With one Voice

A brief guide to the role and work of the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (PARE)
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Foreword

More than 120 million people in Europe are currently affected by rheumatic and musculoskeletal diseases (RMDs); experiencing pain, reduced mobility, limited capacity to work and often a drastically reduced quality of life.

It is for these people that the European League Against Rheumatism, EULAR, has been active in research, prevention, treatment and rehabilitation as well as education for more than 70 years. More recently, awareness-raising and advocacy activities towards the European Union have had additional impact by creating public and political interest in RMDs and in people suffering from these.

The patient voice has been instrumental in EULAR’s history of alleviating the burden of RMDs. National organisations of people with arthritis/rheumatism from 36 countries have been members of EULAR for many years and contribute to its programmes and initiatives directly through PARE, the Standing Committee of People with Arthritis/Rheumatism in Europe.

PARE has been in EULAR in one form or another for over ten years. In this time, PARE has pursued a vision that people with RMDs should be able to live full and independent lives. People with RMDs deserve the best available treatments and should not be denied access to services, amenities or public transport through short-sighted design or non-inclusive policies.
But, above all, people with rheumatic diseases should be able to influence the health care and policy decisions that have a direct impact on their wellbeing and on their lives. In short, they deserve to be heard.

At a local and national level, EULAR member organisations of people with arthritis/rheumatism offer support, advice and lobbying power that serve to improve the life chances of the people they represent. However, health policy initiatives and medical practice are increasingly subject to influences that extend beyond local and national borders. PARE, therefore, provides an umbrella under which patients’ disparate voices can be united and focused at a Pan-European level. Through its initiatives, PARE allows user-led organisations from all over Europe to combine their forces and speak with one single and powerful voice. By sharing their skills, experience and lobbying power, these user-led organisations have become greater than the sum of their constituent parts. Moreover, they are able to look beyond their local and national boundaries and make their voices heard by the European decision makers who have a direct influence on their lives.

We hope this guide provides a useful insight to the valuable contribution that PARE makes to EULAR and to improving the lives of people living with RMDs.
What is PARE?

PARE stands for the Standing Committee of People with Arthritis/Rheumatism. It represents one of the three constituencies that form the European League Against Rheumatism (EULAR).

This organisational embedding ensures that PARE has the weight of a highly credible and scientifically respected organisation behind it. But, equally, it ensures that all EULAR initiatives are informed by the patient voice, regardless of which group an initiative has originated from. Respectively, PARE ensures that all patient-led activities involve health professionals and scientific representatives.

PARE exists, essentially, to encourage and support user-led organisations of people with RMDs. It does this through its three primary aims:

**Primary Aims of PARE**

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

Developing Networks

The underlying ethos of PARE is to improve the communication between like-minded groups of user-led organisations. By creating networks, experiences can be shared and knowledge can be pooled to create a more forceful bargaining power in seeking to effect change.

Under the EULAR roof, PARE does this in a number of ways:

It offers direct support to new and developing organisations that are committed to being user-led. It encourages the exchange of information, skills and best practice between these organisations. It also circulates regular reports and organises meetings where information can be exchanged.

Finally, the concept of “user-led” organisations with the aim of increasing both the number and the status of such groups is promoted.
Seeking Influence

Too often, health and social policy decisions are made without having properly consulted the people they most directly affect. It is PARE’s aim to ensure that this does not happen within the field of RMDs.

Together with the clinicians and health professionals, PARE works to establish mechanisms that are accountable for representing the views of people with RMDs to those who make policy decisions. It also seeks to provide support and resources for those who are lobbying and campaigning on issues that affect members.

Building Bridges

There are many organisations within health care, patient advocacy and professional representation whose aims and objectives overlap with those of EULAR and of PARE. By working effectively with these groups, PARE can reduce the duplication of effort and join forces towards common goals.

In partnership with EULAR’s ‘other pillars’, the health professionals and the Clinicians, PARE also has numerous working relationships with disability groups, external stakeholders, policy makers and other relevant bodies.

It is important that these partnerships are formed on an understanding of equality and that the voice of one partner is not drowned out by another, simply because that partner is no longer established or is better resourced.

For this reason, PARE works hard to keep its own profile high and to ensure that the activities are well respected for their professionalism and their success among key stakeholders.

From its position within EULAR, PARE is also unique in its ability to foster partnerships between people with RMDs and the clinicians and health professionals in rheumatology who are involved in their care.
What does PARE do?

PARE supports a number of initiatives to further its goals and in support of meeting the over-arching objectives of EULAR. These include:

World Arthritis Day (WAD)

PARE has co-ordinated World Arthritis Day (WAD) since 2003, a special awareness-raising day developed in 1996 by Arthritis and Rheumatism International (ARI). Supported by a major financial contribution from EULAR, PARE takes a major leadership role in WAD activities today.

