ASIF
AXIAL SPONDYLOARTHRITIS
INTERNATIONAL FEDERATION

ASIF Newsletter: March 2025

Message from the President

Dear friends,

With 2025 now well under way I am excited about what this year will bring for our community. Preparations are well under way for World AS Day – you can read more about this year's campaign below.

In February, the ASIF Trustees met in Istanbul, where we had the pleasure of welcoming René Bräm as our new Treasurer. René has been an important part of ASIF's journey in the past, and we're delighted to have him rejoin the Board of Trustees. You can learn more about René and his role in the pages that follow.

Best wishes,

Zhivko

Zhivko Yankov
Chair of ASIF

Contents

News from ASIF

New Treasurer for ASIF

We are delighted to welcome René Bräm as ASIF's new Treasurer. Rene is the director of the Swiss Ankylosing Spondylitis Association and is a board member and trustee of national associations and foundations in Switzerland. René has supported ASIF since its foundation, when for many years he was the treasurer as well as working as an auditor. With his renewed involvement as treasurer, he commented that he would like to contribute to people with axSpA being diagnosed earlier, being able to cope with everyday life and participate in social life despite the disease.

As our previous Treasurer, Susan Davies stepped down between AGMs, the Trustees co-opted René at their meeting in Istanbul in February. René will be invited to nominate himself prior to the election at the AGM later this year where ASIF members will have the opportunity to vote for him to remain in the role.

New Expert Advisory Committee

ASIF has recently established a multi-disciplinary Expert Advisory Committee (EAC), which provides a healthcare perspective on ASIF's work. Alongside patient organisations, the committee includes rheumatology; physiotherapy and rehabilitation; nursing; psychology; and epidemiology experts. The EAC is geographically diverse with members from five continents. The steer of the committee ensures that ASIF's work is impactful, relevant and credible; and that we are able to explore new opportunities from a range of different healthcare perspectives.

The committee met for the first time on 4 March laying the foundations for their role in guiding ASIF's future work.

We are grateful for each of the members of the committee for their guidance and commitment to improving the lives of people living with axSpA.

The committee includes:
Tuncay Duruöz, Turkey - EAC Chair
Wilson Bautista-Molano, Colombia
Deniz Bayraktar, Turkey
Christine Bundy, UK
Moataz Daoud, Canada
Marco Garrido-Cumbrera, Spain
Muhammad Asim Khan, USA
Robert Landewé, Netherlands

Ajesh Maharaj, South Africa
Nadia Malliou, Greece
Helena Marzo-Ortega, UK
Mwidimi Ndosi, UK
Andri Phoka, Cyprus
Yeliz Prior, UK
James Cheng-Chung Wei, Taiwan

Read more about the EAC members here.

ASIF Council Meeting Report

The ASIF Council Meeting in Bogota at the end of last year was a great success with nearly 50 representatives from 25 countries across all continents. Our members shared ideas and experiences, whilst experts spoke about the latest developments in axSpA research, the role patient organisations can play in psychosocial health and many other topics.

Read more about the Meeting in our Report.

HCP Education: ASIF Member Webinar

One of the major factors in the delay to diagnosis is the lack of knowledge about axSpA with non-axSpA specialist health care professionals (HCP). In this webinar, we will hear from ASIF members who have run successful HCP education programmes in their country. There will be the opportunity for questions and discussion.

Join us on Monday 19 May at 14:00-15:00 BST on Zoom. Contact Jo de Bry (communicationsmanager@asif.info) to register.

World AS Day

World AS Day takes place on Saturday 3 May 2025.

This year the theme is **'Lace up for axSpA'**. The campaign highlights the everyday challenges of living with axSpA. Tying shoelaces is just one example of an 'everyday challenge' – the materials feature other tasks including drinking from a water bottle, checking traffic before crossing the road, reaching for something from a high shelf and bending to pick up something from the floor.

Working together, ASIF, our members, industry supporters and other key stakeholders, along with individuals who are affected by axSpA can raise awareness of axSpA with a global audience.

The World AS Day **webpage** is live and the campaign has begun with save the date messages being shared on social media. Over the coming months we hope to see many of our assets being shared across different challenges by you – our colleagues around the world.

The campaign assets have been designed to be used as is – or as templates. It is important that the campaign works for you and your organisation – so please translate and personalise the content. The most important thing is that you use it!

