VOLUNTEERING WITH EULAR PARE
Making a difference for people with RMDs*

*Rheumatic and musculoskeletal diseases
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EULAR PARE would like to thank all volunteers who make a difference for people with RMDs every day and particularly those who have contributed to this publication.
Volunteering for an organisation like the European Alliance of Associations for Rheumatology, EULAR, shows a commitment to supporting people with rheumatic and musculoskeletal diseases (RMDs). These diseases are typically painful and limit people’s ability to move easily. In severe cases, they can result in significant disability, having a major impact on both quality of life and people’s life expectancy.

People’s motives for doing voluntary work are diverse – such as coping with personal problems, communicating with others and feeling understood. Voluntary work means investing a lot of time and energy in providing support to others, but it also means great gains for the volunteer. You acquire skills and knowledge about self-management and your rights in the social system. And you gain recognition and appreciation.

Most of you are already volunteering in self-help groups where it is essential to exchange information with those in similar situations. It will certainly be your key target to represent those affected by RMDs and be active in enabling better standards of care.

The fact you have started reading this brochure shows you have an interest in EULAR. Thank you. We hope this brochure will tell you all you need to know about the organisation and EULAR PARE’s work with people with RMDs.

I hope we can welcome you to our EULAR family.

DIETER WIEK
EULAR Vice President representing EULAR PARE 2017 – 2021

“The best way to find yourself is to lose yourself in the service of others.”

MOHANDAS KARAMCHAND GANDHI
Volunteering is an enriching experience. Not only does it make a valuable difference to the people, organisation or cause you choose to support, it also has a positive impact on your health, well-being and quality of life.

The joy of volunteering is that you can decide how much time or commitment you are able to give. It shouldn’t take over your life – it should enhance it.

Connect with people: Living with an RMD can be isolating. Volunteering can bring you friendships and connections.

Become part of a community: Meeting people with a shared interest can be enriching. Volunteering for a common goal can give you a real sense of purpose.

Grow in confidence: Trying something new can be a real ambition. Volunteering helps you build a real sense of achievement and improves your self-esteem.

“I’ve had the chance to meet other people with RMDs. Now these people are my friends.”

BORYANA BOTEVA
Bulgaria

“Volunteering brings fun and fulfilment to my life. I was a volunteer with my national RMD organisation even before I was diagnosed with scleroderma because I believe that in some way – small or large – volunteering is a way of doing good. Through my actions and involvement, I’m benefiting others as well as myself.”

HRISTINA BANKOVA
Bulgaria
HOW EULAR MAKES A DIFFERENCE

EULAR exists to reduce the burden of RMDs on individuals and society, and to improve treatment, prevention and rehabilitation outcomes. It demonstrates the impact of RMDs on society, the economy and individuals – including families and loved ones.

The EULAR family gives its time to share experiences of living or working with a condition, and to raise awareness of the need for early diagnosis and the right treatment at the right time.

EULAR’s success lies in:

- improving patient care by providing education opportunities to patients, health professionals and clinicians
- bringing together 18,000 specialist and patient audiences from around the world at the Annual European Congress of Rheumatology
- raising awareness of RMDs to improve the lives of people with RMDs
- influencing change to benefit people with RMDs through an active presence in the Brussels political arena
- staying at the forefront of research into RMD treatment and care.

“At least 100 million people in Europe have RMDs: the EULAR network is motivated by making a difference for all of them.”

SIMON STONES
United Kingdom
HOW EULAR PARE CONTRIBUTES TO EULAR’S WORK

The EULAR PARE Committee represents the patient voice within EULAR. We believe that people with RMDs deserve the best available treatments. No matter where they live or what socio-economic background they have, they should not be denied access to care, education, work, services or public transport.

EULAR PARE is led by volunteers who have personal experience of living with an RMD. With the support of the EULAR Office, we bring together representatives who act on behalf of the national organisations of people with RMDs across Europe. The more we raise awareness about RMDs, the more positive change we can achieve.

We aim to:

- make sure the voices of people with RMDs have influence within EULAR and among decision makers across Europe
- support and empower user-led organisations of people with RMDs to be effective and develop strong networks
- create strong alliances that will help us make a difference to the lives of people with RMDs.

EULAR PARE voices the interests of people with RMDs in all aspects of EULAR’s work and elsewhere. It is uniquely placed to foster partnerships between people with RMDs, the clinicians and health professionals in rheumatology who are involved in their care.

