

ASIF Newsletter: March 2024

Message from the President

Dear friends,

Thank you to everyone who attended our World AS Day webinars recently. We are excited about this year's campaign and knowing that the theme 'Signs and Symptoms' resonates with so many of you. Thank you to our dedicated World AS Day Sub Committee members who have guided the development of the campaign.

We recently announced our first World AS Day Social Media Grants. Congratulations to Arthritis Consumer Experts; Axial Spondyloarthritis Association of South Africa; Bekhtrev Norge (Norway); Canadian Spondyloarthritis Association; Cyprus League for People with Rheumatism and INBAR Association (Israel) who will receive funding to promote the campaign in their own countries. We received more applications than grants available so thank you to all who applied and we hope to expand this programme in future years.



The opportunity for our members and key supporters to meet face-to-face is invaluable. The Board and team are creating an unmissable agenda for the ASIF Council Meeting in October in Columbia. Bringing together such experience, knowledge and dedication from around the world always results in an inspirational meeting, and I know that this year will be no different.

I look forward to seeing you all soon - either online or in person.



Zhivko Yankov, President of ASIF

A Message from Mike

I hope you have been following ASIF's news about IMAS, the International Map of Axial Spondyloarthritis. In January, ASIF took ownership of IMAS (following an in-kind donation of the project by Novartis Pharma AG), and a few weeks later we published the

Global Report, which presents the survey results from more than 5500 axSpA patients. We will launch the report at a webinar on 13 March where I hope to see many of you.

IMAS will be a central theme of our Council Meeting in October, as part of our work with members to translate the data into changes that improve patient lives around the world.

It has been exciting for ASIF to be at the centre of this unique research, working with colleagues at Novartis, the University of Seville, and alongside our members who promoted and encouraged people to complete the survey. ASIF aims to scale up our work to amplify the patient voice in research that aims to provide a better understanding of the impact of axSpA, develop more accurate diagnostics and improve multi-disciplinary care.

In January, I attended the annual meeting of Assessment of SpondyloArthritis international Society (ASAS), the leading organisation involved in supporting and promoting research into spondyloarthritis. This inspiring meeting brought together international experts to discuss the latest research developments. I was delighted to present the IMAS data and answer the audience's questions. The feedback was very positive and I hope will lead to further collaboration with our colleagues at ASAS and new research opportunities.



As part of our growing involvement in research, we want to help our members take up opportunities in their own countries and regions. Please do contact us if we can provide any advice or support on working with researchers to ensure the patient experience is firmly embedded in research projects.

With my very best wishes,



Mike Mandelbaum, Executive Director

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ASIF Programmes

 in 2024	
January	ASIF takes ownership of IMAS (following an in-kind donation of the project by Novartis Pharma AG) IMAS Global Report is published New interactive webpages explore the IMAS results
March 13	IMAS Global Report Webinar
June 11	Spotlight on IMAS, Vienna
October 16-18	IMAS: A central theme of the ASIF Council Meeting in Columbia

[Read the report](#) on our new [IMAS webpages](#), where you can discover the results from survey participants in 27 countries, shining a light on the burden of living with axSpA. The report includes calls to action for healthcare professionals and policymakers, which target better public and professional understanding of axSpA, so that people with symptoms get an

accurate diagnosis with minimal delay and the ongoing support and care they need.

To showcase the report and discuss what the evidence and calls to action mean for patients and patient organisations, we are holding a webinar on 13 March (12:00 to 13:30 GMT). As well as highlighting some of the key results from the report, we will hear clinician and patient organisation perspectives on how IMAS can be used as a tool for change. Please email [Jo Lowe](#) to confirm your attendance.

A celebratory event will take place in Vienna, the evening before the EULAR congress commences. The event, on Tuesday 11 June (18:30-21:30 CET), will bring together our members, industry partners, rheumatologists, HCPs, and other key stakeholders. It will be an opportunity to celebrate the success of IMAS so far, its transition to ASIF and the patient community; and to share our plans for the future. Please contact [Jo Lowe](#) to secure your place.



