ASIF Newsletter: September 2025

Message from the President

Dear friends,

We recognise that local patient organisations know better than anyone the needs of their communities. This is why ASIF is run by our members, for our members. We recently invited our members to tell us what they thought our priorities should be, what we were doing well, what we could do better and how we could support them. We are grateful to everyone who completed the *Voice of the Members* survey and for the feedback and direction they have given us.

As we take steps towards the next stage of the International Map of Axial Spondyloarthritis (IMAS) project, the guidance of our members is critical. We have recently established a new IMAS Sub Committee which includes ASIF members from around the world. We will rely on them to ensure that IMAS continues to collect data that is both relevant and useful to our members' work.

I am delighted to welcome our newest member, 3majmy Się Razem (Polish Association which focuses on Inflammatory Connective Tissue Diseases as well as axSpA) from Poland. A small volunteer-led organisation, they have expanded their support to people living with axSpA and are the only such organisation in Poland. I personally look forward to working with them over the coming years.

Best wishes,

Zhivko Yankov
Chair of ASIF

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World AS Day

23.7 million people reached

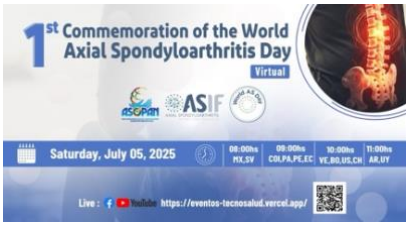
This year's World AS Day campaign reached approximately 23.7 million people worldwide on social media. In addition, many of our members held events, in person and virtual, raising awareness with an even greater number of people. The campaign targeted rheumatologists and other heathcare professionals (HCPs), people living with axSpA but without a diagnosis, those with a diagnosis and the general public.

Read more about the results of the campaign in our World AS Day Report (https://asif.info/wp-content/uploads/2025/09/World-AS-Day-2025-Report.pdf).

Thank you to everyone who raised awareness through World AS Day this year.

Save the date for next year's campaign: Saturday 2 May 2026

News from ASIF



A Shared Voice for axSpA: Highlights from the ASIF–ASOPAN World AS Day Event

The Spanish speaking axSpA community were invited to an informative and interactive webinar on 5 July. The event, held in commemoration of World AS Day was co-hosted by ASIF and ASOPAN the pan-American network of rheumatic patient associations. The half-day webinar, held in commemoration of World AS Day, was streamed on Facebook and YouTube. Inspiring talks from international experts, diving into topics that matter most to our community, included:

- **Comprehensive treatment approaches** that look at the whole person, not just the symptoms.
- How **women and children** can experience the disease differently—and why this matters for diagnosis and care.
- The vital role of **physical activity and good nutrition** in managing axSpA and boosting quality of life.

For people living with axSpA, it wasn't just an educational event—it was a space to connect, ask questions, and share experiences with people who truly understand. Many described feeling part of something bigger: a global community with a shared voice and vision**.**

One of the strongest messages of the day was the importance of early diagnosis. Delays in detecting axSpA—a global average of over seven years—can lead to irreversible damage, functional limitations, and significant emotional burden. By highlighting this issue, ASIF and our partners continue to push for earlier recognition and better outcomes for people living with the condition.

The event was more than a commemoration—it was a step toward a healthier, more informed future. By bringing together evidence-based knowledge, personal stories, and expert guidance, the event showed the power of collaboration in tackling the challenges of this disease head-on.

We hope that this event is the first of many collaborative initiatives between ASIF and ASOPAN as we work to improve the lives of people living with axSpA in Latin America.

📺 **Watch the full event here:** First World AxSpA Day – YouTube Live Recording

Watch this space: We are interested in creating French and German speaking ASIF groups. More information coming soon!

Save the Date: ASIF AGM

12:00 GMT, 15 October 2025

ASIF Members are invited to join our online Annual General Meeting (AGM). Meeting details and the TEAMS link will be emailed to members on 12 September.

Member Spotlight

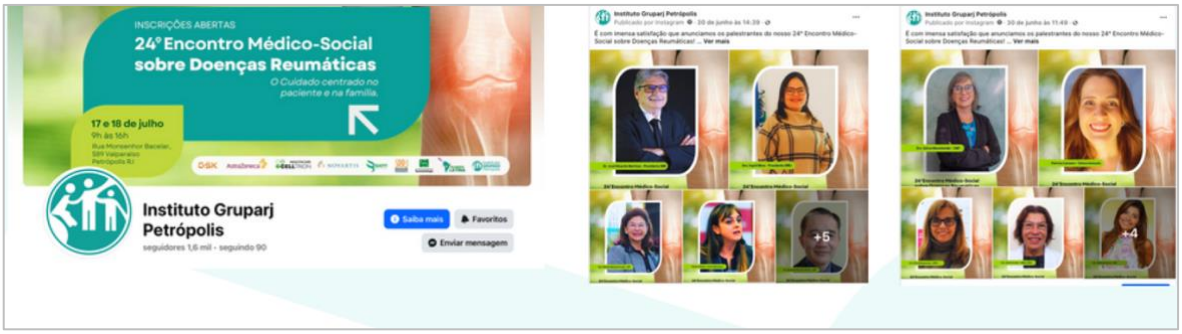
Brazil's 24th Medical-Social Meeting on Rheumatic Diseases

The Gruparj Petrópolis Institute hosted the 24th Medical-Social Meeting on Rheumatic Diseases in Petrópolis, Brazil in July. Over two days, more than 250 participants—patients, families, health professionals, researchers, and policymakers—came together to exchange knowledge and lived experiences of rheumatic conditions.

