

Message from the President

Dear friends,

I am delighted to welcome Mike Mandelbaum as ASIF's first Executive Director. Over the last few weeks the Trustee Board and I have spent time with Mike, discussing ASIF's priorities and our vision for the future. I have no doubt that working with our existing team, Mike will help us do even more to improve the lives of people living with axSpA around the world.



For the first time, ASIF was represented at the African League of Associations for Rheumatology's (AFLAR) Annual Conference. You can read about the event in Maranda van Dam's report below. We know there is a huge unmet need across Africa and we are committed to helping change this.

World AS Day is fast approaching. This year's theme of *movement* draws attention to one of the most important things people living with axSpA can do to improve their quality of life. We hope that the campaign will resonate with people around the world. We are committed to providing our members with a campaign that they can easily use and adapt for their organisation.

Please visit our new Member Resources webpages; the new axSpA and organisational guides contain invaluable information.

We were saddened to learn of the passing of Prof. Dr. Ernst Feldtkeller. Professor Feldtkeller dedicated his life to improving the lives of people living with axSpA. He will be sorely missed by many in our community. My thanks to Dr Muhammad Asim Khan who has written a fitting obituary for this newsletter.

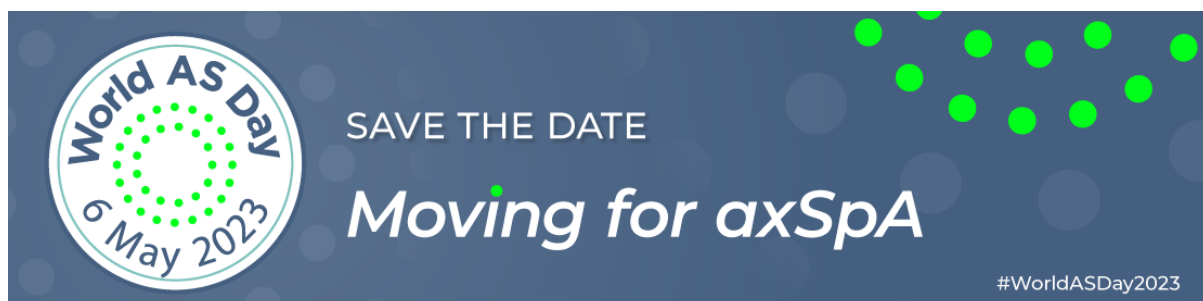
I would like to thank everyone who has contributed to the newsletter; it is thanks to them that we can share so much with you.

Best wishes,

Zhivko Yankov
President of ASIF

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World AS Day 2023



This year's theme is movement!

World AS Day is only two months away. If you missed our World AS Day Webinar, you can watch it [here](https://youtu.be/9GTkQPIfBn8) (<https://youtu.be/9GTkQPIfBn8>). The Webinar talks you through the campaign, the available assets, and how you can make the most of World AS Day.

One of the downloadable assets is a template calendar for social media. It includes the dates that ASIF will post/tweet content. We encourage you to follow the calendar; however, you are welcome to adapt it to your organisation's existing social media calendar and post/tweet when it works best for you. ASIF

will begin sharing content slowly from the end of March, launching the campaign fully in April.

Following feedback from one of our members, the editable templates have also been made available in Canva for those not using Photoshop. The link to the templates can be found in the downloadable Tool Kit.

Visit the [webpage](#) to find out more about the campaign and download the Tool Kit and editable assets (asif.info/worldasday).

Global Stretching Events

On World AS Day, we will host two online stretching events to enable as many people around the world to join as possible (the times will be confirmed soon). The sessions will be designed for everyone with axSpA, giving options for each stretch from very gentle for those with limited movement, to more of a challenge for those who are more flexible. We are excited about bringing the global axSpA community together through movement.

The events will be run by Jamie Boder, co-Founder of [Yoga for AS](https://yogaforas.com) (<https://yogaforas.com>). Jamie is a qualified yoga instructor and has axSpA himself, so understands the challenges posed by the disease and the positive impact movement makes.

Jamie commented, "I am delighted to share these sessions with you; it will be an opportunity for you to find something that works for you. I understand the many ways AS / axSpA presents itself. These sessions are open to everyone. In my experience, after sharing these types of sessions with thousands of people with axSpA, many people come out from the sessions with less pain, stiffness and fatigue. That is the magic of movement. My classes are very inclusive, fun and welcoming and I look forward to seeing you there!"

