

EULAR PARE Volunteer Policy

1. ABOUT EULAR PARE AND VOLUNTEERS

The European Alliance of Associations for Rheumatology, EULAR, is the organisation which represents the people with arthritis/rheumatism, health professionals in rheumatology (HPR) and scientific societies of rheumatology of all the European nations.

EULAR aims to reduce the impact of rheumatic and musculoskeletal diseases (RMDs) on the individual and society and to improve the quality of life of people with rheumatic and musculoskeletal diseases in Europe. To this end, EULAR fosters excellence in education and research in the field of rheumatology. It promotes the translation of research advances into daily care and fights for the recognition of the needs of people with RMDs by the governing bodies in Europe.

PARE stands for the Committee of People with Arthritis/Rheumatism in Europe and it is one of EULAR's Representation Committees, bringing together the network of national organisations of people with RMDs across Europe. EULAR PARE voices the interests of people with RMDs in all aspects of EULAR's work and elsewhere, aiming to make sure the voices of people with RMDs have influence within EULAR and among decision makers across Europe, to support and empower user-led organisations of people with RMDs, to be effective and develop strong networks, and to create strong alliances that will help us make a difference to the lives of people with RMDs. Therefore, it is uniquely placed to foster partnerships between people with RMDs, the clinicians and health professionals in rheumatology.

EULAR as a non-profit organisation follows the principle of voluntarism. Volunteers work together with and are supported by the EULAR Office. All together work for the common aim to reduce the impact of RMDs on the individual by promoting and supporting education, research, prevention, and treatment of RMDs.

All this makes it essential for PARE to have volunteers, who possess the knowledge, experience, and expertise of their own disease, being willing to be involved in EULAR PARE activities. Volunteering activities undertaken within EULAR serve a non-profit cause, aiming to benefit people affected by rheumatic and musculoskeletal diseases.

2. Purpose of this policy

This volunteer policy outlines the principles by which EULAR PARE works together with volunteers, the benefits volunteers bring to our organisation and the benefits and support that volunteers should expect in return. It sets out the standards in terms of recruitment, induction, and appointment of volunteers to ensure that both volunteer and EULAR PARE expectations are met. It provides for fair and equal treatment of its volunteers and a framework for implementation at EULAR level.

3. Who the policy applies to

The policy will provide support to volunteers within EULAR PARE and for volunteers themselves who contribute to EULAR and EULAR PARE activities. The policy will be provided to all EULAR PARE volunteers, and relevant EULAR stakeholders whenever working with EULAR PARE volunteers.

4. Who are EULAR PARE volunteers

A volunteer is a person that, by free will and own choice, carries out activities which are benefiting society. These activities are undertaken for a non-profit cause by the volunteer, who commits her/his time and energy for the general good without financial reward.

A EULAR PARE volunteer is a person freely performing mutually agreed tasks or roles, for which he or she has applied and/or has been invited, with the aim to support EULAR activities, without payment or the expectation of payment (expenses may be covered). The agreement is voluntary on both sides and either party can bring this to an end.

There are several areas within EULAR PARE where volunteers can be engaged:

- i. Share insight & informing - Shape the development and delivery of activities, projects, or services by sharing opinions, ideas or approaches within the EULAR PARE working groups.
- ii. Developing communications - Bring the experience of living with an RMD to help shape EULAR PARE's publications, podcasts, and social media.
- iii. Planning and delivering events – Volunteers are part of the team planning PARE's presence at events. Especially exciting is the experience of being part of the EULAR Congress or EULAR PARE Conference activities – like chairing or facilitating a session or supporting face-to-face networking opportunities.
- iv. Informing about educational opportunities - PARE provides formal education for patients and patient organisations through the EULAR School of Rheumatology and offers knowledge transfer opportunities to help organisations develop skills in specific areas.
- v. Raising the voice of people with RMDs - The experience of living with an RMD matters. Volunteers bring an understanding of the disease and its impact which will inform EULAR's work and help improve services and treatments for people with RMDs across Europe.
- vi. Young PARE – Young people get RMDs, too, and can face extra challenges. EULAR PARE supports 18 – 35-year-olds to influence agendas and become leaders of the future.

EULAR PARE seeks and values the following attributes that volunteers bring:

- Ability to apply the experience of living with an RMD to help others;
- Commitment and reliability;
- Cooperation spirit and ability to work in a team.