If you can't post directly – please share our posts.

Resources

The downloadable **Toolkit** provides information about the campaign and how you can best use it. A **social media content calendar** provides template copy for use on social media as well as the date on which ASIF will be posting key content (this is in the social media downloadable assets folder). **Editable social media assets** have been created in Canva to enable them to be translated and adapted for use by our colleagues around the world. In addition to social media assets, there are **website banners** and **email footers**, both static and animated versions of the **World AS Day logo**. Non-editable assets are also available to download and are ready to be used.

A new short **video** and social media teasers have been created, featuring people living with axSpA completing everyday tasks. The videos tell a story of how these tasks can be challenging for people living with axSpA. If you would like the videos translated into your local language, please contact Jo de Bry (CommunicationsManager@asif.info).

We recently held **webinars** introducing the campaign and sharing how to make the most of the materials. If you missed it, you can watch it by clicking on the link below.

World AS Day webpage: https://asif.info/worldasday
Resources: https://asif.info/worldasday/#wasd-resources
Webinar recording: https://youtu.be/ynSVxd39WlQ

Lace up for axSpA Challenge

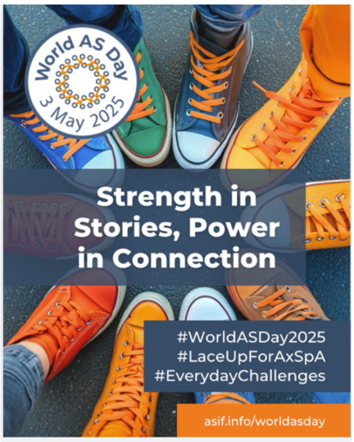
We invite you to 'Lace up for axSpA'! Please share the corresponding social media posts and encourage your local community to get involved and raise awareness through their own social media channels.

Simply, take a photo or video of you tying your shoelaces - get some orange laces if you can - or you can use your regular laces. Post your photo or video on social media using #WorldASDay2025, #LaceUpForAxSpA and #EverydayChallanges.

Add something about your personal experience with axSpA – do you or a loved one have the condition?

You can add the following to your post:

I'm raising awareness about axial spondyloarthritis (#axSpA) by participating in #LaceUpForAxSpA on #WorldASDay2025.



You can add something about your story here.

Or use the following:
AxSpA is a chronic rheumatic disease that can cause severe pain and stiffness in the lower back, hips and buttocks and if left untreated can cause permanent damage to your spine. The pain often gets worse with rest and often appears before the age of 40.
Find out more at asif.info/worldasday

You can insert the URL to your organisation's World AS Day webpage or an article on your website.

Hashtags

Use our hashtags to amplify your voice and be part of the conversation! #WorldASDay2025, #LaceUpForAxSpA and #EverydayChallanges.

Events

Promote your events on our webpage! Simply complete the form on the page and we will promote the event on our site and on social media.

The Chronic Pain Club Talk Show

Tune into Joel Nelson's Talk Show on Sunday 4 May at 19:00 BST. Joel will chat to ASIF Trustee and psychologist Nadia Malliou about all things World AS Day and her experience of life with axSpA. (www.youtube.com/@JoelvsArthritis)

Alfasigma's World AS Day Webinar
Alfasigma will raise awareness with their staff about axSpA during a webinar. Jo Davies, Jo Lowe and Jo de Bry will speak about ASIF, World AS Day, IMAS and living with axSpA.

We would be delighted to assist industry, our members and other stakeholders in raising awareness. Please contact Jo de Bry (communicationsmanager@asif.info) to find out how we can help.

Global Spondyloarthritis Summit
Registration is now open! Join us on May 2-3, 2025, for the Spondylitis Association of America's 7th Annual Global Spondyloarthritis Summit—a free, virtual event bringing together top experts to explore the latest in SpA care.

This year's theme: "Comorbidities: A Whole-Body Approach to SpA". Explore how SpA connects to cardiovascular disease, IBD, osteoporosis, mental health, pain & fatigue, uveitis, and more.

Event Details:
Dates: May 2-3, 2025
Time: 8:00 AM – 4:00 PM PDT
Location: Online – Join from anywhere in the world!
Cost: FREE

See the full agenda and register here: https://spondyloarthritissummit2025.vfairs.com/

For the first time the Summit will include a Virtual Poster Hall. ASIF members are invited to submit a poster and presentation about their work. Contact Kristine at SAA (Kristine.eskandari@spondylitis.org) if you have any questions or to find out more.

