

EULAR Standing Committee of People with
Arthritis /Rheumatism in Europe

**Terms of Engagement for the
Board of the Standing Committee of
People with Arthritis/Rheumatism in
Europe (PARE Board)**

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1. Background

In EULAR, the interests and needs of people with rheumatic and musculoskeletal diseases (RMDs) are represented and promoted by an elected EULAR Vice-President representing People with Arthritis/Rheumatism in Europe and the Chair of the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (SC PARE). Both are members of the Executive Committee of EULAR, which is the managing and supervisory body of EULAR, and of the EULAR Congress Scientific Programme Committee.

SC PARE is one of eight Standing Committees of EULAR¹. They are its main organisational units appointed to deal with particular aspects of EULAR's activity e.g. developing recommendations and standards of care, developing and organising courses, performing health service research, articulating the needs of patients, etc. The Standing Committees report to the Executive Committee on all matters of programme, activities and finance. Each national member organisation of EULAR may propose one delegate to serve on SC PARE for a maximum of six years.² In addition, the Chair-elect, Past Chair, Vice-President-elect are full members of SC PARE for the duration of their term of office. The Chair of SC PARE has the opportunity to co-opt additional members³ (See Appendix V). SC PARE meets once a year during the EULAR Congress to discuss and plan future activities.

SC PARE acts in line with the By-Laws and objectives of EULAR to improve and implement standards of care for people with RMDs, to promote and improve access to care, and to reduce the impact of RMDs on the individual and on society. SC PARE also strives to establish and promote a common agenda for people with RMDs in Europe.

The Chair of SC PARE is supported by a board of up to nine members that is known as the **PARE Board**. The Board includes delegates elected from EULAR national member organisations, from organisations that have a co-opted delegate in SC PARE, and the ex-officio members (Chair, Vice-President, Vice-President-elect and Chair-elect/Past Chair).

1 Standing Committee on Investigative Rheumatology; Standing Committee for Clinical Affairs; Standing Committee on Education and Training; Standing Committee on Epidemiology and Health Services Research; Standing Committee on Musculoskeletal Imaging; Standing Committee on Paediatric Rheumatology; Standing Committee of People with Arthritis/Rheumatism in Europe; Standing Committee of Health Professionals in Rheumatology.

2 EULAR By-Laws 2014, Article 9.2

3 EULAR By-Laws 2014, Article 9.2

2. The PARE Board

Role and responsibilities of the PARE Board

The PARE Board's role is to act in support the Chair of SC PARE as a strategic “think tank” for developing and articulating patient perspectives and views within EULAR, and for delivering the EULAR Strategic Objectives.

The PARE Board has specific responsibility for ongoing programmes such as the annual World Arthritis Day, the EULAR Annual European Conference of PARE, the Knowledge Transfer Programme, together with other recurring activities and one-off projects. It has responsibility for the oversight of all these programmes and projects and ensures that they are in line with the EULAR Strategic Objectives, are effectively managed, delivered on time and within budget.

By communicating on a regular basis with the EULAR national member organisations, the Board ensures that their opinions are included and represented in its programme of activities and priorities, and that they reflect the views of the RMD patient community across Europe.

Specifically, the PARE Board has the following tasks:

- Discuss and develop project ideas and project proposals
- Receive project proposals from EULAR national organisations and from individuals
- Review project ideas and propose modifications, if necessary
- Review budgets for PARE projects and propose modifications if necessary
- Discuss the annual budget plan for approval by the Executive Committee
- Suggest individuals as Task Force or Working Group members for specific project proposals
- Send supported project proposals to the EULAR Secretariat for further processing
- Organise internal elections of the Chair-elect and propose a final candidate to the EULAR Executive Committee
- Develop and review the Terms of Engagement for the PARE board
- Report to the SC of PARE annually
- Advise the CEO of the EULAR secretariat regarding PARE matters (e.g. staff appointments, job descriptions, task forces)
- Represent PARE at national and international level after approval by the Executive Committee.

3. Chair of the PARE Board

The Chair of SC PARE acts concurrently, and ex-officio, as Chair of the PARE Board. To ensure continuity, the Chair serves for a term of four years in total: one year as Chair-elect, two years as Chair, and one year as Past-Chair. In the event of the Chair being unable to fulfil the role, the Chair-elect, or the past-Chair or the Vice-President, may take over.