“I have become a communicator, practiced in lobbying, media appearances, networking, promotional events, leading groups, giving lectures and public engagement.”

MARIJA KOSANOVIC
Serbia
“Engaging in volunteering makes me forget my own condition and problems. It also provides me with greater intelligence that is useful to me as a patient, to my organisation and to all the people it represents. Being a volunteer is very enriching and I trust my contribution is meaningful to others.

By volunteering for EULAR PARE, I’ve learned that my experience of living with an RMD offers a useful insight, and that my personal and professional skills are valuable in many areas. In the process, the knowledge and experience I’ve acquired – through networking, training opportunities and taking part in EULAR PARE activities – have really exceeded my expectations.”

ELSA MATEUS
Portugal
There is no one better at highlighting the very personal impact of RMDs than the people who live with the conditions day in, day out. PARE volunteers bring their skills, experience and enthusiasm to a broad range of activities within the organisation.

We strive to involve a range of people to ensure cultural, social, geographical and age diversity is reflected in our work. Additionally, your experience of volunteering with your national RMD organisation means that you bring with you an understanding of issues which matter to the wider RMD community. This all helps support our work to reduce and remove the barriers people with RMDs face.

We look for volunteers whose skills are suited to the specific needs of PARE’s projects, tasks and activities, and who have the ability to co-operate with clinicians and health professionals.

Volunteering matters: Winners of the Edgar Stene Prize and the EULAR Meritorious Award

“I had to learn some special skills to participate in EULAR, including improving my English.”

MASCHA OOSTERBAAN
The Netherlands

“We give our time to PARE to share our experiences of living with RMDs, and to raise awareness of the need for early diagnosis and the right treatment at the right time. Working together, we continue to have great success.”

DIETER WIEK
Germany

“Meeting and talking to others from EULAR Young PARE across Europe is really interesting and I’ve learnt things I’ve taken back to my national RMD organisation.”

BETH DILLON
United Kingdom
By volunteering for EULAR PARE, you will be joining a family of people dedicated to making a difference to improve the lives of people with RMDs.

Our volunteers tell us that they benefit from being involved with EULAR PARE by:

- receiving professional support to develop skills
- working as part of a team
- meeting like-minded, committed people
- learning more about their own disease and options.

"Volunteering with EULAR PARE has helped me gain a lot of experience in leading workshops and presenting. My leadership skills have improved and I’ve had the chance to upgrade my knowledge about RMDs."

BORYANA BOTEVA
Bulgaria
EULAR PARE offers a wealth of opportunities for people with RMDs to get involved and make a difference to the RMD community. We organise a range of high-quality activities and programmes which establish a shared agenda for people with RMDs in Europe. Our volunteers play a vital role in this work.
You can do this by:

**Sharing insight**
Shape the development and delivery of activities, projects or services by sharing your opinions, ideas or approaches with EULAR PARE working groups.

**Developing communications**
Bring your experience of living with an RMD to help shape EULAR PARE’s publications, podcasts and social media.

**Planning and delivering events**
Be 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 a session or supporting face-to-face networking opportunities.

**Informing 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.

**Raising the voice of people with RMDs**
Your experience of living with an RMD matters. You will 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.

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.

Regardless of your background and your contribution, you’ll find that volunteering with EULAR PARE is rewarding and enjoyable.

“I love being part of the editorial board – one of PARE’s most dynamic working groups. Firstly, I find it personally fulfilling to know that my professional skills are helping other people with RMDs across Europe to cope with their condition. Secondly, it gives me the chance to get in touch with people from different countries and cultural backgrounds and discuss issues that are relevant for my health condition.”

**OVIDIU CONSTANTINESCU**
Romania
You can find out more information about our volunteering opportunities on the EULAR PARE website where you will be able to see role descriptions for current openings.

If you see something that appeals to you, you should follow the online instructions to express your interest. The EULAR PARE team will then be in touch with information about how to make a formal application.

"Through volunteering on PARE’s patient research partners working group, I enjoy ensuring people with lived experiences are involved in designing and delivering research. I see this as an incredible opportunity to reach a wider group of people, to help them shape RMD research. This new opportunity coincided with me stepping away from the EULAR Young PARE working group after four exciting years, and felt a natural evolution in my work at European level with EULAR.”

SIMON STONES
United Kingdom