

Article

European Alliance of Associations for Rheumatology (EULAR)

The?European Alliance of Associations for Rheumatology (EULAR) is a European?<u>non-governmental</u> <u>organisation</u>?which represents the people with rheumatic and musculoskeletal diseases (RMDs), health professional and scientific societies of?<u>rheumatology</u>?of all the European nations.

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The aims of EULAR are to reduce the burden of RMDs on the individual and society and to improve the treatment, prevention and rehabilitation of RMDs.

It promotes the translation of research advances into daily care and fights for the recognition of the needs of people with musculoskeletal diseases by the governing bodies in Europe.

To find out more about the work of EULAR, click here: https://www.eular.org/index.cfm

How NRAS works with EULAR

NRAS has worked with EULAR, in particular with PARE (patient) pillar of EULAR since our launch in 2001.

Every year the EULAR congress attracts approximately 14,000 rheumatology professionals, researchers, industry representatives and patient organisations from across Europe and indeed the world who come together to share new research, best practice examples, oral and poster presentations and to network. NRAS is always represented, and this year was the first time ever the congress had to go online due to COVID. NRAS submits abstracts of our work and social research data, and for the last 12 years or more, we have presented at the congress.

NRAS is a member of the PARE CEO group which is funded by EULAR to meet annually. This is a limited group of the larger patient organisations across Europe with paid CEOs and paid staff whose CEOs come together to share knowledge, data and collaborate to the benefit of people with RMDs across Europe. We also co-operate with the EULAR Brussels office in regard to the EU Commission and the Brussels parliament when it comes to influencing policy relating to RMDs.

Our CEO Clare attends the CEO meetings and said: "It's really valuable to be able to network with and learn from the other larger patient organisation CEOs at these meetings and in particular to share ideas, share best practice and problem solve together".

We have frequently sent volunteers to the PARE Autumn / Spring conferences to represent NRAS and share their experiences of living with RA, and this has been a particularly rewarding experience for us both. These conferences are held in different cities in Europe, and often it is the first time our volunteer will have had the opportunity to represent NRAS in this way and network with other people with RMDs from across Europe, and sometimes even do an oral or poster presentation.

Our National Patient Champion, Ailsa Bosworth, is a member of the EULAR Patent Expert Partners Group which is developing a patient training course to provide training to Rheumatologists/Doctors in training, on how to examine joints, take a patient history and in shared decision making.

She is also a convenor with rheumatologist Elena Nikiphorou of a EULAR Taskforce which is developing recommendations for the implementation of self-management strategies in patients with inflammatory arthritis (for health professionals). These recommendations will be published in 2021.

We have also worked on a number of major Europe-wide campaigns, the most recent of which have been 'Don't Delay Connect Today' and 'Time to Work'. Many patient and healthcare organisations in EULAR came together with a unified voice to raise awareness of the importance of early diagnosis in rheumatic diseases in the case of the first, and the importance of supporting people with RMDs in the workplace in the case of the latter.

We were one of the organisations involved in working with EULAR to help shape their new 5year strategy from 2018-23.

For more information about our work with EULAR, please contact Clare Jacklin, clare@nras.org.uk

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