WAD aims to raise awareness of all forms of RMDs among the medical community, people with RMDs and the general public. It also seeks to ensure that all people with RMDs and their caregivers are aware of the vast support network available to them.

Each year, a specific theme is chosen to highlight an issue that is important to people with arthritis:

<table>
<thead>
<tr>
<th>Year</th>
<th>Theme</th>
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<tbody>
<tr>
<td>2003</td>
<td>‘Arthritis and Sport’</td>
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<tr>
<td>2004</td>
<td>‘Early Diagnosis, Less Pain’</td>
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<tr>
<td>2005</td>
<td>‘Living without Pain’</td>
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<td>2006</td>
<td>‘Take Action!’</td>
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<td>2007</td>
<td>‘Small Things Matter’</td>
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<td>2008</td>
<td>‘Think Positive’</td>
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<tr>
<td>2009</td>
<td>‘Let’s Work Together’</td>
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<tr>
<td>2010</td>
<td>‘Let’s Work Together’</td>
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<tr>
<td>2011</td>
<td>‘Move to Improve’</td>
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The website [www.worldarthritisday.org](http://www.worldarthritisday.org) promotes WAD activities run by national organisations in support of the day. PARE develops material such as brochures, posters, leaflets, press releases or surveys. National and local activities around the world are captured on a Google Map which highlights the creativity of contributors to WAD from around the world.

Autumn Conference

Each autumn PARE holds an annual conference in one of the EULAR member countries. The event is hosted by a national member organisation of people with arthritis/rheumatism and is organised by the EULAR secretariat with the help of the local representatives. The conference focuses on a different topic each year, closely linked with the WAD theme. Each year, the conference gathers, inspires and educates some 120 delegates from national organisations from around Europe. For the host organisation it is also a goal to raise awareness of RMDs with their authorities. EULAR has, in the past, supported national round table discussions involving national and European key stakeholders. The event is also seeking to involve more health professionals and scientific representation.
The conference includes: presentations from invited keynote speakers, workshops to share best practice, networking opportunities and the opportunity to develop practical materials that can be adapted for use at national level. The EULAR Charter for Work for People with RMDs was the outcome of the EULAR Autumn Conference in 2008 in Budapest. EULAR launched the Charter in the European Parliament in 2009 and developed several tools to help national organisations promote this important document. It has, since then, been translated and launched in about 20 EULAR member countries and the topic is still high on the agenda of EULAR.

‘Very informative. It was nice to find out about the situation in other countries so that we can spread the knowledge and are in a better position to inform young people with RMDs about ways to manage and live with their situation.’

Quotes from Autumn Conference Delegates:

‘It is always so impressive, informative, and well organised, that it cannot get much better, but despite this the event is improving and getting better every year.’

‘Congratulations to all of you! You organised an excellent conference!’

‘This topic – young people - is important for my organisation since it is our weak point to attract young people with arthritis. This workshop helped to have new ideas.’

‘Very useful indeed as I got back home with lots of feedback and ideas and gained knowledge about the status of rehabilitation in other countries. The conclusions and solutions provided were very practical as well.’
PARE Programme at EULAR Congress

The EULAR Congress is an annual event with about 16,000 attendees. These include a growing number of delegates from the EULAR member organisations of people with arthritis/rheumatism. The EULAR PARE Standing Committee is responsible for organising the PARE programme at the congress. PARE has not only significantly increased the quality of these sessions but also the outreach to health professionals and scientific representatives. Topics such as political campaigning, patients in research, impact of RMDs on quality of life, informed decision making and the health care team are just some of the various areas relevant for delegates of organisations representing people with RMDs to discuss with invited expert speakers.

‘I would like to highlight the professionalism of all members and also their willingness to work and to improve things. It is better and better with every year going!’

The EULAR Congress is the second event in the PARE calendar designed to facilitate sharing best practice, to offer networking opportunities, including the PARE dinner, as well as receiving the latest information about treatment and management of RMDs. The PARE booth in the exhibition area informs congress delegates about the various EULAR activities for PARE and serves as a meeting and discussion point for representatives of people with RMDs.

Quotes from Delegates 2010:

‘This was my 7th EULAR Congress, of course there are things I have heard and seen before, but still I hear new ideas and get affected by all the enthusiasm and energy of everybody. So EULAR gives me new energy to work even harder when I am back home.’

