

PARE Standing Operating Procedures (SOPs)

Former Terms of Engagement; Appendix V – co-option to the Standing Committee of PARE

Now: Supporting members to EULAR / Scientific Affiliates which represent people with RMDs – defining possible membership and relationship to the work of PARE and the PARE Committee

Context

With the new EULAR - European Alliance of Associations for Rheumatology - Statutes coming into force from 1.1.2021 the former co-option of representatives to the former Standing Committee of PARE was terminated.

A way for PARE organisations not in a position to apply as ordinary EULAR members and thus be connected to EULAR and to collaborate with EULAR PARE more closely, is referred to in the EULAR Statutes article 2.3.. These organisations can apply to become a Supporting Member of EULAR. According to the definition of Supporting Members PARE organisations can apply as Scientific Affiliates:

“A company or scientific organisations active in the field of rheumatology, that wishes to become a Supporting Member of EULAR has to send its application to the Board after recognition of rights and obligations of Supporting Member. The Board decides upon the admission as Supporting Member.”

Framework and eligibility for PARE organisations to apply for Supporting Membership

Applications to become a Supporting Member of EULAR can be sent by 3 categories of patient organisations:

1. European national umbrella organisations for RMD patients, which are not yet eligible / ready to apply for Ordinary Membership of EULAR (e.g. recently started or small organisations) from countries where there is no Ordinary PARE Member yet. The organisation will apply for joining EULAR as ordinary member as soon as it fulfills the official criteria.
2. National, International and European umbrella organisations for disease specific RMD patient organisations.
3. European regional organisations of RMD patients.

In the longer term, category 1 candidates may be expected to apply for ordinary membership when/if they meet the EULAR membership criteria.

Categories 2 and 3 may only apply for supporting membership of EULAR, not full membership of EULAR.

Term of Office for Supporting Members

EULAR Statutes 2.3.4: “The membership of the Supporting Members lasts for an indefinite period until the Supporting Member terminates its membership or until membership is otherwise terminated. The Supporting Member may terminate its membership with six months prior written notice to the Board, taking effect at the end of the calendar year.”

Supporting Members representing PARE

PARE would like to set up a framework and define the relationship to those Supporting Members / Scientific Affiliates which represent people with RMDs.

This PARE framework will be in addition to any other rules and regulations set by the EULAR bodies on how to collaborate and are in addition and not replacing or superseding any such arrangements.

Every Supporting Member / Scientific Affiliate representing people with RMDs can nominate a EULAR PARE Liaison Officer as a direct contact for the EULAR Office. Organisations are requested to inform the EULAR Office in case there is a change in the contact details as early as possible and proactively.

All Supporting Members / Scientific Affiliates which represent people with RMDs are invited to send two delegates to the annual PARE Assembly which is organized during the EULAR Congress or any extraordinary PARE Assembly meeting which might be arranged virtually. Travel or related costs to attend the PARE Assembly are not financed or reimbursed.

For the PARE Conference a dedicated number of bursaries for representatives of Supporting Members / Scientific Affiliates representing people with RMDs might be provided by the EULAR Board, for which they can apply. A process will be suggested by the PARE Committee to the EULAR Board. The budget will need to be included in the overall PARE Conference budget.

In line with the EULAR Statutes, the PARE By-Laws and PARE Committee Working Group Regulations, representatives of Supporting Members / Scientific Affiliates which represent people with RMDs can apply via the official PARE Vacancy call to join one of the PARE Working Groups or via the official EULAR call to join the PARE Committee.

If representatives of Supporting Members / Scientific Affiliates which represent people with RMDs are involved as volunteers in EULAR PARE activities, they are treated as any other volunteer.

All Supporting Members / Scientific Affiliates which represent people with RMDs will be offered the following additional opportunities:

- Information about the Stene Prize competition (participation can only follow the existing rules and procedures)
- Attendance at the EULAR PARE Conference (application through available bursaries and depending on final selection based on pre-defined criteria)
- Presentation of organisation activities through EULAR PARE Communications channels either via e-Breakthrough newsletter, podcasts or other means
- Participation in the EULAR PARE Knowledge Transfer Programme
- Support through the EULAR PARE Engagement Programme

Duties of Supporting Members / Scientific Affiliates which represent people with RMDs

All Supporting Members / Scientific Affiliates which represent people with RMDs are obliged to follow and support the EULAR Statutes, the PARE Committee By-Laws as well as the PARE Committee Working Group Regulations.

Volunteers representing Supporting Members / Scientific Affiliates which represent people with RMDs in EULAR PARE activities must comply with the EULAR PARE Volunteers Policy as well as the Statement of Expectations.

Addendum:

Questions and answers from the PARE Committee to clarify the interpretation of the new EULAR Statutes on Supporting Members / Scientific Affiliates:

- a. When at national level there is a national federation representing organisations of people with RMDs including disease specific national organisations and that federation is already an ordinary EULAR member e.g. ARMA in the UK – can the individual national organisations e.g. NRAS or NASS become supporting members of EULAR in addition?
 - i. Yes, the individual national organisations can become in addition Supporting Members.
- b. Are national RMD organisations from all over the world able to join e.g. from China?
 - i. Yes, if they promote EULAR`s aims, mission and value.
- c. Are international RMD organisations / networks able to join e.g. ASIF who have worldwide membership but are registered in Europe?
 - i. Yes, if they promote EULAR`s aims, mission and value.
- d. If an organisation fulfills all criteria to apply for ordinary membership but the position is already taken by another organisation, can they apply to become a Supporting Member?
 - i. PARE`s understanding: It depends: If more than one national organisation applies for membership, the national organisations in question must find an agreement amongst themselves. If the organisations cannot find an agreement within six months, the General Assembly decides which organisation becomes Ordinary Member. The other organization can apply to become Supporting Member.
- e. Can organisations which are devoted to patients but covering not only RMDs but different diseases e.g. autoimmunological inflammatory arthritis, Crohn`s disease and other inflammatory bowel diseases, diabetes type I, psoriasis etc. become a supporting member?
 - i. PARE`s understanding: If organisations are also actively engaged in projects to support people with RMDs and if they promote EULAR`s aims, mission and value – yes. If no connection – no.
- f. Can regional organisations representing either a disease specific RMD community or covering RMDs in general join e.g. like Agora (Southern European RMD network)?

- i. PARE`s understanding: Yes, if they promote EULAR`s aims, mission and value.
- g. Can disease specific organisations at national level join (e.g. Lupus organization in Poland)?
 - i. PARE`s understanding: Yes, if they promote EULAR`s aims, mission and value.
- h. Question from PARE: What is EULAR`s policy for membership in general?
 - i. Quantity does not count. Only active members and those who support EULAR`s aims, mission and values should be accepted. What if quantity of supporting members grows bigger than ordinary PARE members? EULAR Board controls the number and admission of supporting members. As they do not have any voting rights they cannot have any undue influence on EULAR`s principles and decisions.
- i. Although the Supporting Membership is for EULAR – Will the PARE Committee be informed if an application is received which comes from an organisation linked to people with RMDs?
 - i. Legally, it is not possible to open a procedure of consultation for any kind of membership. The decision is taken by the EULAR Board.