Walk Your AS Off
Walk Your AS Off has taken on the World AS Day theme! The SAA has produced durable, vibrant orange laces with SAA branding that will be eye catching on your sneakers. The SAA encourage you to wear your orange shoelaces while you count steps for Walk Your AS Off for greater visibility and conversation! Order today at*:
https://spondylitis.org/product/saa-orange-shoelaces/

Walk Your AS Off is an international virtual walking event! You can walk anywhere at any time, log your steps and be part of this exciting initiative to get people moving whilst raising awareness about axSpA. You can find out more about Walk Your AS Off at the SAA's website: https://spondylitis.org/walk-your-as-off/.

*North American shipping only. For international orders, please contact Sean Ewert at sean.ewert@spondylitis.org

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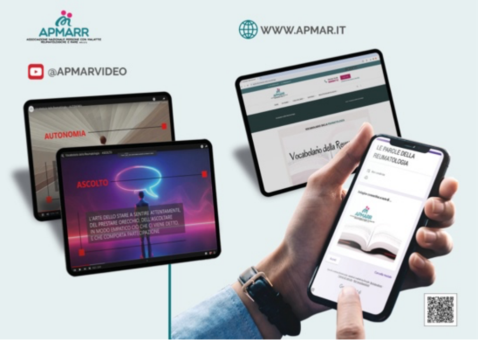
Social Media Grants

ASIF awarded full World AS Day Social Media Grants to Axial Spondyloarthritis Association of South Africa, Bekhterev Norge (Norway), Coordinadora Española de Asociaciones de Espondiloartritis (CEADE) (Spain), Panamanian Arthritis Foundation of Panama (FUNARP), Hellenic League Against Rheumatism (ENEANA) (Greece). We also granted matched grants to Canadian Spondyloarthritis Association (CSA) and Instituto Gruparj Petrópolis (Brazil). We are excited to see how the grants help each organisation raise awareness during the World AS Day campaign.

Spotlight on our Members



APMARR

Associazione Nazionale Persone con Malattie Reumatologiche e Rare (APMARR), celebrated its 40th anniversary last year. APMARR's mission is "to improve the quality of assistance and to improve the quality of life" offering help and information to people with rheumatic and rare diseases through volunteering, psychological support, awareness campaigns. APMARR runs national and local activities throughout the year, including free screening to assist in early diagnosis. It's advocacy efforts include organising workshops and meetings with political decision makers and media to highlight the social and human rights of children and adults with rheumatic diseases.

APMARR also promotes research in the field of rheumatology. On its 40th anniversary, APMARR launched a research project, conducted by WeResearch Institute, investigating the quality of life for people affected from rheumatic and rare diseases.

The results suggest that the negative impact rheumatic diseases have, may result in people having to rethink and reshape their "Life Plan", particularly in relation to work, leading to a reduction in hours, change in job or having to stop work.

The study suggested that people who were unaffected by rheumatic diseases didn't feel they had enough information about the conditions. It is thought that this lack of understanding in the general population is a contributing factor in the delay to diagnosis.

In recent years, research has better understood the mechanisms underlying numerous rheumatologic diseases. It has identified the role of inflammation and therapeutic targets, and developed innovative drug classes that can block the inflammatory cascade and lead to remission, if not cure. The goal of these medicines is to prevent disease progression and disability.

This new scenario necessitates a review of the changes in treatment and the diagnostic paradigm and, therefore, a revision in the language used to talk about rheumatologic diseases. The language must adapt to innovation, emerging needs and to the increased awareness of patients, who must be active participants in their treatment pathway.

For this reason, APMARR launched an educational project named "The vocabulary of rheumatology" to help patients navigate the wealth of information found on the web. It provides them with the tools to become protagonists of their own care pathway, exploring the terms that accompany the world of rheumatology. These terms come from the scientific sphere, including those related to drugs and biomedical science. This project is aimed at patients and caregivers, with the goal of familiarising them with the lexicon of rheumatology and making the concept of empowerment and engagement tangible.

The "vocabulary of rheumatology" is one of several initiatives promoted by APMARR to educate and inform people on the rheumatic and rare diseases. APMARR also involves and assists people through the toll-free number, its magazine "Morfologie" and its social media which reaches an online community of more than 5,000 users.

