

ASIF Newsletter: June 2023

Message from the President

Dear friends,

The ASIF team spent last week at the annual European Alliance of Associations for Rheumatology (EULAR) congress. They raised awareness about ASIF and how we can support patient organisations. If you met the team at EULAR and you are receiving this newsletter for the first time – welcome! We look forward to continuing our conversations with you.



During this year's World AS Day campaign, more than 48 million people were reached with information about axSpA! For so many of us, the first time we heard about axSpA was when we were diagnosed. We know the global delay in diagnosis is around 7 years – raising awareness of axSpA is part of the solution. So, thank you to everyone who posted, tweeted and shared the campaign on social media; to those that organised and attended events and told people about this life changing disease. Together we are stronger.

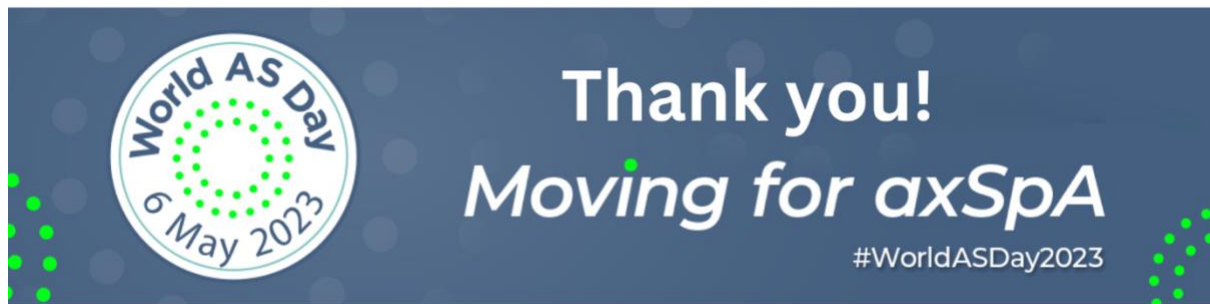
Best wishes,

Zhivko Yankov
President of ASIF

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World AS Day reached more than 48 million

The World AS Day awareness campaign reached more than 48 million people around the world. This is a significant jump from previous years. And that is just half the story – our members, industry partners, healthcare practitioners and people living with axSpA posted, tweeted and shared content through their own channels resulting in the awareness campaign reaching a much larger number. In addition to social media, in-person and online events were held around the world, including a series of walks in South Africa, workshops in Colombia, and conferences in Italy and Spain.

More than 70,000 people visited the ASIF website during the campaign, with over 90% of them spending enough time on the World AS Day page to understand the campaign and learn more about axSpA.

A comprehensive report on the campaign is being written and will be shared with members soon.

Global Stretching Events



Two 'Stretch and Move' events got people moving on World AS Day. The events, run by Jamie Boder and Geoff Lindsay, co-Founders of [Yoga for AS \(yogaforas.com\)](http://yogaforas.com), were designed specifically for people with axSpA. Jamie and Geoff, who both have axSpA, provided options for each pose, making the sessions accessible to everyone

regardless of their level of flexibility. The sessions were watched on our website and social media channels. Delegates at the SAA's Global Spondyloarthritis Summit had the opportunity to watch the sessions during the Summit in the Activity Lounge.

The sessions are available to watch on our website (asif.info/worldasday). They will feature on our Resources webpage long-term so they can be used at any time.



Liked by [all_about_that_as](#), [healing_ankylosing_spondylitis](#) and 5 others
[a_chronic_pain_in_the_as](#) Kicking off the Walk Your AS Off Challenge with a walk around the block 🐾
[#walkforarthritis](#) [#walkyourasoff](#) [#walkyourasoff2023](#)

Walk Your AS Off

Written by Jennifer Visscher, Walk AS One

This virtual walking campaign brought together people from around the world, united by a common goal—to raise awareness and support for axSpA and related spondyloarthritis diseases. The campaign's achievements are a testament to the strength, determination, and unwavering support of the incredible community of participants.

Uniting for a Shared Cause:

The Walk Your AS Off campaign rallied individuals affected by axSpA and AS, their families, friends, and supporters, generating a powerful sense of unity. Together, participants embarked on a journey, symbolising the daily challenges faced by those living with the disease.

The impact of the 2023 Walk Your AS Off Campaign was felt not only within the community but also in the broader public sphere. Through the dedication and passion of participants, the campaign spread awareness, educating others about the condition, and broke down stigmas associated with invisible illnesses.

As Cheryl said, "I had no idea I could do even 200 steps a day. When I was inspired to join Walk Your AS Off, I couldn't believe I was doing thousands of steps a day and I could see and feel my progress. Walk Your AS Off gave me the courage and community I needed to take steps to be more active and I'm so very grateful for that."

A Global Movement:

One of the most remarkable aspects of Walk Your AS Off is its ability to connect individuals from all over the world. The campaign transcends borders, fostering a global movement that promotes solidarity, empathy, and understanding. It has created an international platform for sharing experiences, providing support, and spreading awareness about axSpa on a global scale.