We do our utmost to match the volunteers' interests and skills with our needs to ensure a mutual benefit. Most important to us is that volunteers enjoy their work with EULAR PARE, are enriched by their involvement, and can see that their contribution matters.

5. Equality and Diversity

EULAR PARE is committed to building a diverse organisation that is responsive to the needs of those living with an RMD and our stakeholders. We are also committed to equal opportunities at all stages of recruitment and selection. Short-listing, virtual interviewing and selection of volunteers should

always be carried out without regard to protected characteristics: age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex; and sexual orientation.

EULAR PARE aims that the involvement of volunteers in our activities also ensures geographical spread, age and gender balance.

6. The value and benefits that volunteers bring to EULAR PARE

None of our activities would be feasible without the support of volunteers - they are at the heart of all our projects. Volunteers drive the EULAR PARE activities.

We rely on their experience, knowledge, and skills. Specifically, EULAR PARE volunteers:

- Deliver direct support to our activities for the benefit of our community;
- Enrich the quality of our service delivery, based on the patient perspective;
- Often provide a unique insight from those living with an RMD that cannot be provided by the EULAR Office or other EULAR volunteers;
- Bring additional expertise (social, academic, professional skills) and offer specialist knowledge in a variety of areas;
- Facilitate reputation building for EULAR PARE in voicing the interests of people with RMDs in all aspects of EULAR's work.

7. The benefits to a volunteer of supporting EULAR PARE

EULAR PARE provides volunteers with:

- Personal development opportunities and experiences;
- The opportunity to make a difference to the lives of those living with an RMD and thereby making a contribution to society as a whole;
- Networking opportunities and interaction with other volunteers, organisations and EULAR PARE staff;
- Access to quality training and research opportunities;
- Experience in being involved in a high level and well-respected European organisation, working with key medical professionals, researchers and health professionals.

EULAR PARE volunteers will have the chance to be involved in projects and activities that will provide them with additional knowledge, skills, and experience such as:

- Improvement of language and communication skills;
- Learning how to work in a team;
- Enhancement of advocacy skills;
- Gaining deeper insights and knowledge about RMDs;
- Learning how to plan and manage projects;
- Feeling integrated in a patient community;
- Gaining self-confidence.

8. EULAR PARE Principles of working with volunteers

EULAR PARE has a number of defined principles and processes relating to a range of areas and aspects that underpin volunteer involvement in its activities. These are outlined below. The principles will ensure fair and equal treatment of all volunteers.

9. Recruitment and appointment of new volunteers

EULAR PARE requires the use of an application form to collect information on all prospective volunteers. Additionally, all volunteers may be interviewed (via videoconference/telecall) to provide relevant information and explore their aspirations, their experience and skills they can bring to the organisation. It is important for all involved to appreciate that the interview is not a competitive process, and the sole selection criteria is suitability for the role.

There are different volunteer roles in EULAR. Some are occasional (e.g. chairing a session at the EULAR Congress) others more long term (e.g. as member of a Working Group or as member of the PARE Committee). Each role is connected to a different election / appointment procedure which is outlined in respective documents (e.g. PARE Working Group Regulations and related SOPs).

10. Training

Volunteers will have a set of skills, knowledge and attitudes gained from their education, work, previous volunteering and life experience. However, to ensure that volunteers are appropriately equipped for their role each volunteer must undergo the appropriate induction and ongoing training process which is provided by EULAR.

Volunteers will benefit from:

- An induction training to better understand EULAR and PARE.
- Training opportunities (online and face-to-face) to develop skills within the scope of the projects and activities the volunteer will be involved in.
- Acknowledgement of skills and experience gained through a personalized certificate and reference letter.

11. Appointment

All volunteers must agree with the **Volunteer Statement of Expectation** (Annex 1) which outlines what is expected from the volunteer and what they can expect from EULAR PARE. In commencing their role, the volunteer commits to the aims, values and key policies of EULAR and of EULAR PARE. They also commit to delivering the key tasks outlined in the relevant role description. This Statement of Expectation is binding in honour only and there is no intention to create a contract of employment between the organisation and volunteers. When appointed, all volunteers must have a named contact at EULAR PARE. The named contact is responsible for guiding and supporting the volunteer in their role and should be available to discuss any aspect of the volunteer's role. A volunteer must be informed in writing (email) if their EULAR PARE contact changes.