World AS Day



Theme: *Signs and Symptoms*

Date: 4 May

The World AS Day social media assets have been created, the animations are ready, the webpage is live, and the Toolkit is ready for download!

It was great to see so many of our members and industry partners at our World AS Day Webinar on 6 February. If you missed it, you can watch the recording [here](#). During the webinar, we explored the social media campaign, demonstrated how the social media assets can be tailored to local audiences, and previewed the animations.

The social media content calendar has now been added to the Toolkit. All the materials are available to download from the [webpage](#).

Tell us about your event! Complete the [online form](#) and we'll add your event to the World AS Day webpage and post about it on our social media channels.

ASIF Council Meeting 2024: Colombia, 16-19 October 2024



ASIF Members from around the world will gather in Colombia in October for our annual Council Meeting.

IMAS will feature as a central theme throughout the meeting. Presentations, discussions and workshops will include raising awareness among

healthcare professionals, emerging therapies and research, and how our members can use IMAS to facilitate their work. One of the most anticipated sessions will be an opportunity for our members to present their organisations, campaigns and work. Importantly, delegates will have time to network, share ideas, build new relationships and create opportunities for collaboration.

Invitations have been sent and we look forward to assisting delegates with their attendance. Please contact Jo Davies (office@asif.info) with questions about the Council Meeting.



Patient Resources

Did you know we have a set of [three new infographics](#), which help to support people living with axSpA? The resources aim to inform people how disease activity is typically measured; support them in building a partnership with their doctor; and assist them in focussing on their personal and lifestyle goals.

The first of these is an infographic that helps to educate patients on the commonly-used disease activity assessments, ASDAS and BASDAI. As well

as the tools themselves and the interpretation of the different scores, it also describes how inflammation is measured.

Recognising that disease activity scores often do not tell the full story, the second resource provides guidance on discussing other measures of wellbeing with doctors. It provides helpful tips on other areas of life that could be useful to talk about.

The third resource gives advice and support on setting personal goals. It provides guidance on how to consider, set and monitor lifestyle goals that can help to motivate and bring meaningful improvements to wellbeing and quality of life.

The set of infographics have been developed to encourage people and give them more confidence in discussing their disease with their doctor. You may also find that they are a useful resource for the rheumatologists in your network to give to their patients. Please let us know if you think healthcare professionals would find them useful or if you decide to share them in this way.

There is an opportunity to translate the infographics for our members; please contact [Jo Lowe](mailto:JoLowe@projectmanager@asif.info) (projectmanager@asif.info) to find out more.

Spotlight on our Members

Panamanian Rheumatoid Arthritis Foundation: championing the well-being of RMD patients

In Panama, where an estimated 80,000 individuals live with the challenges of rheumatic and musculoskeletal diseases (RMDs), the Panamanian Rheumatoid Arthritis Foundation (FUNARP) stands as a beacon of hope and support. Established in 2004 by patients and guided by a renowned rheumatologist, FUNARP has become a respected non-profit organisation, driven by five core pillars:



1. Early Diagnosis: Early identification is crucial for optimal outcomes. FUNARP actively promotes diagnostic pathways and access to specialists through free monthly educational sessions.
2. Specialist-Led Care and Treatment Adherence: We advocate for consistent care under rheumatologists and promote patient adherence to prescribed treatments, maximising their effectiveness.
3. Joint Health through Physical Activity: Recognising the importance of movement, FUNARP emphasises exercise programs as a fundamental part of our educational programmes.
4. Nutritional Guidance: We provide evidence-based nutritional advice to empower patients to make informed dietary choices and manage their RMDs effectively.



5. Mental Health Support: Understanding the emotional burden of RMDs, FUNARP offers programmes and resources to address the mental health needs of patients and their families.