Congratulations and Appreciation:

To every participant, supporter, and volunteer involved in this year's campaign, we extend our heartfelt congratulations and deepest appreciation. Each step taken, every conversation initiated, and every dollar raised has made a difference in the lives of individuals living with AS.



Recap of SAA's 5th Annual Global Spondyloarthritis Summit

Written by Jason Blackwell, SAA

SAA's 5th Annual Global Spondyloarthritis Summit is a two-day virtual event designed by and for the spondyloarthritis community. Held each year across World AS Day during SpA Awareness Month, the Summit features 12 global rheumatology and health experts, presentations and speakers are vetted by an advisory committee composed of patients and physicians to identify the topics that are most important for people living with the disease. Now in its fifth year, the Summit had more than 3,000 registrants attend from 92 countries. Our post event survey found that 98% of respondents would recommend the Summit to others living with SpA, and 99% plan to attend in 2024!

This year's program featured the topics below:

- What is Spondyloarthritis? An Overview presented by Christine Stamatou, DNP, ANP-C, Northwell Health
- Medications for SpA - Including New (i.e., JAKs) and What's on the Horizon. Drug Combinations & Interactions presented by Robert Inman MD, FRCPC, FACP, FRCPC (Edin), Schroeder Arthritis Institute at University of Toronto
- SpA Research Update (Advanced Topic) presented by Kristi Kuhn, MD, Ph.D., University of Colorado Anschutz Medical Campus
- Cardiovascular Disease and Spondyloarthritis presented by Jean Liew, MD, MS, Boston University School of Medicine
- When is Spine Surgery Recommended? Albert P. Wong, MD, DOCS Surgical Hospital
- The Role of Genetics in Spondyloarthritis. Genes Associated (HLA-B27 and Beyond), Heritability (Advanced Topic) presented by Judith Smith, MD, Ph.D., University of Wisconsin School of Medicine and Public Health
- Women & Spondyloarthritis: Childbearing Years Through Menopause presented by Peter Taylor, MA, Ph.D., FRCPC, FRCPE, University of Oxford
- Sleep & Spondyloarthritis presented by Soha Dolatabadi, MD, Arthritis and Pain Relief Medical Center
- We'd Like to Know: Cannabis Update presented by Mary-Ann Fitzcharles, MD, McGill University
- Diet & Nutrition: How/Why Does Gut Microbiome Affect Spondyloarthritis (Advanced Topic) presented by Mathew Stoll, MD, Ph.D., MSCS, University of Alabama at Birmingham
- Flares: Possible Triggers to Avoid & How to Treat a Flare presented by Pendleton Wickersham, MD, FACP, Arthritis Associates PA
- Tai Chi: Meditation in Motion with Live Demonstration presented by Soneka Lee, DPT, Golden Days Wellness Training, LLC



In addition, the Summit also featured other interactive elements such as a Leaderboard Challenge, Daily Quizzes, BASDAI calculator, Exhibit Hall, Poster Hall, and yoga programs in the activity lounge. We are grateful to everyone who played a role in helping to make the Summit successful, including our sponsors and our partners.

Learn more about this year's program by visiting: spondylitis.org/resources-support/educational-materials-resources/global-summit-2023

Projects

New awareness and advocacy tools to support your work!



We are finalising our new Delay to Diagnosis materials, which help raise awareness of the key signs and symptoms of axSpA; and the devastating effects of the diagnostic delay. As well as three short films, translated into nine languages, ASIF will provide an infographic on the diagnostic delay, including the physical, psychological and socio-economic impacts. These materials will be delivered in a toolkit alongside key messages and suggestions for social media content. These resources will be available in August, but can be used at any time. Look out for a forthcoming invitation to a webinar, where we will introduce the full set of resources.

Read more about the campaign at asif.info/delay-to-diagnosis-campaign



The inaugural IMAS global report will be published over the next few months. With key messages and chapters suggested by our members, the report will be published with a set of calls to action for policymakers, healthcare professionals and others. The publication will give an overview of the most important data collected by IMAS as well as demonstrating the daily reality of living with axSpA. The report can be used with a range of stakeholders and, alongside the IMAS advocacy toolkit, we hope it will provide an important resource to advocate for changes to improve the lives of people living with axSpA.

Read more about IMAS at asif.info/imas



New Infographic: Preparing for Medical Appointments

The first in a set of infographics, aimed at preparing and supporting people for appointments with their doctors, is available on our website. It explains how disease activity is measured, particularly through the BASDAI and ASDAS, as well as other assessments that may be done. Future

infographics will focus on what types of treatment targets are important to patients and addressing barriers to shared decision making. Please let us know if you would like the infographic translated.

[See infographic \(asif.info/resources-about-axspa/#tools\)](http://asif.info/resources-about-axspa/#tools)



Member Spotlight: NASS

The National Axial Spondyloarthritis Society (NASS) recently launched [Your SpAce](#), which has been created in partnership with people living with axSpA and healthcare professionals.

Your SpAce allows people living with axSpA to engage with their condition, learn more about axSpA, and build skills to manage the impact it has on their life.

