

ASIF Newsletter: September 2023

Message from the President

Dear friends,

During our recent AGM, we updated our members on the work the ASIF team is undertaking. We shared the success of World AS Day, the progress of the Delay to Diagnosis campaign and the development of the IMAS Global Report, which is due to be released at the end of this year.

We also acknowledged the invaluable support given by our Trustees. Ruta Grigiene and Thierry Vannier have recently retired from the Board of Trustees and I want to offer my personal thanks to them both on behalf of ASIF for their efforts.



Many of you will know Michael Mallinson, who has been ASIF's champion volunteer, advisor and ambassador for many years. While Michael remains involved, he has reduced his workload to spend more time with his family, including his adored grandchildren. Michael's unwavering dedication to improve the lives of people with axSpA, wherever they live in the world, has been inspirational and has had an immense impact on the growth of ASIF and many of our members.

Best wishes,

Zhivko Yankov
President of ASIF

A Message from Mike



Mike, pictured with Lillann Wermskog (Trustee), Thierry Vannier (recently retired Trustee), Jo Davies (Assistant Director) and Michael Mallinson (Ambassador)

Since I joined ASIF earlier this year, I have been inspired by how our members are helping many thousands of people improve their quality of life and connect with others facing similar challenges. Together we have made great progress. We have a long journey ahead of us, however, when we consider there are more than 50 million people around the world with axSpA - most of them without access to optimal treatment or, as yet, undiagnosed.

At ASIF, our aim is help you succeed in serving these people. As well as developing resources, providing



guidance and publishing evidence, we work on the international stage so that funders and policymakers have a better understanding of axSpA and will open their doors more widely to you. In my previous work in tuberculosis and palliative care, however, I saw that while many countries face similar challenges, each country works within its own social context and healthcare system.

For axSpA, those country differences can include the availability and accessibility of diagnostic and treatment services; health inequalities between different population groups; the number of healthcare professionals, especially rheumatologists, and the knowledge, attitudes and skills of those professionals; the role of family and other informal caring structures, and many others.

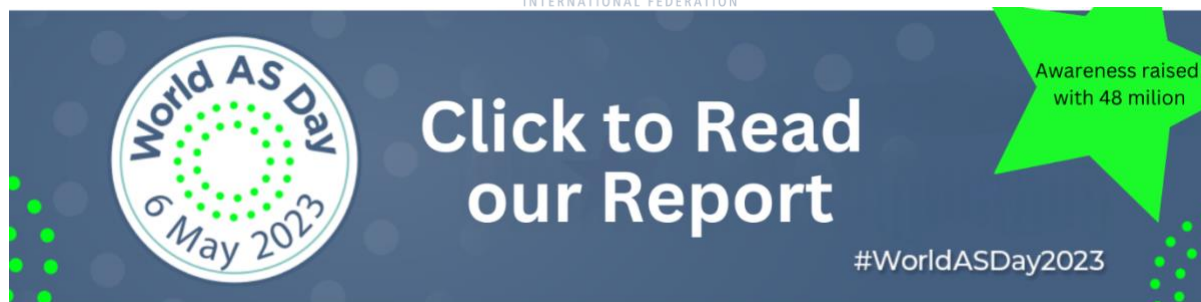
During the coming years, we want ASIF's activities to better reflect these national and regional differences. This will mean our resources, our advocacy and our capacity building are more tailored to your challenges and your needs. While ASIF has access to global expertise in axSpA, our member organisations are our primary source of insight into axSpA and RMDs in their countries. That is why the emails I most welcome are from our members suggesting we spend 30 minutes discussing the situation in their country. So please contact me at executivedirector@asif.info so we can arrange to speak – you will be helping ASIF better help you.

With my very best wishes,

A handwritten signature in black ink that reads 'Mike Mandelbaum'.

Mike Mandelbaum
Executive Director

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<https://asif.info/wp-content/uploads/2023/09/World-AS-Day-2023-Summary-Report-External.pdf>

Projects

New awareness and advocacy tools!



Our new Delay to Diagnosis materials will help raise awareness of the key signs and symptoms of axSpA; and the devastating effects of the diagnostic delay.

Three powerful short films, translated into nine languages, and an infographic on the diagnostic delay, including the physical, psychological and socio-economic impacts, will support our members in their advocacy and awareness raising efforts. These materials are available in a toolkit alongside key messages and suggestions for social media content. The resources have not been designed for a specific timescale or timed campaign and so can be used at any time.