Beyond direct patient support, FUNARP tirelessly advocates for raising awareness, dispelling myths, and combating the stigma associated with RMDs. We educate the public and healthcare professionals through workshops, seminars, and informative materials, fostering a more understanding and supportive environment.

Our Impact:

- **Enhanced Access:** FUNARP's advocacy has improved access to timely diagnosis and effective medication access for patients.
- **Empowered Patients:** Our educational programmes and support groups equip individuals with the knowledge and confidence to manage their condition effectively, improving their quality of life.
- **Reduced Stigma:** By raising awareness, we contribute to dismantling social barriers faced by patients. We actively collaborate with the National Disability Secretariat to educate patients on their rights and responsibilities.
- **Stronger Healthcare System:** We collaborate with healthcare professionals to strengthen the system's capacity to manage RMDs, providing information regarding patients' needs.

Looking Ahead:

- **Expanding Reach:** We strive to provide our support across Panama, ensuring all RMD patients have access to our resources and programmes.
- **Strengthening Advocacy:** We will continue championing equitable access to healthcare and quality treatment for all RMD patients, engaging with policymakers and healthcare providers.
- **Empowering Patients Further:** We will provide patients with even more tools and resources to manage their condition, fostering their independence and well-being.
- **Building a Patient Care Center:** We envision a dedicated center with access to medical experts, physical therapy facilities, and a climate-controlled swimming pool.

In this journey, partnering with organisations like ASIF is crucial. Through knowledge exchange and collaborative efforts, we can collectively advance the fight against RMDs, ensuring no patient faces this challenge alone.

Find out more about FUNPAR at www.funarp.org



Nationale Vereniging
**ReumaZorg
Nederland**

The National Association ReumaZorg Nederland is the national Dutch user-led patient organisation, that strives to make a difference in the lives of people with rheumatic and muscular diseases (RMDs).

Having an RMD is a battle against a (lasting) disease, but also against pain, fatigue, loneliness and lack of understanding. Everyday people simply struggle to keep participating: at home, at school and at work.

We work and lobby for an early diagnosis, good healthcare and a healthy active life for people with axSpA. AxSpA mostly affects the spine, causing damage visible on X-ray (ankylosing spondylitis) or damage that doesn't show up on X-rays (non-

radiographic axSpA). Our advocacy aims at supporting people in the best way possible. We want to achieve this together with all people with axSpA and their families, researchers, healthcare providers and other stakeholders who can contribute to this.

As a national patient organisation, RZN is the member of EULAR for PARE for the Netherlands. It is also an associated member of EURORDIS.

Find out more about us at reumazorgnederland.nl



Axial Spondyloarthritis Association of South Africa wins Award

The Academic Excellence and Recognition Award was presented to Maranda van Dam, Chair of ASASA during the SARAA Congress 2024.

ASASA won a similar award of excellence at the EULAR PARE (People with Arthritis/Rheumatism across Europe) Congress 2022.

The SARAA award was based on significant advances made by ASAS towards improving the quality of life of people living with axSpA in South Africa, as well as training done to build awareness in the medical fraternity around the condition.



An impressive 36 posters were entered into the awards from organisations around the world. Congratulations to Maranda and ASASA! Maranda is also an ASIF Trustee and an active member of a number of our sub committees.

Dates for your Diary

March

13 ASIF: IMAS Global Report Webinar

April

10-13 [PANLAR](#), Columbia

18-20 [Annual General Assembly and Scientific Meeting of the Japan College of Rheumatology \(JCR\)](#), Japan

24-26 [British Society for Rheumatology](#), UK

June

11 ASIF: Spotlight on IMAS event, Austria

12-15 [EULAR](#), Austria

27-29 [World Psoriasis & Psoriatic Arthritis \(IFPA\) Conference](#), Sweden

August

21-25 [APLAR](#), Singapore

September

5-7 [International Congress on Spondyloarthritis](#), Belgium

October

16-19 ASIF Council Meeting, Columbia

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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