

Message from the President

Dear friends,

What a fantastic few days many of us shared in Copenhagen recently. It was wonderful to see old friends and meet new ones. I hope those of you who attended the ASIF Council Meeting in person and on-line, enjoyed it as much as I did.



You can read the highlights from the meeting below. One of my favourite parts of the meeting were the conversations I had outside the meeting room. Learning about other associations, the challenges they are facing and the successes they have had was inspiring. I know many of us left with an invigorated sense of determination and a head brimming with new ideas. I want to thank everyone who participated in the meeting – bringing everyone together is ASIF's most important role.

At the AGM we re-elected Cassie Shafer from SAA to serve another term on the Board of Trustees. We are delighted continue to benefit from Cassie's experience and insights.

Aleksei Sitalo, President of the Russian Ankylosing Spondylitis Association stood down as a Trustee having served 4 years. We are grateful for his commitment to ASIF and the valuable input he provided to the Board.

We also had the great pleasure of welcoming Maranda van Dam from Axial Spondyloarthritis Association of South Africa (ASASA) to the Board. Maranda received a unanimous vote in support of her application and a heartfelt round of applause from all the attendees when it was accepted. You can read about Maranda below.

While in Copenhagen, I attended a number of meetings with our pharmaceutical partners. We discussed how we could continue to collaborate for the benefit of people living with axSpA. It is exciting to know that these companies believe in our work and want to support our projects.

It is with great sadness, I share the news of the untimely passing of Marg Lewington from AS Queensland, Australia. Many of you knew Marg and had the

pleasure of working with her over the years. Our thoughts are with Marg's family at this time.

Best wishes,

Zhivko Yankov
President of ASIF

Our Projects

World AS Day 2022



Raising awareness of axSpA

This year our World AS Day social media campaign reached 11.5 million and our posts and tweets were engaged with 1.4 million times. Excitingly, that is just from ASIF's digital channels. The number of people who were exposed to World AS Day messaging is much larger than that, when considering the numbers reached through our members' social media pages; the pages of our industry partners; and of course, the posts and tweets of people living with axSpA themselves.

More than 33,000 people visited the ASIF website. Our Members' Symptom Checker Questionnaires in six languages, were the most clicked links on the website. Visitors also read our key messages, downloaded resources; and viewed the social media wall, which pulled together posts and tweets that used #WorldASDay2022.

Leave Your Footprint

"Don't let the pain beat you. Keep your energy for the things you love and you will get through it."

"Stay strong. Share your knowledge and lessons learnt. Connect. Together we can win the battle."

"Hoping diagnosis will be so much quicker in the future."



These are just some of the many messages of support and hope left on the 'Leave your Footprint' webpage. Each of the footprints shares a powerful message and has become an inspiring place to visit.

Visit Leave your Footprint (<https://asif.info/worldasday/#footprint>)

Walk Your AS Off

 National Axial Spondyloarthritis Society
May 11, 2021 · 🌐

"I'm taking part in the Walk Your AS Off challenge with my boy Milo because I have axial SpA and for a while, it controlled my life. I've always been independent and proud, but I struggled physically and mentally with not being able to do everything I used to. I'm now learning to adjust and gain some control back. Having to get up and walk Milo regardless of how much I hurt has helped immensely. There's so little knowledge about AS, so I'm happy to help raise awareness in any way I can 😊"

Thank you to Tracy, Milo and everyone taking part in this year's #WalkYourASOff challenge with #TeamNASS to raise awareness about axial SpA and funds to support our work.

To show your support for #TeamNASS please visit 📍 <https://bit.ly/3nP0hGu>



Participants from 41 countries around the world participated in Walk Your AS Off this year.



The 335 participants in 45 teams walked over 40,000 steps. The event raises awareness each year as people post about their walks on social media – often including their personal story to explain why they are participating in the initiative. It is inspiring to read posts, like the one pictured left, about why people chose to take part.

A lot of the participants have participated in the event for many years. Some raise awareness and funds for their local axSpA organisation while others use it as motivation to get out and move every day during May – hopefully starting a lifelong habit.



