

EULAR 2023

What is EULAR?

EULAR (The European Alliance of Associations for Rheumatology) represents people with arthritis and rheumatism, health professionals in rheumatology (HPR) and European scientific societies of rheumatology. Its annual congress has become the primary platform in Europe for the exchange of scientific and clinical information about rheumatology.



Opening Lecture

The congress is one of the largest rheumatology conferences, attracting more than 12,000 delegates from around the world. There are many other important congresses including [APLAR](#) (Asia-Pacific League of Associations for Rheumatology Congress); [PANLAR](#) (Pan-American Congress of Rheumatology); and [ACR](#) (American College of Rheumatology), but EULAR is perhaps the most supportive of the patient community.



EULAR Exhibition Hall

Attendees listen to lectures and abstract presentations, and participate in smaller 'meet the expert' sessions. Posters highlighting key research are displayed, with researchers given time to discuss their work. Representatives from pharmaceutical companies meet with attendees in impressive exhibition spaces. Patient organisations and rheumatology associations have the opportunity to talk with people from around the world at their booths.

ASIF is a member of EULAR's PARE community (People with Arthritis/Rheumatism across Europe) and participate in the PARE meetings during the congress.

Why attend EULAR – and how?

EULAR provides an opportunity to meet people living with RMDs, doctors, scientists, health professionals, representatives from the pharmaceutical industry, rheumatology associations and patient organisations.



EULAR Poster Hall

Having an abstract or poster selected for EULAR may result in an invitation to present in person - this is invaluable recognition of your work and provides a complimentary pass to the congress. You may also get assistance with travel costs. EULAR PARE are running a webinar on 22 August at 16:30 CEST entitled **'How to write a successful abstract for the EULAR Congress'**. The webinar link will appear the day before the event on the [PARE Events Platform](#),

Key Outcomes for ASIF at EULAR 2023



Jo Davies and Maranda van Dam

ASIF's Booth was located on a main thoroughfare in the conference centre. Our team had the opportunity to speak with people from Argentina to Iraq, from New Zealand to Pakistan, Singapore to Ukraine, and many places in between! We strengthened relationships with leading rheumatologists and key figures within the international rheumatology field.

A number of applications to become members of ASIF have been received following conversations at EULAR. The ASIF team also offered support to fledgling organisations as well as the potential of assisting with the creation of new patient organisations. During the congress, we met with many of our industry supporters to discuss our projects. We are grateful to Abbvie, Galapagos, GSK, Lilly, Novartis and UCB for their time.



Maranda van Dam with Prof M Ahmed Saeed from Arthritis Care Foundation in Pakistan

Key Presentations

Of the 4582 submitted abstracts, ASIF's abstract was one of only 307 that were chosen to be presented as an oral presentation.

DATA MATERS: keeping track of your health information



Jo Lowe presenting at EULAR

During the Data Matters session, ASIF's Project Manager, Jo Lowe, presented the IMAS global report and its use as an advocacy tool for our members. The presentation was an expansion of the abstract which was accepted by PARE: 'The International Map of Axial Spondyloarthritis Global Report: supporting the inclusion of the patient perspective in policy and clinical practice'.

In her presentation, Jo underlined the need for IMAS to bring the patient perspective and experience to the attention of those involved in the care of people living with axSpA. She gave an overview of the breadth of data covered by the survey; and demonstrated the important role of ASIF and our members in helping to expand the survey internationally.

Jo presented a sub-set of the IMAS results, highlighting the significant physical disease burden and the daily life impact of living with axSpA. She concluded the presentation talking about the content of the global report and how our members will be able to use it. The evidence provided by the IMAS data, alongside the report's calls to action can be used by ASIF members to advocate for changes in policy and healthcare provision.

[See presentation slides.](#)

NOTE: The IMAS Global Report will be published by the end of 2023.

Links to Key Abstracts

The IMAS Scientific Committee, led by Professor Marco Garrido-Cumbrera (pictured below), University of Seville and Scientific Advisor to ASIF, also had the following abstracts published at EULAR. This means an excellent start for the dissemination of the IMAS findings, with abstracts also submitted to ACR and full papers currently being prepared for publication.