‘I can take lots of useful information home that I can use in our organisation – even more than we can afford to do! Besides, I have also personally benefited a lot, which makes my life worth living as a patient.’
Educational Visit Programme

The EULAR Educational Visit Programme aims to enable patient groups to exchange information and to share experience and ideas. Financially sponsored by EULAR, the programme is designed for organisations representing people with RMDs that wish to develop their skills by learning from other organisations within PARE’s network. Applicants are asked to demonstrate that the award will bring lasting benefit to their organisation and to people with RMDs in their country. Preference is given to programmes that actively involve people with RMDs.

Country Visits

By visiting and attending national events PARE aims to keep close and personal contact with its membership. Country visits by PARE officials serve a dual purpose: first, for EULAR and PARE it is important to keep the national member organisations involved to act successfully, for instance, when working at the EU level; second, for the national member organisations it is important to have the official representation of EULAR when working at national level to attract high-level politicians and other key stakeholders to events to make their voices heard.

After a PARE delegation visited the national member organisation in Russia, the organisation was given their own office in the Institute of Rheumatology in Moscow. This was a major achievement for the organisation in order to work more effectively and they were very grateful and satisfied with this outcome. In the Former Yugoslavian Republic of Macedonia, a high level delegation of EULAR met with several representatives from the national government. This led to the national member organisation achieving advisory status to government as a “public interest organisation”.

Left: EU Presidency conference on RMDs, 2010
Middle and right: Country Visit to Skopje, Macedonia
Network of Patient Research Partners

EULAR recognises the important role of representatives of people with RMDs in the development of recommendations and other research activities. EULAR task force leaders include people affected by RMDs in their projects to improve methodology and research outcomes as well as to give credibility to the results. For political reasons, people affected by RMDs are also involved in health care and health research initiatives when it is expected that decisions in these areas will have an impact on their daily life.

As a special initiative in this area, EULAR has developed recommendations for the inclusion of representatives of people with RMDs in projects, providing guidance to task force leaders and people affected by RMDs alike. These recommendations were published in the EULAR Journal “The Annals of the Rheumatic Diseases”. EULAR has also supported the establishment of a PARE network of trained patient research partners from around Europe to contribute patient perspectives to research projects and other activities.

Edgar Stene Prize

Each year, the Stene Prize is awarded to the person with a RMD submitting the best essay describing his or her individual experience of living with their condition. Each year, the competition has a different topic that goes alongside the overarching theme also used for WAD and the Autumn Conference. First awarded in 1975, the Edgar Stene Prize was created by EULAR to honour the memory of Edgar W. Stene, the founder and Secretary-General of the Norwegian Rheumatism Association and himself a person with ankylosing spondylitis.

All organisations are invited to run the competition on a national level and to choose one entry as the national winner to be sent to the EULAR secretariat. A Stene Prize Jury rates the creativeness, writing skills and inspirational factor. A selection of the best 10 texts is made into a booklet distributed to the member organisations, various key stakeholders and at the EULAR Congress. The winner of the competition is invited to attend the annual EULAR Congress and to present the essay within the PARE programme.
How does PARE operate?

In organisational terms, people with RMDs are represented in EULAR by a Vice-President as well as the PARE Standing Committee headed by a chairperson.

Within EULAR, the PARE Standing Committee focuses on all aspects of EULAR activity directly involving or serving people with RMDs and fostering close relations with the national member organisations. In addition, the Standing Committee is committed to keeping the voice of people affected by RMDs heard in EULAR and elsewhere.

The PARE Standing Committee, headed by a chairperson, is set up by delegates from the national organisations who are members of EULAR. The committee is led by a board of eight members, each of whom must have experience of living with a RMD.

‘PARE gives us the chance to voice the interests of people with RMDs’

The PARE Board acts as a think-tank and leadership group for all the projects that PARE undertakes.

The national organisations of people with arthritis/rheumatism play an important role in the concept of PARE. There are currently 36 European countries represented in EULAR by 37 national organisations. These organisations differ in size, structure and in the activities they carry out. But they all work with and for people with RMDs.
**EULAR Executive Committee**
- 2 PARE reps elected

**PARE Board**
- 5 members elected by Standing Committee
- +3 Ex officio members

**PARE Standing Committee**
- 37 national organisations of people with arthritis/rheumatism
- 3 co-opted members

**People with Arthritis/Rheumatism**

**EULAR Member Organisations of People with Arthritis/Rheumatism**
- 37 national organisations represented in 36 countries

**Individuals with RMDs in Europe**

**Health Professionals**

**Clinicians/Researchers**
Principles of PARE

PARE operates under a strict code of principles as outlined below:

1. PARE believes that organisations of people with RMDs are most effective when they are user-led or at least user-centred. PARE should promote and reflect this in its own activities and leadership.

2. PARE will also prioritise activities and projects which are led by and/or focus on and actively involve people with RMDs.