12. Management and support of volunteers

Each volunteer will be provided with relevant management and support. This will include regular, appropriate and mutually agreed contact. As a minimum, volunteers will be offered an annual review, which offers the opportunity to discuss their role, share feedback and identify individual development and support needs. EULAR PARE will also provide appropriate recognition and occasions to celebrate volunteers and their work, on an individual and group basis, according to

specific role(s), commitment and length of service. EULAR PARE has a procedure to help resolve any type of problems that arise and will be carried out by an appropriate person to ensure fair and equitable treatment of volunteers. The procedure for managing volunteers can be found in our Volunteer Handbook. Volunteers cannot commit EULAR to expenditure, e.g. events, contracts, expenses (other than those incurred in the course of their work for EULAR PARE, upon previous approval).

13. Health and Safety

EULAR will ensure that all volunteers are provided with the appropriate information, supervision and training required to enable them to complete voluntary work safely. This includes providing suitable systems and procedures and that guidance is outlined beforehand. Volunteers must take reasonable care of themselves and others while volunteering for EULAR PARE and follow any health and safety advice and instruction given for their role. Volunteers should co-operate on health and safety matters and immediately report accidents/incidents (including near misses – accidents/incidents that may have led to injury). Volunteers should not intentionally or recklessly interfere with or misuse anything provided in the interests of health, safety and welfare. If a volunteer finds themselves in a situation which is a threat to personal safety, their first point of contact should be their allocated EULAR PARE staff member. Volunteers should put their health first and not take any risks if not feeling well.

14. Expenses

EULAR will reimburse volunteers for any reasonable out of pocket expenses that have been induced when carrying out their tasks, and previously approved, according to the EULAR Expense Payment Regulations (Annex 2). These include travelling expenses (economy class) or overnight stays in mid-class hotels. To claim expenses, tickets and receipts must be provided (scanned copies accepted) together with the reimbursement form provided by the EULAR Office. Bank charges and expenses occurring on the recipient's side will not be covered by EULAR.

15. Insurance

Liability insurance is provided by Eular for volunteers, after they reach the site or venue of an activity or event. During the time needed for travelling, insurance is up to the individuals to provide. The coverage for accident and health insurance is the responsibility of the volunteers and is not covered by Eular.

16. Confidentiality and data protection issues

All volunteers are required to only process personal data on a need-to-know basis and solely upon instruction of EULAR and to keep confidential any EULAR information they become aware of through their volunteering that is not in the public domain.

When engaging as volunteer, the volunteer will provide his/her personal data to EULAR, such as his/her name, contact data, date of birth, cv, expertise, references, information about his/her health (RMD and particular support). EULAR processes these data so that the volunteer can fulfil his/her tasks (art. 6 para. 1 lit. c GDPR). EULAR will not provide these data to third parties, except where the volunteer expressly consents to and except to EULAR's usual service providers, such as IT service providers.

EULAR solely processes the volunteer's personal data in Switzerland, in the EEA and in the UK. EULAR processes the volunteer's personal data for as long as the volunteer is engaged as volunteer and, if required by bookkeeping purposes, for a period of 10 years thereafter.

The volunteer herewith expressly consents that EULAR publishes his/her name and role as volunteer on the EULAR website, on its brochures and other materials relating to EULAR PARE. For these publications, the processing occurs worldwide and until the volunteer withdraws his/her consent.

The volunteer has the right to withdraw his/her consent at any time, the right to access his/her personal data, rectify them, have them erased or the right to restrict the processing or object to the processing. The volunteer has the right to complain with the Federal Data Protection and Information Commissioner or lodge a complaint with another competent supervisory authority. EULAR data protection representative is Genevieve Schaerer-Lim and you can contact her by letter: Seestrasse 240, 8802 Kilchberg or by email: eular@eular.org.

17. Leaving EULAR PARE

Volunteers are free to cease volunteering with EULAR PARE at any time, although, wherever possible, an agreed period leading up to this point would be helpful in order to give EULAR PARE time to make any alternative arrangements required. It could happen that the organisation will ask a volunteer to cease volunteering. Wherever possible we will offer the volunteer the opportunity to feedback before leaving their role, and ensure they are appropriately thanked for their support including a certificate and reference letter highlighting their engagement with EULAR PARE

18. Volunteer Feedback

We provide a range of opportunities for volunteers to offer feedback on our processes, support and work including an annual volunteer survey. Should a volunteer wish to make a complaint, they are invited to put their complaint in writing and address to their respective contact person or the Chair of the PARE Committee. We invite volunteers and staff to send any comments or suggestions regarding the Volunteer Policy to the Chair of the PARE Committee.