[Diagnostic delay in patients included in the international map of axial spondyloarthritis: associations with geographic, socio-demographic and disease-related factors](#)

[Females with axial spondyloarthritis report higher burden of disease and worse patient-reported outcomes. Results from the international map of axial spondyloarthritis \(IMAS\)](#)

[Regional differences in clinical phenotype of axial spondyloarthritis. Results from the international](#)

[map of axial spondyloarthritis \(IMAS\)](#)

[The international map of axial spondyloarthritis \(IMAS\). Results from the perspective of 5,557 patients from 27 countries around the world](#)

[Which factors are associated with clinically high disease activity in axial spondyloarthritis? Results from the international map of axial spondyloarthritis \(IMAS\)](#)

FACILITATE data sharing, re-use and return of clinical trial data to study participants



The Facilitate project aims to address issues around data sharing, and the re-use and return of clinical trial data to patients. It aims to create a social alliance amongst key public and private stakeholders committed to global health improvement, by reducing barriers present in the current ethical and legal data eco-system. As a first step it will identify and drive actionable steps to return clinical trial data to patients.

There is an increasing focus on patient-centricity in clinical trials. Currently there is a lack of trust from patients stemming from the fact that patients rarely get their data back.

Johanna Maria (pictured) discussed the importance of trust; privacy: the right to opt out; truly informed consent; clarity on data ownership and access; and the need to access high quality data. She also commented on the value of building in safeguards to the new

system, with different structures across different countries and states. The EMA and FDA have already expressed interest in the FACILITATE project.

The presentation concluded, noting that building a fair and transparent alliance will build solidarity and trust – something that is critical for patients.

The EULAR RMD Registry – a web-based system to collect data for research directly from patients

Anna Moltó (pictured below) began her presentation stating that patients are at the centre of modern RMD research, and must share in decision making. However, the problem is often that patient and doctor treatment goals are different. The doctor may be focused on reducing inflammation, whereas the patient is focused on being able to take their child to school.



Patients are the experts, especially when it comes to the impact of the disease on their daily life. Patient Reported Experience Measures (PREMs) are an important source of information, and can assist in considering patients holistically, rather than looking at one isolated aspect of their condition. Outcomes such as pain, function, fatigue and depressive symptoms can only accurately be reported by the patient themselves.

The EULAR RMD Registry aims to provide EULAR with robust data from a large patient population. Patients will be invited to join the registry and participate in repeated surveys which will identify gaps in care and the impact of the disease long-term. Data will only be collected from patients and not HCPs.

Watch session reviews and discussions

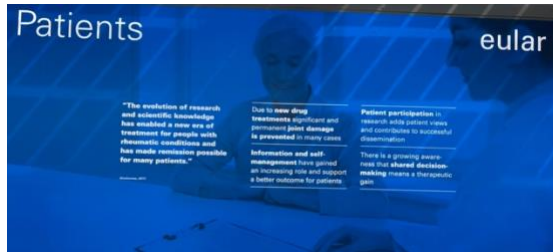
AiArthritis have produced a series of excellent videos from EULAR.

[Watch now](#)

Key Press Releases

Harnessing Patient Power

Patient organisations drive change in rheumatology. EULAR includes PARE, a network of national organisations of People with Arthritis/Rheumatism across Europe. This body is united in its mission to ensure the voice of people with RMDs is heard. [Read more](#)



A Closer Look into Axial Spondyloarthritis

New data expand disease understanding from the longitudinal SPondyloArthritis Caught Early cohort (SPACE) study and an online survey into regional differences in clinical phenotypes. [Read more](#)

Managing Anxiety and Depression in Arthritis

In 2021, EULAR published recommendations for the implementation of self-management strategies in people with inflammatory arthritis. These focused on empowering patients to become active team partners and take a more proactive role. Now, new data examine the link between self-management and mental health in this patient group. [Read more](#)

EULAR Launches 'RheumaFacts', a Unique and Pan-European Data Depository for Rheumatic and Musculoskeletal Disease Indicators

'RheumaFacts' draws a map of the socio-economic and healthcare realities in the field of rheumatology across Europe. It will serve as a powerful tool to provide data-driven insights on the status of rheumatological care across EULAR's member countries. [Read more](#)



EULAR Press Conference

CV Risk in Psoriatic Arthritis

Patients with psoriatic arthritis (PsA) have an increased risk of cardiovascular disease, possibly due to a chronic inflammatory state. New evidence shared at supports this, showing that aortic vascular inflammation is increased in patients with active PsA compared with controls. [Read more](#)

Physiotherapy in Your Pocket

Digital Apps may be useful to support people with RMDs when they are undergoing functional rehabilitation. New data suggest that Apps which provide support for exercise can significantly improve a range of outcomes, including physical function, quality of life, and adherence. [Read more](#)

The 6th Annual EAfPA Meeting for RMD Patient Advocates

The annual European Alliance for Patient Access (EAfPA) meeting for RMD (Rheumatic and Musculoskeletal Diseases) patient advocates took place as a Related Meeting of the EULAR Congress. The meeting was attended by various representatives and experts in the field. [Read more](#)

EULAR 2023 took place in Milan, Italy, 31 May – 3 June