3. PARE will prioritise activities and projects which demonstrate that they will benefit the wider community of people with RMDs as well as the individuals directly participating; the ‘wider community’ includes people at risk of developing RMDs.

4. PARE believes in promoting the social model of disability and will seek to promote this through its work; it is committed to equal opportunities, recognising that the diversity of the RMDs’ community is one of its strengths.

5. PARE will be transparent, accountable, representative and inclusive in its governance structures and activities.

6. PARE will determine objectives and outcomes for its activities, and monitor and evaluate its work against these.

7. PARE will be collaborative in its activities, seeking opportunities to work in partnership with others both within and outside the RMDs’ community. It will also prioritise activities and projects which promote partnership.

8. PARE will review its values and principles regularly.
History of PARE

The history of PARE began in May 1999, when three international groups met to discuss how they could work together to raise the quality of life of people with RMDs.

These included the Social Leagues of the European League Against Rheumatism (EULAR), Arthritis/Rheumatism International (ARI) and the International Organisation for Youth with Rheumatism (IOYR).

The result was a “European Manifesto” for people with RMDs. The ten-point plan, which laid out common areas of concern and interest, was published in June 2000 and became a powerful lobbying tool, being translated into over 20 languages.

The ‘European Manifesto’

1. To raise the profile of RMDs with European policy makers
2. To assert the contribution of people with RMDs
3. To encourage change in the way services are delivered (in health, education, employment and social services)
4. To provide a framework for addressing the social model of disability
5. To support work for greater social inclusion
6. To provide a consensus for legal support of people with RMDs
7. To be a tool that national organisations can use to develop their identities and programmes
8. To provide consistent messages and reinforce points for campaigning at European and national levels
9. To be a vehicle to discover the true costs of RMDs
10. To provide a framework for the development of best practice

From 2001, the European Manifesto was implemented in close co-operation with EULAR and its member Social Leagues. It operated its own secretariat. In 2004 the Social Leagues’ Strategic and Operational Plan stated that PARE Manifesto was seen as the campaigning arm of the Social Leagues.

In the next few years with the co-operation becoming even closer it was felt that, ideally, PARE Manifesto would not continue to exist as a separate body outside of EULAR but merge with the EULAR Social Leagues so that there would be one body working within EULAR and under the EULAR roof to promote the needs of people with RMDs. It was felt that it would be much more powerful if people with RMDs, doctors and health professionals would all speak with one voice and belong to one entity.

With the official merger of PARE Manifesto and the EULAR Social Leagues in January 2008, PARE was born.

In 2008, EULAR published its five-year strategy and this officially integrated PARE into EULAR, standing alongside health professionals in rheumatology, clinicians and researchers.
The Value of PARE

A consultation exercise was undertaken in November 2011 to find out what the 37 national member organisations of people with arthritis/rheumatism think of PARE and its activities.

PARE: Immense Value for Patients

‘It is a forum for inspiration’

‘PARE . . . gives us the chance to voice the interests of people with RMDs’

‘PARE and its activities are absolutely important in our life’

‘PARE voices the interests of people with RMDs’

‘International support of our local activities’

‘Great opportunity to exchange knowledge and experiences’

PARE: Most Useful Activities

‘The Annual Congress is the most important activity’

‘The Patient Research Partner project and of course World Arthritis Day’

‘The PARE sessions at EULAR Congress as they provide a lot of knowledge and information’

‘Educational Exchange Visit Programmes’

‘Having a window on WAD is wonderful’

‘The Edgar Stene Prize ... involves patients on a National level, makes EULAR familiar to patients in all countries’

‘EULAR PARE autumn conferences because of getting the opportunity to meet each other face to face’

‘To know that there are people all around Europe that want to fight RMDs is a wonderful feeling’
The Value of World Arthritis Day

‘The most useful and the best way to present current problems’

‘An important date to raise awareness of RA’

‘A huge stimulator for groups, institutions and organisations’

‘Joint action increases the level of interest’

‘A very efficient tool for achieving media coverage’

‘International support of our local activities’

‘Very important for the patient movement’

‘A great platform for exchanging experiences, networking and education’

‘Gives us the guiding principles that place us within the European patient movement’

‘Keeps us connected to the strategic issues that are at the very heart of the patient leagues’

‘Opportunity to discover, learn, hear, see the experience of other countries’

‘Feeling you are not alone’

‘Great place for networking and exchanging good practice’

PARE: Final Comments

‘PARE is a MUST in our life’

‘PARE is a very powerful tool for disabled people’

‘I think PARE has a lot of benefits for its members’

‘Working with the national organisations of people with arthritis/rheumatism across Europe gives us the opportunity to learn from each other, improve our knowledge and skills and make our voice stronger and louder. For this, we would like to thank EULAR and PARE.’