3.1. Specific tasks of the Chair of the PARE Board

- Chairing the PARE Board and the annual SC PARE meetings
- Submitting project applications and overall plans of SC PARE to the Executive Committee for discussion and approval
- Monitoring projects managed by SC PARE
- Leading and running the PARE Board in accordance with its role description
- Ensuring that appropriate records of meetings and decisions are recorded and circulated by the Secretariat
- Ensuring an exchange of information amongst the members of the Board
- Co-ordinating the work between the Board and the Secretariat and overseeing implementation of decisions
- Taking decisions on all questions arising in the period between Board meetings, which do not require Board discussion. In principle, and in order to highlight the team approach of the Board, members should have the opportunity to discuss all major topics and try to reach consensus before decisions are taken.

3.2 Process for selecting the Chair-elect

- The PARE Board invites nominations for a new Chair-elect. Historically, candidates have been nominated from among the serving members the PARE Board. However, if no serving member is willing to stand, all EULAR national member organisations will be invited to nominate suitably qualified candidates.
- Nominees must be qualified persons active in their national member organisation and should ideally have previous PARE Board experience.
- Nominees must agree that they are willing to stand as candidates.
- In the event of more than one nomination, a secret ballot will be held in the PARE Board. Each board member shall be entitled to one vote.

- In the event that there is a tie in the Board votes, a second round of voting shall be held between the candidates with the highest number of votes in the first round. In the event of a second tie, the Chair will be given a casting vote.
- The result will be announced at the next meeting of SC PARE.
- The winning candidate will be proposed to the Executive Committee for approval, and for final ratification at the EULAR General Assembly.

4. Membership of the PARE Board

The PARE Board consists of a minimum of five and a maximum of nine core members, including a co-opted member from the Youth Working Group and three/four ex-officio members: the Vice-President; the Vice-President-elect; the Chair of SC PARE; and either the Chair-elect or Past-Chair. If board membership drops below five, the Board will continue to function but further candidates will be sought as soon as possible. In order to achieve a spread of representation across Europe, all elected members must be from different countries.

The Chair may also co-opt up to 3 additional members, on the advice of the Board. These members have voting rights and are expected to participate at the PARE Board meetings and ongoing work on a regular basis. Co-opted members are appointed for a period of up to 2 years, after which time all parties will review participation (see Appendix IV). The Chair may also invite guests to advise the PARE Board on an ad hoc basis. Guests may not vote.

Members of the EULAR Secretariat staff attend the meetings of the PARE Board in an administrative and advisory capacity.

4.1 Election of PARE Board members

Members of the PARE Board are elected for a two-year term of office, which starts immediately after the annual EULAR Congress. Re-election is permissible.

PARE Board members, excluding the Chair, Chair-elect/Past-Chair, Vice-President and Vice-President-elect are elected by the EULAR national member organisations. Recommended criteria, including desirable/essential skills and experience, are set out in a separate paper (Appendix I). In the event that there is a tie in the voting, a second ballot shall be held between those candidates.

Elected members may resign at any time. In such an event, an election will be held at the next available opportunity with all EULAR PARE national member

organisations being invited to nominate candidates. Pending this, the Chair may appoint an interim replacement.

If a Board member consistently fails to meet the expectations and requirements set out in Appendix 1 and above, the Chair may recommend to the SC PARE that she/he is replaced.

5. Decision-making by the PARE Board

Decisions are taken by majority vote. Four members shall constitute a quorum of the PARE Board, of which one must be the Chair, Chair-elect, Past-Chair or the Vice-President. In case of a tied vote, the Chair will be given an additional casting vote. Provided that no debate is requested, the Board may also vote on resolutions by remote voting, e.g. by e-mail.

6. Task Forces and Working Groups

In managing its activities, the PARE Board may mandate Task Forces or Working Groups to carry out specific work. The PARE Board will select the Task Force leader to organise assigned work and to structure the decision making process within the boundaries of the agreed project plan and budget. The Secretariat staff have an advisory and/or supportive role in every Task Force and Working Group. The Task Force/Working Group leader is responsible for reporting on the status of the project to the PARE Board twice a year, and as required at telecalls and meetings. The role and responsibilities of the Task Force and Working Group leaders are listed separately (Appendix III).

7. Changing the Terms of Engagement

Where necessary, a resolution to amend these terms of engagement may be put to the delegated representatives in the SC PARE for approval. Decisions are taken by simple majority. In case of a tie, the Chair of SC PARE is given an additional casting vote.

These Terms of Engagement were approved by the delegated representatives of the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe at its meeting held on 13 June at the EULAR Congress in Rome.