Walk Your AS Off

Written by Jennifer Visscher, Walk AS One



Walk Your AS Off is excited to share that the new language translation has been implemented on the Walk Your AS Off website and will be on the *step reporting application* at [Walk AS One](#)



(<https://walkasone.org>) soon! With language translation available to any Google Translator language we are looking forward to more ASIF teams and walkers!

There are also a number of small changes happening to both websites to help make navigation easier and information on participation simple and clear.

New information for email subscribers will be sent to help ensure your teams are up to date on all event information including a weekly prompt/reminder each Sunday in May to log in and record steps. This will include a direct link to login and a QR code, and printable log for those that prefer having something that isn't digital.

Walk Your AS Off is really excited about our 2023 campaign! We will be looking for walk selfies (a photo 'selfie') again this year especially during World AS Day! Please use the hashtag #ASwalkselfie or #axSpAwalkselfie on Instagram and Facebook so that we may track and share our members and teams where they walk across the globe! These will work amazingly in conjunction with the ASIF key messages and hashtags being used on World AS Day.

We are two months into our Walker Wednesday live feed each Wednesday at 2pm US Eastern Time/7pm GMT. If your organisation would like to share about your team and organisation we'd love to have you on a Zoom call. These Zooms are shared live on Facebook as well. We're also compiling a library for them on YouTube.

Feedback and suggestions from all ASIF member organisations on what future features you would like to see on the website and Walk Dashboard are really appreciated. Please email us at info@walkasone.org with any thoughts, suggestions, or concerns.

Global Spondyloarthritis Summit

As the premier virtual health event for the spondyloarthritis community, the 5th Annual Global Spondyloarthritis Summit features renowned rheumatologists and other health experts who provide the most up-to-date findings and medically reliable and comprehensive information on essential topics that matter to those living with the disease. Whether you are newly diagnosed or



were diagnosed some time ago, the Summit is your opportunity to learn tips and tools for managing your symptoms while also connecting with others.

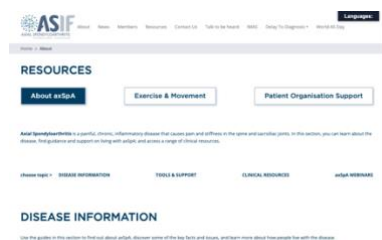
Under the theme “Moving Together Towards Better Health Outcomes” this year’s program features 12 experts from the international community who will discuss topics such as Flares and Possible Triggers; SpA Research Updates; Sleep Issues; Women & SpA; Diet & Nutrition; Surgery & Joint Replacement Recommendations; Cardiovascular Disease, and more!

ASIF will have a Booth at the Summit and will display information about our Members. Please send your organisation’s leaflet to Jo de Bry before 31 March at communicationsmanager@asif.info.

Please use the downloadable social media asset on our World AS Day webpage to promote the event to your members and encourage them to register.

[Find out more](#) about the Summit

New Member Resources Webpages



ASIF are delighted that our new resources [webpages](#) are now live. The materials can be used by our members, and by patients and caregivers. The improved site will also signpost healthcare professionals to relevant axSpA information and tools.

Our mission is ‘to advocate globally to improve the lives of people affected by axial Spondyloarthritis and related conditions. To grow, strengthen and empower our community, and to raise awareness around the world’. We want to help our members to do that too, so we have created a range of guides that support members’ work. The materials range from a step-by-step guide to create a new patient organisation to guidance on getting support from pharmaceutical companies; from social media and websites to fundraising and working with volunteers.

We are proud to have also produced four new guides about axSpA, including a detailed overview of the disease, as well as how to live well with axSpA and treatment options. We have a comprehensive guide on exercise and movement

that is complemented by a new set of exercise videos. All of these guides are editable and can be adapted by our members to include their own logo and contact details, providing a ready to use resource for your own members.

The existing resources and links to members' resources remain in place. But they are now organised over three sections: about axSpA; patient organisation support; and exercise and movement. We encourage you to look through the new webpages and, as always, we welcome your feedback.

[Visit Resources](#)

Introducing Mike

Written by Mike Mandelbaum, Executive Director of ASIF



"I joined ASIF a few weeks ago, excited to embark on a voyage of discovery into the world of axSpA and rheumatology. While I have not yet sailed the high seas of axSpA, I have been inspired by the view from the shallow waters and am glad to share my early thoughts with you (although maybe with no more sea-faring metaphors!).

