPs)

EULAR recognises the pivotal role of patients in the development of recommendations for the management or diagnosis of rheumatic and musculoskeletal diseases.



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Patient Research Partners (PRPs)

Patient representatives should engage with researchers to help improving methodology and research outcomes to give credibility to the results and to acknowledge the fact that for normative reasons patients should have a say in health care and health research when it is expected that decisions in these areas will have an impact on their daily life.



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PARE in EU projects

- New activity to respond to requests from the scientific community & to bring the patient perspective to scientific projects on RMDs
- Main tasks of EULAR/PARE as a full partner in European consortia and research projects: communication and dissemination of project results, patient perspective (PRPs)
- PARE involved in 5 applications in 2020



HarmonicSS

HarmonicSS is a private-public funded research project entitled HARMONIsation and integrative analysis of regional, national and international cohorts on Sjörögen's Syndrome towards improved stratification, treatment and health policy-making disease. PARE has an advisory role, monitoring and evaluating the project in terms of impact on patients, as well as a major role in the dissemination of results.



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EULAR Recommendations Lay versions

For EULAR, it is essential that lay versions of recommendations / Points to consider are disseminated and reach patient organisations as well as healthcare professionals to support patients and carers in managing their disease. We encourage the translations of these lay summaries.



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Young people with RMDs

Young PARE aims to improve the quality of life of young people (18 to 35 years old) with rheumatic and musculoskeletal diseases (RMDs) by raising the profile of these conditions, and by creating a network of individuals who work in European countries on behalf of young people with RMDs.



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EULAR COVID-19 Database

The EULAR COVID-19 Database is a European paediatric and adult database to monitor and report on outcomes of COVID-19 occurring in patients with RMDs. This helps guide rheumatologists and other clinicians such as specialist nurses in advising and caring for their patients.



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PARE COVID-19 Working Group

- Disseminate relevant and updated information on COVID-19 to PARE community
- Develop appropriate communication materials (e.g. webinars, videos, podcasts) on COVID-19
- Analyse and respond to requests for PARE participation in COVID-19 projects (e.g. research, surveys)



New! Volunteers Framework

- PARE volunteers need to be embedded into a framework ensuring a professional approach of EULAR to engage with them
- First steps: survey to catalogue the current volunteers, assessment of opportunities for volunteers in EULAR PARE and the development of an Orientation Manual and a Handbook



New! PARE By-Laws

- New EULAR Statutes require all committees to develop By-Laws
- PARE already has Terms of Engagement – review necessary and adaption to new rules where needed



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Standing Committee – co-opted members

Pre-condition:

- Active interest of organisation in the activities and work of EULAR PARE e.g. through support of WAD, participation in the PARE Conference, promotion of Edgar Stene Prize, reporting about EULAR PARE in relevant magazines, on website or social media



Collaboration with PARE

- Invitation to participate in Standing Committee Meeting of PARE
- Offer to participate in PARE Working Groups
- Invitation to EULAR PARE Congress Dinner
- Invitation to participate in PARE Conference
- Opportunity to publish in PARE e-Breakthrough



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Thank you for your attention!

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