On 12 September, ASIF will host two webinars to introduce the materials to our members. To register for the webinar, please email Jo Lowe, ProjectManager@asif.info.

The three main videos will be available on our website on 12 September and Jo will be able to give access to the full toolkits in different languages on request. Read more about the campaign at asif.info/delay-to-diagnosis-awareness.

Thank you to Dr Raj Sengupta for providing his expert opinion, and to Tseleng, Zhivko, Percival and Jo for their honesty and openness in sharing their personal experiences in these compelling videos.

Building a Partnership with Your Doctor

Building a partnership with a doctor can help patients get the most out of their axSpA treatment. A new infographic highlights how people living with axSpA can guide decisions about their healthcare and what that can look like in practice.

View infographic here: asif.info/resources-about-axspa/#tools

This is the second infographic in a series produced in collaboration between ASIF and UCB.

View Disease Assessment infographic here: asif.info/resources-about-axspa/#tools



The psychological burden of axSpA

It is becoming clearer that depression and anxiety are prominent among people living with axSpA.

The psychological burden of axSpA and the support patient organisations' can offer to their members: Highlights from an ASIF Webinar presented by Nadia Malliou (pictured).

The European Map of Axial Spondyloarthritis (EMAS) and the International Map of Axial Spondyloarthritis (IMAS) describe how people living with axSpA experience their disease physically, psychologically and socially. Results show long diagnostic delays and a substantial physical and psychological burden, indicating important unmet needs for patients. Furthermore, axSpA can restrict their ability to participate in their daily routine and to lead a productive work life. Understanding the patient's perspective can improve both health outcomes and enhance shared decision-making between patients and rheumatologists.

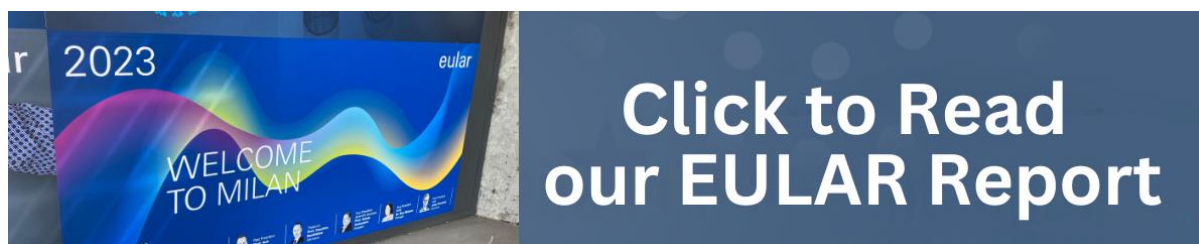
[Read more \(https://asif.info/the-psychological-burden-of-axspa-and-the-support-patient-organisations-can-offer-to-their-members/\)](https://asif.info/the-psychological-burden-of-axspa-and-the-support-patient-organisations-can-offer-to-their-members/)

Conference Spotlight: Scandinavian Rheumatology Conference



Spafu Norway attended the Scandinavian Rheumatology Conference (SCR 2023) in Copenhagen in August. While there, they raised awareness of the challenges facing people living with axSpA, with rheumatologists, healthcare professionals and researchers.

[Read their Report \(https://spafu.no/https-spafu-no-aktuelt/spafu-norge-pa-jobb-i-hjertet-av-skandinavisk-revmatologiforskning/\)](https://spafu.no/https-spafu-no-aktuelt/spafu-norge-pa-jobb-i-hjertet-av-skandinavisk-revmatologiforskning/)



What is EULAR? Why attend – and how? What were the key outcomes for ASIF this year? What were the key presentations for axSpA? Find the answers to these questions and more in our report!

[Click to read our Report \(https://tinyurl.com/ASIFEULAR\).](https://tinyurl.com/ASIFEULAR)

Member Spotlight

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

Dates for your Diary

September

13-14 [BritSpA 2023 Annual Scientific Meeting, UK](#)

October

07 [Virtual Fall 2023 Spondyloarthritis Educational Seminar, USA](#)

November

06 [International Conference on Gastroenterology and Rheumatology, South Africa](#)

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](#)

February 2024

15 [International Conference on Rheumatology \(ICR\), UK](#)

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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