"My previous knowledge of back health comes from personal experience, having had back problems for more than 20 years. While not axSpA, I have insight into back pain and how easily a flare-up can be triggered.

"For many years I led a tuberculosis NGO, a disease with high levels of health inequalities. I also see inequalities in access to diagnosis and treatment for axSpA: the pain and disability will disproportionately affect countries with less developed healthcare systems, as well as people without access to quality healthcare or the ability to insist the pain is not in their head.

"ASIF's mission is to 'grow, strengthen and empower our community'. In my first contact with members I have been impressed by your energy, ability and determination to make change happen in your countries. As an international organisation we understand that some of our members' ambitions and challenges are similar, while others must adapt to local healthcare systems and structures. Our approach is based on combining ASIF's access to global expertise

with your local skills and knowledge, all aimed at helping you improve the health of your communities and countries.

“I hope to talk with many of our members during the coming weeks and months to learn more about AS and axSpA in your countries, the work of your organisations and how ASIF can best support you. Our members are the reason for our work – first and foremost we are guided by your needs. Please contact me at any time on executivedirector@asif.info – I will always be glad to hear from you.”

Obituary – Prof. Dr. Ernst Feldtkeller (1931 – 2023)

Written by Dr Dr Muhammad Asim Khan

It was with great sadness that we learned of the passing of Prof. Dr. Ernst Feldtkeller at 92 years of age (October 19, 1931 -- January 4, 2023). He was truly a remarkable and inspiring person, scientist, and researcher, with a PhD in Physics. He was appointed Professor at the Universities of Stuttgart and Munich, and a researcher at the Siemens Research Laboratories in Munich. He had suffered all his adult life from ankylosing spondylitis (frequently called Morbus Bechterew in German-speaking countries), and in 1980 he played a pivotal role in the formation and subsequent management of the German Ankylosing Spondylitis Society named Deutsche Vereinigung Morbus Bechterew (DVMB).



He authored an excellent book in German on ankylosing spondylitis for educating patients and their families and was the Scientific Director of the editorial office of the DVMB membership journal called Bechterew Brief. He was fluent in English, and he used to translate important English publications into German for the readers of his Journal. He selflessly put all his creativity, knowledge, and skills into the service of the DVMB and other organisations over the last 42 years.

On 8 April 1988, Ernst became a member of a committee that was formed, at the invitation of Fergus Rogers (of National Ankylosing Spondylitis Society, U.K.), to carry out the preliminary preparations necessary for the foundation of an International Ankylosing Spondylitis Association (which later became Axial Spondyloarthritis International Federation - ASIF). He was invited to attend the first ASIF Council Meeting in Leukerbad, Switzerland in July 1989, hosted by

another remarkable patient and scientist Dr. Heinz Baumberger, PhD [1]. He was elected as a Vice-President of ASIF in 1992, a position he held until 2009. Thereafter, he served as ASIF's Scientific Adviser until retiring from this role in 2017.

After his retirement from Professorship in 1992, Ernst devoted his full attention to doing scientific studies and clinical research in ankylosing spondylitis. In 1996 he obtained financial support from the German Federal Health Ministry and initiated a professional survey among the more than 14,000 patient members of SVMB. 1614 patients responded to this survey, and extended reports of the results were published in five issues of Bechterew Brief in 1997-1998. He then presented these results in English at the 1st International Congress on Spondyloarthropathies, in September 1998 in Gent, Belgium. Over the years Ernst had published many highly cited articles in German and English, and based on his extensive contributions, he was awarded membership of the Assessment of SpondyloArthritis international Society (ASAS).



Ken Mulholland (ASIF Secretary 2002-2011) recalls meeting Ernst at the first ASIF Council Meeting; "My early impression of Ernst was his extensive knowledge of the disease, his research, and his extensive publications. Over the years, I got to know Ernst a little more and see how instrumental he was in introducing Ankylosing Spondylitis to the world through his development of the ASIF website. Ernst was very meticulous in all his workings."

I first met Ernst at the first ASIF Council Meeting in Leukerbad in 1989 and we became lifelong friends and co-authored two of his many highly cited publications [2, 3]. I frequently exchanged with him articles of interest and helped maintain Ernst's remarkable personal library of articles from medical journals stored either digitally in a PDF format or, in some cases, as printed documents. He shared his personal library with me, and I sincerely hope that it will be kept alive and up to date.