Date 13 June 2015

Chair EULAR Standing Committee
of People with Arthritis/Rheumatism
in Europe

EULAR Vice-President,
Representing People with
Arthritis/Rheumatism in Europe

Appendix I: EULAR Standing Committee of People with Arthritis/Rheumatism in Europe – PARE Board Elections

Eligibility and Skill Requirements for Board Members

Eligibility

- The candidate should be officially nominated by their organisation, which must be a EULAR member or an organisation having a co-opted delegate in the Standing Committee of People with Arthritis/Rheumatism in Europe (SC PARE). A country may not have more than one representative on the Board at a time.
- The candidate should be actively involved in a user organisation in that country, with experience in different fields of its work and if possible in the international arena
- As the SC PARE promotes the user led approach, the candidate must have personal experience of living with a rheumatic or musculoskeletal disease (RMD)

Skills and experience

Essential

- To facilitate communication within the Board and between members and other bodies, a good oral and written working knowledge of English is necessary
- The candidate should be willing to work in a team, and to take active responsibility for certain working areas within the Board
- The candidate must be able to operate strategically

Desirable*

- Presentation and negotiation skills.¹
- Experience of PARE's work, and/or working knowledge of EULAR infrastructure

Availability

- Attendance at the official Board meetings is essential (twice a year, usually held at a weekend over 1.5 days)
- Attendance at the annual EULAR Congress
- Attendance at the Annual European Conference of PARE
- As most of the Board correspondence is done by email or telecalls, the candidate should have a personal computer, internet and Skype access, or at least regular access to these communication systems. The working

1 These skills are essential for the Chair

time (hrs/week) is approximately 4-5 hours on average (longer for the Chair) but the workload will vary considerably over the year.

- Willingness and ability to attend project meetings within a core group, and events the Board organises with third parties, is essential.

Note:

The time Board members spend on PARE Board activities is not reimbursed: PARE Board membership is a voluntary position. Costs for travel, accommodation and meals are reimbursed according to the current rules of EULAR.

Appendix II: Roles and Responsibilities of the Chairs of the Standing Committee of People with Arthritis/Rheumatism in Europe (SC PARE) and the EULAR Vice-Presidents representing People with Arthritis/Rheumatism in Europe

This document is based on the result of a discussion held at the Standing Committee (SC) Chairpersons meeting in London May 2011 and its aim is to support the SC Chairs in their roles and working with the Secretariat. It has been amended to reflect the specific responsibilities of the Chairs of SC PARE and the Vice-Presidents representing EULAR. It contains references to the wider infrastructure of EULAR. More information can be found in the EULAR By-Laws 2014 and on the EULAR website.

TASKS AND RESPONSIBILITIES: Chairs

Chair-elect

- Using the introductory year to become familiar with EULAR procedures and activities, especially those of the Standing Committee
- Interacting with Chair as much as possible during the year
- Replacing Chair or Vice-President if needed.
- Member of SC PARE
- Ex officio Member of the PARE board
- Member of the Chairs Standing Committee
- Attending the Executive Committee meetings (3 meetings a year)
- Member of the Scientific Committee (meet 3 times a Year)

Chair

1. Standing Committee management / PARE Board

- Chairing the PARE Board and SC PARE meetings
- Chairing the Annual European Conference of PARE
- Administering and managing all matters of the SC PARE together with the Vice-President and the EULAR Secretariat
- Proposing the Chair-elect to the Search Committee
- Introducing the Chair-elect to SC PARE procedures, projects and strategy
- Arranging a handover meeting at the end of active term as Chair
- Preparing regular updates of SC PARE section on EULAR website upon request
- Reviewing updates of SC PARE section of EULAR Activities Portfolio upon request
- Using EULAR Standing Committee Database for document handling, exchange and filing

- Representing the interests of SC PARE at the Executive Committee meetings (3x/year)
- Member of the Scientific Committee
- Member of the Chairs Standing Committee
- Attending EULAR Annual General Assembly

2. Projects and initiatives

- Overseeing ongoing SC PARE projects and initiatives (projects and task forces divided between Chair and Vice-President)
 - Reporting or solving emerging or reported issues
 - Requesting annual progress reports from project and task force leaders
 - Managing internal manuscript review process
- Accepting and reviewing incoming project applications
 - Handling reviews according to SOPs (incl. HPR Research Grants)
 - Presenting final applications to Executive Committee
- Bringing up for discussion ideas for new initiatives, e.g., topics for calls

3. PARE Board / Standing Committee membership/ delegates

- Keeping and regularly updating member lists in cooperation with the EULAR Secretariat
- Welcoming new members to SC PARE and explaining SC workings
- Co-opting additional members as needed
- Corresponding with SC PARE delegates and co-opted members

4. Meetings and reporting

- Organising annual SC PARE business meeting (at EULAR congress)
 - Sending invitation and agenda to SC PARE members
 - Writing/approving minutes of meeting
- Writing annual report on SC activities for General Assembly

5. Representative role

- Acting as an ambassador for EULAR SC PARE, e.g. occasionally giving presentations.