The event was organised with the support of the Brazilian Society of Rheumatology (SBR), the Rio de Janeiro Society of Rheumatology (SRRJ) and Alianza Latina, and highlighted the power of collaboration between patient groups and medical societies.

Key themes for patient organisations worldwide

- **Patient-centred dialogue**: The meeting prioritised the voices of people living with rheumatic diseases, creating a space where patients could ask questions directly to specialists. This openness fostered mutual learning between clinicians and the community.
- **The importance of early diagnosis**: Several sessions highlighted warning signs for conditions like lupus, psoriatic arthritis, and axial spondyloarthritis, stressing the role of primary care and patient awareness in achieving earlier, more effective treatment.
- **Living well with chronic illness**: Panels addressed nutrition, mental health, and non-pharmacological approaches such as dance, meditation, and skin care routines—reminders that holistic wellbeing is as crucial as medication.
- **Addressing comorbidities**: Diabetes, obesity, and cardiovascular risks were discussed alongside rheumatic diseases, recognising the broader health challenges patients face.
- **Equity of access**: The journey of people with lupus in Brazil underscored global challenges in accessing timely diagnosis and effective treatment, something that is frustratingly shared across many rheumatic diseases.



Reaching wider audiences

The event gained visibility beyond the two days of sessions. Coverage included features in local and specialised media, while Gruparj Petrópolis Institute's own communication strategy—using newsletters, website updates, and social media—helped drive engagement. On Facebook and Instagram alone, the campaign reached more than 34,000 people and achieved high levels of interaction, amplifying the event's messages and ensuring patient voices were heard more widely.

A model for others

Dr José Eduardo Martinez, President of the Brazilian Society of Rheumatology, described Gruparj's work as a potential model for replication across Brazil. This is a great example of how grassroots initiatives can influence national practice—and why collaboration between stakeholders is vital.

Although this meeting took place in Brazil, its themes resonate regionally and internationally. The growing emphasis on patient–doctor partnerships, early detection, and comprehensive care mirrors priorities shared by patient organisations in many countries. The programme also demonstrated how partnerships between local patient organisations, national medical societies, and global networks like Alianza Latina can strengthen advocacy and improve care.

Read report in Brazilian Portuguese (https://asif.info/wp-content/uploads/2025/09/Relatorio-Encontro-2025.pdf).

Go With Us

Written by Julia Mani, Ai Arthritis

"Go With Us" is a unique experience where patients and caregivers around the world can virtually join the AiArthritis team as we attend research conferences. This is a one-of-a-kind opportunity to connect to the latest research, communicate with those attending, and learn how this information ties into improving disease management.

In June, the AiArthritis team attended the European Alliance of Associations for Rheumatology (EULAR) conference in Barcelona. Our team created recap videos to provide a patient-centric perspective on the topics and research presented at the conference. To watch all of the videos, click here (https://www.youtube.com/playlist?list=PLZW5ZyvNnYl3wsrI7usV495JH2OMfUdzN)

This October, the AiArthritis team is headed back to the American College of Rheumatology (ACR) convergence, one of the biggest rheumatology research conferences of the year. Interested parties can virtually "Go With Us!" to this conference and learn about the latest

research ***from patients*** who attend the sessions, meet people we meet, and better understand how the information we share can help you better navigate your own journey with AiArthritis diseases. To sign up for this experience, fill out this interest form (https://zfrmz.com/DDhRnzQrJyxXEuTfA26M .

AiArthritis Voices:

AiArthritis Voices is a free service provided by the International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis) that connects our community to patient-inspired resources, guidance, and programmes that are based on patient-identified issues and patient-infused solutions. Through this, we also connect our community with opportunities to get more involved in our programmes and resource creation. Anyone who is connected to persons living with AiArthritis diseases is eligible to join, including: those diagnosed, those who are not yet diagnosed, parents/guardians of juvenile patients, caregivers, healthcare professionals, researchers, companies, etc.

Additionally, we send an **AiArthritis Voices Monthly Newsletter** is sent to the Voices participants. Each monthly newsletter will share opportunities to get more involved including the latest patient-centric events, participation opportunities, and updated tools and resources that will help those affected by AiArthritis diseases. If you're interested in signing up for AiArthritis Voices, follow this link (https://forms.zohopublic.com/internationalfoundationforau1/form/AiArthritisVoicesApplication/formperma/HrkDedZcNSxR8518zKX9Y4CmxNBH4Z86DSQBNViSw88).