The programme is free to access on the NASS website and YouTube channel. It includes co-produced, short informative videos on topics such as pain, fatigue and flares. There are downloadable resources in each topic, so people living with axSpA can create their own personalised toolkit.

Your SpAce provides a community for people who are at the start of their axSpA journey or who are struggling and feeling isolated. Building a supportive community through monthly online meetups, which provide a relaxed way to connect with others living with axSpA, share ideas and get support. Embedded in the topics are videos of people with axSpA sharing their experiences.

Find out more about the programme at nass.co.uk/about-as/your-space.

Would your organisation like to be featured in the next newsletter? Please email Jo de Bry at communicationsmanager@asif.org to find out more.



EULAR 2023

Rheumatologists from Aruba to Argentina, Pakistan to Panama and so many countries in between spoke to the ASIF team about our work and the impact patient organisations make to the lives of people living with axSpA. During EULAR, some of the world's leading researchers and rheumatologists discussed the importance of patient centric research and care. We explored our priorities with our industry partners and how, by strengthening our relationships, we can develop projects that our members can use to change lives. We will share a report on EULAR soon.

AiArthritis' Go With Us to EULAR 2023 Live Debrief

Saturday, Jun 17, 2023 on [Facebook](#) at 12:00 pm EST / 9:00 am PST (USA).

[Click here](#) to attend the debrief live or find out how to watch it on demand.

Why I'm an ASIF Trustee



Cassie Shafer is the CEO of the Spondylitis Association of America (SAA) and tells us why she joined our Board of Trustees.

“As a long-time non-profit executive, I've had the honour to work with many different groups of people that are often underserved. Serving these people, in whatever way I can, has been both fulfilling and humbling.

“Shortly after joining the Spondylitis Association of America, I discovered something truly unique about those living with spondyloarthritis. The word ‘community’ is often used to describe groups of people bound by a common

thread. But after working side by side with the patients, loved ones, caregivers, and the dedicated medical professionals who devote their efforts to improving outcomes, I discovered a true community of people whose strengths define them much more strongly than their disabilities.

“The Axial Spondyloarthritis International Federation helps to ensure that spondyloarthritis organisations across the globe, large and small, have access to the tools and information needed to serve their constituents. I am honoured to play a part in their important work. We are always stronger together.”

See our full ASIF Board (asif.info/about)

ASIF AGM

The Annual General Meeting of the Axial Spondyloarthritis International Federation will be held virtually on Wednesday 28 June 2023 at 13:00 BST by Zoom.

The link and agenda have been shared with members via email. Please email Jo Davies at office@asif.info with any questions.

Member Webinars

The psychological impact of axSpA and the role of patient organisations



Nadia Malliou will address the emotional and psychological impact of axSpA and how patient organisations can support their communities. Following Nadia’s presentation there will be an opportunity for discussion and to share ideas.

Date: 27 June
Time: 14:00-15:00 BST

Link: <https://meet.goto.com/JoannedeBry/asifmemberwebinar4>

About Nadia...

I am a professional psychologist, with experience in various professional contexts in mental health services and administration. I have specialised through further training with the European Pain Federation EFIC in chronic pain management and for the last few years I have been working with the Pain Unit at the Thessaloniki General Hospital AHEPA to offer help and support to as many patients with rheumatic diseases as I can.



My experience both in management positions and my training and involvement with teams has helped me to offer, and continue to wish to offer, as much as I can to the Hellenic League Against Rheumatism EL.E.AN.A. For the last 5 years I have been intensively involved in chronic pain management, both academically and clinically, through projects and collaborations of the association, such as the collaboration with the Medical Physics and Digital Innovation Laboratory of the Aristotle University of Thessaloniki to create pain management applications.

I have represented my country in the EULAR PARE and EULAR conferences and in the congress of the EUROPEAN PAIN FEDERATION EFIC. At the first congress of the World Patients Alliance, I had the pleasure of meeting many patients from around the world, to associate with health professionals and to gain useful experience and knowledge, always aiming to apply them in Greece.

Please RSVP to Valeria (admin@asif.info) by 20 June to attend the webinar.

[Watch](#) our previous Webinars.

Let everyone know you are a member of ASIF

Do the people you support, the HCPs you work with and your donors know you are a member of ASIF? Being a member of ASIF demonstrates your organisation's commitment to improving the lives of all people living with axSpA. Highlighting your membership shows your community that you are dedicated to being part of a global advocacy effort by working collaboratively with other patient organisations from around the world.

Adding the ASIF logo and link to our website, to your website and materials is a great way to highlight your membership.

Download our 'Member of ASIF' logo [here](#).

Dates for your Diary

June

27-29 IFPA Conference, Sweden

July

5 IFPA Forum, Singapore

August

23-26 39th Scandinavian Congress of Rheumatology, Denmark

September

13-14 BritSpA 2023 Annual Scientific Meeting, UK

November

10-15 The American College of Rheumatology (ACR) Convergence, USA

December

7-11 25th Asia-Pacific League of Association for Rheumatology Congress 2023 (APLAR), Thailand

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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