Past-Chair

- Acting as adviser to SC PARE Chair and Executive Committee
- Helping to ensure continuity
- Member of SC PARE
- Ex-officio member of the PARE board

- Attending the Executive Committee meetings
- Member of the Scientific Committee
- Member of the Chairs Standing Committee

TASKS AND RESPONSIBILITIES: Vice-Presidents

Vice-President-elect

- Using introductory year to become familiar with EULAR procedures and activities, especially those of the PARE pillar
- Interacting with Vice-President as much as possible during the year
- Replacing Chair or Vice-President if needed
- Member of the Executive Committee (no voting rights)
- Member of the Scientific Committee?
- Ex-officio member of the the PARE Board

Vice-President representing People with Arthritis/Rheumatism in Europe

1. PARE pillar management / PARE Board

- Replacing Chair if needed in all items, especially in PARE Board and SC PARE meetings
- Administering and managing all matters together with Chair SC PARE and the EULAR Secretariat
- Introducing Vice-President-elect to procedures, projects and strategy
- Arranging handover meeting at the end of active term as Vice-President
- Consulting members of SC PARE
- Using EULAR Standing Committee Database for document handling, exchange and filing
- Ex-officio member of the PARE Board
- Representing the interests of SC PARE at the Executive Committee meetings (3x/year)
- Attending meetings/discussions of the EULAR Steering Group on matters of relevance and interest to PARE
- Attending the EULAR Annual General Assembly

2. Projects and initiatives (projects and task forces are divided between Chair SC PARE and EULAR Vice-President)

- Overseeing ongoing SC PARE projects and initiatives
 - Reporting or solving emerging or reported issues

- Requesting annual progress report from project leaders
- Managing internal manuscript review process
- Accepting and reviewing incoming project applications
 - Handling reviews according to SOPs (incl. HPR Research Grants)
 - Presenting final applications to Executive Committee
- Vice-President is formally responsible for the EULAR PARE Congress programme (June)
 - Consulting SC PARE members
 - Working with the Congress co-ordinator
 - Attending three Scientific Committee meetings
 - Chairing the Congress working group (abstract scoring)
- Bringing up for discussion ideas for new initiatives, e.g., topics for calls

3. European Public Affairs, lobbying, International Work

- Responsible for Public Affairs towards the European Institutions on behalf of EULAR SC PARE
- Liaising with EACON and EULAR international liaison officer
- Organising lobbying activities

Appendix III: Role and Responsibilities of Task Force and Working Group leaders

Overview: Task Forces and Working Groups and criteria for selection of their members

In managing its activities, the PARE Board may empower Task Forces (TF) - short term, or Working Groups (WG) – permanent or longer term, to carry out specific work. New TFs and WGs are set up and approved by the PARE Board. Their 3 – 10 members are recruited by the Secretariat in co-operation with the TF/WG leader using the following criteria: expertise and interest in the specific topic, geographical spread, mix of PARE Board members and volunteers, involvement of the Youth Group, mix of experienced and new members. The Secretariat staff have an advisory and/or supportive role in every Task Force and Working Group.

Members usually serve in the TF/WG for two years.

The following Task Forces (TF) and Working Groups (WG) are in existence:

- EULAR Annual European Conference of PARE TF
- World Arthritis Day TF
- Knowledge Transfer TF
- Stene Prize TF/Jury
- EULAR Congress TF
- Engagement Programme TF
- Breakthrough and e-Breakthrough TF (Editorial Board)
- Youth WG

ROLE AND RESPONSIBILITIES: Task Force and Working Group leaders

- Define and update aims and objectives of TF/WG. Updated aims and SMART objectives must be in accordance with EULAR Strategic Objectives
- Define rough schedule of project and major deliverables/ outcomes during the year
- Communication of major milestones /deliverables to TF/WG members and the PARE Board
- Manage TF/WG members, communicate expectations and roles to TF/WG members
- Administer and manage all matters of the TF/WG together with Secretariat
- Chair TF/WG telecalls and meetings
- Structure the decision making process within the boundaries of the agreed project plan and budget