International News

Global Remission Coalition

ASIF is a founding member of the newly-launched Global Remission Coalition (GRC), a platform for remission stakeholders to collaborate, advocate, and elevate the narrative about the value of remission to the patient, health systems and society. Its founding members and leadership envision healthcare systems that prioritise the pursuit of remission in chronic inflammatory conditions so that patients can do more than just manage their symptoms and can ultimately live fuller lives.

The GRC realises that not every patient with an inflammatory condition such as axSpA can achieve remission, but it should be the goal for all.

ASIF played a key role in bringing the Coalition to life – following stakeholder conversations in early-2025. In April, the Global Alliance for Patient Access (GAfPA), who serve as the GRC Secretariat, hosted a webinar. ASIF Trustees, Lillann Wermskog, Nadia Malliou and Programme Manager, Jo Lowe spoke about the importance of pursuing remission, or the best possible disease control, in axSpA, and setting the stage for a broader conversation on remission as an important treatment goal. Following the webinar, the GRC was officially launched by GAfPA in May 2025 alongside the World Health Assembly in Geneva. ASIF's Director of Operations, Jo Davies, attended the roundtable event that served as the Coalition's official launch vehicle and is a member of the GRC Steering Committee.

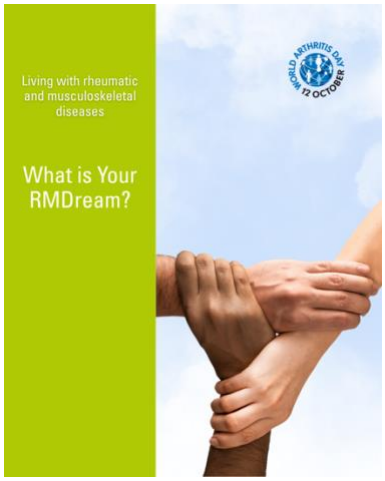
Despite having launched just three months ago, the Global Remission Coalition has already released a number of valuable resources for the community, such as an Evidence Glossary (https://globalremission.org/2025/06/12/the-value-of-achieving-remission-in-inflammatory-rheumatic-conditions-an-evidence-glossary) on the value of achieving remission in inflammatory conditions. The Glossary introduces new data that deepens our understanding of remission and what it means to patients – in particular, the Glossary provides updated evidence that highlights the links between rheumatic conditions and chronic pain and stresses the importance of early interventions in the workplace. The Glossary is now available in English, Spanish, French, Portuguese, German, and Italian.

Along with its resource library hosted on the website, the Coalition holds regular webinars. The last webinar, held in July, provided the opportunity for Coalition members and interested stakeholders to interact with some of the researchers and clinicians behind the Evidence Glossary, learning more about its development process and key findings.

ASIF member organisations are all eligible for membership of the Global Remission Coalition and can register here: https://globalremission.org/membership-form.

If you are interested in keeping up to date with the Coalition's work and upcoming events, you can also register for them via https://globalremission.org.

World Arthritis Day – 12 October 2025



World Arthritis Day (WAD) is a global awareness day aimed towards increasing knowledge of the existence and impact of rheumatic and musculoskeletal diseases (RMDs). This year's theme is: What is Your RMDream?

EULAR have created a set of social media assets and key messages. The assets and more information about the campaign can be found at www.eular.org/world-arthritis-day-2025.

Webinar: "Achieve Your Dreams"
Four EULAR Communities (EMEUNET, HPR, PARE, PAED) come together to share their dreams and visions.
15 October, 16:00-17:00 CEST. Register at the link above.

Calling all ASIF Members: The Global Remission Coalition are exploring the development of a video campaign for World Arthritis Day that features the lived experiences of people who have achieved remission. If there is someone in your network who has achieved remission and might be interested in speaking in a brief video clip to support their World Arthritis Day campaign plans, please contact Cassie Dormond at c.dormond@globalremission.org. GRC will also highlight World Arthritis Day activities in their next newsletter – please contact Cassie to be featured.

What's New with You?

Are you working on a new campaign? Have you had success with a new initiative? Is there some interesting research happening in your country? What would you like to read about in this newsletter?

If there is something that you think others around the world would be interested in hearing, let us know! Send an email to Jo de Bry at CommunicationsManager@asif.info.

Dates for your Diary 2025/6

October 2025
12 World Arthritis Day
15 ASIF AGM

November 2025
24-29 ACR Convergence, USA

April 2026
27-30 PANLAR, Panama

May 2026
2 World AS Day
14-16 SPARTAN (Spondyloarthritis Research and Treatment Network) Annual Meeting, Canada
14-17 CORA (Controversies in Rheumatology & Autoimmunity)

June 2026
3-6 EULAR, UK

October 2026
12 World Arthritis Day
28-1 November APLAR, South Korea

For more dates, visit our events page (https://asif.info/events)

ASIF is grateful to its industry partners

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