For more information about APMARR's work please visit: www.apmarr.it

International Meetings

ASAS Annual Meeting

Jo Davies and Jo Lowe were delighted to attend the ASAS annual meeting in January. This year's event marked 30 years of ASAS and was held in Maastricht, in the

Netherlands where the organisation was founded in 1995. It was a fitting way to commemorate the success and achievements of ASAS over the last three decades.

Pictured: Jo Davies, Victoria Navarro Compán, Xenodib Baraliakos and Jo Lowe

During the meeting, Désirée van der Heijde gave a keynote speech describing how and why ASAS was founded and reflected on the main contributions to the spondyloarthritis field over the years. During the gala dinner, a birthday cake was presented and awards given to the members of the first Executive Committee. The ASAS founders, Sjef van der Linden, Désirée van der Heijde, Maxime Dougados, Asim Khan, Andrei Calin and Nick Bellamy were celebrated for their achievements.

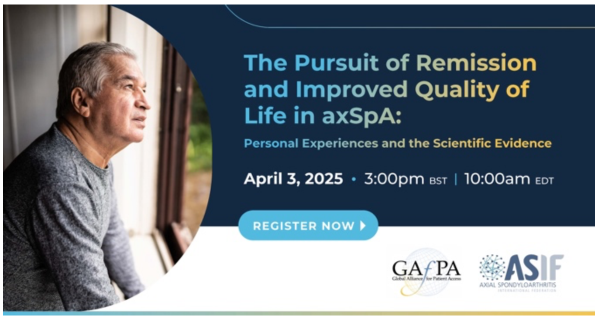
In recent years, the collaboration between ASAS and ASIF has developed significantly and ASIF now has a place on the working groups of two key ASAS projects. Discussing these projects in person and hearing them presented to the wider ASAS membership was a fantastic opportunity. It helps us to understand the engagement and enthusiasm of ASAS members' contributions and puts into context the rigour with which the organisation's guidelines and endorsements are developed.

There were also some changes in personnel with Raj Sengupta from The Royal National Hospital for Rheumatic Diseases in Bath (UK) being elected to the Executive Committee; two new leaders of Young ASAS (Clementina Lopez Medina and Murat Torgutalp) and a handover in ASAS leadership from Xenofon Baraliakos to Victoria Navarro Compán.

During the final session of the meeting, this handover was an opportunity for Xenofon to thank the members of ASAS and reflect on his five years leading the organisation. Victoria discussed the future of ASAS and what the next five years under her leadership might look like; she also had some wonderful words of admiration for Xenofon and used the occasion to present him with gifts to celebrate his tenure.

The Pursuit of Remission and Improved Quality of Life in axSpA

Join the Global Alliance for Patient Access (GAfPA) and ASIF's for a webinar highlighting the value of pursuing remission in rheumatic and musculoskeletal diseases.



The Pursuit of Remission and Improved Quality of Life in axSpA:

Personal Experiences and the Scientific Evidence

April 3, 2025 • 3:00pm BST | 10:00am EDT

REGISTER NOW

ASIF Trustees Nadia Malliou and Lillann Wermskog, and Jo Lowe, Project Manager at ASIF, will be talking to Neil Betteridge, Strategic Advisor for European Alliance for Patient Access, about axSpA, an overview of the disease, an introduction to ASIF and IMAS data and the value of achieving remission or low disease activity from a personal perspective as a patient.

Resources

What is axSpA? Treatment options, Living well with axSpA, Getting the most out of your rheumatology appointments, Building a partnership with your doctor – these are just some of the guides available for download on our Resources webpage. In addition to patient-focused guides, there is information about ASDAS and BASDAI, webinar recordings, videos and guides on exercise and movement and guides specifically for patient organisations.

Visit our Resources pages now! https://asif.info/resources-about-axspa

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March	
6-8	Controversies in Rheumatology and Autoimmunity (CORA), Italy
April	
3-4	Biosimilars Medincines Conference, Netherlands
23-26	PANLAR, Mexico
28-30	British Society for Rheumatology Annual Conference (BSR), UK
May	
	Walk Your AS Off, virtual
2-3	Global Spondyloarthritis Summit, virtual
3	World AS Day, virtual
19	ASIF Member Webinar: HCP Education
June	
11-14	EULAR, Spain

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

ASIF is grateful to its industry partners

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