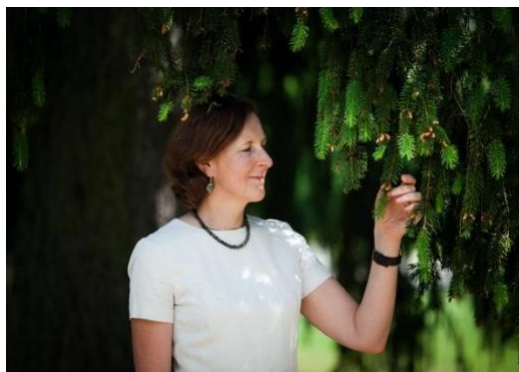
Ernst's other interests extended to mountaineering, cycling, playing the flute, and painting beautiful watercolour landscapes (pictured), many of which he generously gave away to friends and colleagues. He was also an avid photographer, always carrying his camera with him, and he regularly summarised important scientific meetings along with pictures of scientific presenters.

With Prof. Dr. Ernst Feldtkeller we have lost a valued companion, a respected fellow patient, and a good-hearted and charismatic personality. His unparalleled commitment, diligence, frugality, and modesty were an example to us all. With his exemplary commitment to those affected, Ernst Feldtkeller earned a high and lasting reputation in the global spondyloarthritis community. Ernst's contributions to DVMB and ASIF, and to the rheumatology and patient communities at large, will be sorely missed.

REFERENCES:

1. Khan MA. Accomplishments of Heinz Baumberger PhD: A remarkable patient with ankylosing spondylitis for 72 years. *Clin Rheumatol*. 2016 Jun;35(6):1637-1641. doi: 10.1007/s10067-016-3259-0.
 2. Feldtkeller E, Bruckel J, Khan, MA. Scientific contributions of ankylosing spondylitis patient advocacy groups. *Current Opin Rheumatol*. 2002 Jul;12(4):239-247. doi: 10.1097/00002281-200007000-00002.
 3. Feldtkeller E, Khan MA, van der Heijde D, van der Linden S, Braun J. Age at disease onset and diagnosis delay in HLA-B27 negative vs. positive patients with ankylosing spondylitis. *Rheumatol Int*. 2003 Mar;23(2):61-66. doi: 10.1007/s00296-002-0237-4.
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Why I'm an ASIF Trustee



Ruta Grigiene from Lithuania tells us why she joined our Board of Trustees.

“I became a member of ASIF's board of trustees in 2014, quite unexpectedly to myself. When I was diagnosed just half a year prior, I almost immediately got involved with the Lithuanian AS patients' association. The association delegated me

to participate in the ASIF conference, held in Sofia that year, with the goal of having the Lithuanian AS association become a member of ASIF. This goal we succeeded in. While I enjoyed the experience, it came to me as a complete surprise when I was myself invited to become a member of the ASIF trustee team.

“At first, I was rather unsure what good I could achieve as a Trustee, how I would be able to help. However, little by little, I got involved in all the activities going on and am proud to be part of the team. We all learn and grow together, bringing more and more member countries into the ASIF family, so that we can help new organisations and execute global projects (IMAS, Delay to Diagnosis, as well as others).”

We are recruiting for new Trustees in anticipation of some of our current Trustees stepping down next year. If you are interested in joining the ASIF Board, please contact Jo Davies at office@asif.info.

See our full ASIF Board (<https://asif.info/about>)

Member Webinars



Community/Direct Fundraising

Tuesday 21 March at 18:00-19:00 GMT

Fundraising, specifically direct or sometimes known as community fundraising, is the topic of our March Webinar (postponed from February).

Liz Marshall will speak about how NASS uses Walk Your AS Off to raise funds. Sean Ewart will discuss the different types of community fundraising that the SAA implements.

Please email us at admin@asif.info to secure your space (Members only).

[Watch](#) our previous Webinars.

AFLAR – Annual Meeting Report

For the first time, ASIF was represented at [AFLAR](https://rheumatologyafrica.org) (The African League of Association for Rheumatology - <https://rheumatologyafrica.org>). The conference, held in Kenya in February was titled: Rheumatology a New Dawn in Africa but what about Advocacy? ASIF Trustee and Chair of ASASA, Maranda van Dam shared a valuable insight into the situation across Africa in her report.

[Read Report](#)

ASAS 2023 – Annual Meeting Report

At the end of 2022, ASAS (Assessment of Spondyloarthritis International Society) and ASIF signed a Memorandum of Understanding (MOU) to put our relationship on a more formal footing. This MOU means that both organisations will aim to keep each other informed of key plans, agree to identify opportunities for collaboration and will contribute expertise and experience towards mutually agreed objectives.