- Hold a vote in the event of split opinions in TF/WG
- Report on or solve emerging or reported issues
- Bring up for discussion ideas for new initiatives
- Prepare regular and timely project updates to the PARE Board at telecalls and meetings as requested; respond promptly to any queries raised by the PARE Board
- Evaluate TF/WG and project at end of project life-cycle, in cooperation with EULAR Secretariat, and report to the PARE Board

Appendix IV: Appointment of Co-opted Members to the PARE Board and the Invitation of Guests

Co-opted members

According to the Terms of Engagement the Chair of the PARE Board “may co-opt up to 3 additional members, on the advice of the Board”. These members have voting rights and are expected to participate at the PARE Board meetings and ongoing work on a regular basis. Co-opted members are appointed for a period of up to 2 years, after which time all parties will review participation.

Potential candidates for co-option may be proposed by Board members. In line with the following criteria, the Board will then discuss the proposal and make a recommendation to the Chair. The following criteria should be applied:

- The candidate should have proven skills or particular knowledge which is not represented on the Board, and which would be an asset to the working of Board
- The candidate must be willing to contribute to the work on the same level as regular Board members and to participate in the official meetings
- The candidate may be a person without a rheumatic and musculoskeletal disease (RMD)
- The candidate must be willing to work in a team, and to take active responsibility for certain working areas within the Board
- To facilitate the communication between Board members and other bodies, a good oral and written working knowledge of English is necessary
- As most of the Board's correspondence is done by email, the candidate should have a personal computer, internet and Skype access, or at least regular access to these communication systems.

Invited guests

The Terms of Engagement also allow the Chair to invite guests to advise the PARE Board on an ad hoc basis. Guests may not vote.

Board members may suggest guests to be invited to join the Board meetings. These guests should be experts on a specific topic where their input to one of the current projects of the Board would be an asset.

Appendix V: Co-option of members to the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (SC PARE)

Context and process

According to the EULAR By-laws article 9.2, the Chair of the EULAR Standing Committee of PARE is allowed to co-opt delegates to join.

Within SC PARE, the Chair is supported by the EULAR Vice-President representing people with arthritis/rheumatism in Europe and the EULAR PARE Board. This group of representatives of the SC PARE will discuss potential candidates and nominate potential co-opted members to the Standing Committee. If the Standing Committee agrees that the candidate should be a co-opted member, the Secretariat will provide an official letter of invitation.

Criteria for co-option of delegates

All organisations with a delegate for co-option need to have shown an active interest in working with SC PARE, for instance having actively participated in World Arthritis Day, the EULAR Annual European Conference of PARE, or the Stone Prize competition, or participated in one of the Task Forces or Working Groups and/or participated in European lobbying for the interests of all people with rheumatic and musculoskeletal diseases (RMDs). All candidate organisations for co-option should also follow the recommended principles of user-led organisations published by EULAR.

SC PARE considers the categories below as a framework for selecting organisations for the co-option of delegates:

1. European national umbrella organisations for RMD patient organisations, not members of EULAR (e.g. recently started or small organisations)
2. International and European umbrella organisations for disease specific RMD patient organisations.
3. European regional organisations of RMD patients.
4. Former Vice-Presidents representing PARE and Chairs of SC PARE, in the period immediately following their period of office.

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

Categories 2 and 3 may only apply for co-opted membership to SC PARE, not full membership of EULAR.

Category 4 is to ensure that continuity of expertise is available to the Chair of SC PARE. It is not automatic and is limited to one two-year term.

Term of Office

The initial term of co-opted delegates is two years. SC PARE will then evaluate the membership and, if positive, the co-option could be extended for a further period. The maximum term is six years. Cvs must be provided by all co-opted delegates.

Co-opted members are allowed to delegate one representative with speaking rights and one observer when attending meetings of the PARE Standing Committee, similar to full members. Co-opted delegates have voting rights.

All co-opted members will be offered the following additional opportunities:

- Participation in SC PARE task forces/working groups
- Participation at the EULAR PARE Congress dinner
- Information about the Stene Prize competition, participation can only follow the existing procedures
- Participation in World Arthritis Day activities
- Access to the PARE network Attendance at the EULAR Annual European Conference of PARE