The Trustees of ASIF were delighted to be invited to send two representatives to attend the ASAS 2023 Annual Meeting which took place in Athens in January. Andri Phoka, Secretary, ASIF and Jo Davies, Assistant Director, ASIF joined the meeting. We are especially thankful to Xenofon Baraliakos, President of ASAS and to the rest of the Executive Committee for making us so welcome. During the meeting, ASAS educational activities and research projects were presented and discussed. This report covers just a few highlights from the ASAS 2023 Annual Meeting.

[Read report](#)

ACR Report

Michael Mallinson attended the American College of Rheumatology (ACR) Convergence Meeting in San Diego in November 2022. He has provided a series of comprehensive reports on key sessions. Thank you, Michael, for your commitment to sharing information for the benefit of people living with axSpA.

[ASAS-EULAR Recommendations for the Management of Axial Spondyloarthritis: 2022 update](#)

[An Exploratory Analysis of the Potential Disconnect between Objective Inflammatory Response and Clinical Response following Certolizumab Pegol Treatment in Patients with Active Axial Spondyloarthritis.](#)

[Bimekizumab Improves Signs and Symptoms, including Inflammation, in Patients with Active Non-Radiographic Axial Spondyloarthritis: 24 Weeks Efficacy and Safety from a Phase 3 Multicentre, Randomized, Placebo-Controlled Study](#)

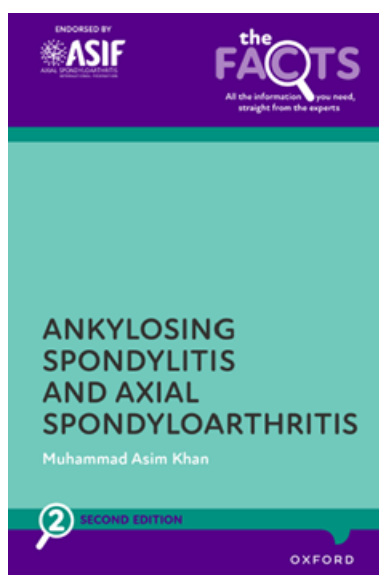
[Continuing \(Full or Reduced Treatment\) versus Withdrawing from Golimumab in patients with non-radiographic axial spondyloarthritis who Achieved Inactive Disease: Efficacy and Safety Results from a Placebo-controlled, Randomized Withdrawal and Retreatment](#)

[Comparison of the Effect of Treatment with NSAIDs added to Anti-TNF therapy versus Anti-TNF therapy alone on Progression of Structural Damage in the Spine over Two Years in patients with Ankylosing Spondylitis: an Open-Label Randomised, Controlled, Multic](#)

[Profiling of Systemic Immune Responses in Axial Spondyloarthritis Patients reveals Strikingly Distinct Cellular and Molecular Mechanisms of Action of IL-17A Inhibitors and TNF Blockers](#)

[Action Council Pathway](#)

Ankylosing Spondylitis and Axial Spondyloarthritis



World expert in axSpA, Dr Muhammad Asim Khan, has published an update to his book Ankylosing Spondylitis and Axial Spondyloarthritis. Dr Khan is Professor Emeritus of Medicine at Case Western Reserve University, USA, and has authored and co-authored seven books on AS and axSpA.

"Written for patients by a patient who is also a leading authority on spondyloarthritis, this book is an essential reference and reading for people living with axial spondyloarthritis — with ankylosing spondylitis as its prototype — and their caregivers who want to learn about the disease and how to manage it well." – Michael Mallinson, ASIF

Use this code: AMPROMD9 to get 30% off your copy. [Order now](#) (<https://bit.ly/3YJvI5R>).

Dates for your Diary

March

- 1-4 ArLAR23, Kuwait
- 10-11 ASAS Core Course, Brussels (HCPs only)

April

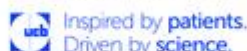
- 26-29 Pan American League of Associations for Rheumatology (PANLAR), Brazil

May

- 1-31 Walk Your AS Off
- 5-6 SAA's 5th Annual Global Spondyloarthritis Summit
- 6 World AS Day
- 19 World IBD Day
- 20 World AUTOimmune & AUTOinflammatory Arthritis Day (AiArthritisDay)
- 31-03 June EULAR, Milano, Italy

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

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