Global Spondyloarthritis Summit – 6-7 May 2022

More than 3,100 people from 103 countries participated in the virtual Global Spondyloarthritis Summit hosted by the SAA. More than 2,000 of the registrants live with axSpA.



The most watched presentations were: Micah Yu speaking about Arthritis and Nutrition (watched 850 times) and Angelo Papachristos' presentation on Exercise, Physical Activity and Staying Active with SpA, which was viewed 568 times.

The majority of participants were from the US (2,006), with participants also from Canada (205), Australia (90), the UK (85), Bulgaria (81), India (65), Norway (62) and 97 other countries.

ASIF has a virtual stand at which we displayed leaflets from many of our member organisations, of which 170 were downloaded. Our Talk to be Heard videos were the most popular videos viewed 230 times.



ASIF Council Meeting, Copenhagen 29-31 May 2022

ASIF Council Meeting

We were delighted to welcome representatives from 23 of our member

organisations to our Council Meeting at the end of May in Denmark. The opportunity to meet face to face after the pandemic was embraced by nearly 40 people, while others participated remotely. We also invited some of our corporate partners to attend a few of the sessions - so they could learn more about ASIF, our members and what we do

A full report will follow, but for now here is just a snapshot...

Nine of our members presented how their organisations support people living with axSpA and work to improve the lives of those affected. Here are just a few of the highlights from those sessions:

Thank you to Merian Bastrup Clasen from the Association for Spinal Arthritis and Morbus Bechterew in Denmark for her help and support with the Meeting.

Lillann Wermskog and Lise Mette Eidet from Spafo Norge shared patient videos that they are using to raise awareness.

Presenting with the South African flag draped around her shoulders, Maranda van Dam from Axial Spondyloarthritis Association of South Africa shocked the room with the reality of the number of rheumatologists in South Africa – just 85 for a population of 60 million.

Iryna Bublyk brought us to tears with the reality facing Ankylosis No and the people living with axSpA in Ukraine.



Wearing traditional Filipino shirts, Clark Ferrer, Percival Escarda and Jose Rivas (pictured) from Ankylosing Spondylitis Association of the Philippines, presented the work they are doing and the challenges they face working in an archipelago of over 7,000 islands.

Julieth Samantha Buitrago described the reality of the Fundación de Espondilitis Anquilosante en Colombia and generously gave each of the participants a traditional Colombian poncho.

Stalo Papamichael from CYLPER the Cyprus League of People with Rheumatism updated us on her organisation's activities.

Martina Irrang presented the work of DVMB the Deutsche Vereinigung Morbus Bechterew e.V. Bundesverband in Germany.

The challenges of reaching patients across Greece was illustrated by Nadia Malliou from ELEANA the Hellenic League Against Rheumatism.

The Schweizerische Vereinigung Morbus Bechterew in Switzerland was introduced by René Bräm who highlighted his organisation's pillars and recent

activities. He included a photo from one of the first ASIF Council Meetings in 1989.

Raj Mahapatra, an ASIF Trustee, provided an update on ASIF's Delay to Diagnosis project, and the project was later the subject of discussion in the workshop sessions. We value the input that we gained and are using it to help direct the next phase of the project.

This year's World AS Day campaign reached 11.5 million people on social media through ASIF's channels alone – this doesn't take into account the numbers reached through our members' social channels. It is exciting to see how much awareness the campaign is raising each year.

The first insights into the IMAS Global Dataset were presented by Professor Marco Garrido Cumbreira. The data provides a valuable augmentation of the European results.

Since the Council Meeting, the Indian survey has closed with 230 people having participated. The final number of participants globally is 5,555. The results will be analysed and presented later in the year.

Professor Denis Poddubnyy shared the latest updates in Spondyloarthritis, including some of the most recent global research. We also heard about the ASAS classification criteria for axSpA and new treatment recommendations. Doctor Victoria Navarro-Compán provided an update on ASAS' work and collaboration opportunities. There is certainly an appetite to work more closely with ASAS. Click on the links below to watch their presentations.



Attendees listened to Dr Dale Webb (pictured) from NASS present an update on the Gold Standard project. This ambitious project aims to reduce the national delay in diagnosis in the UK from 8.5 years to 1 year.

Zhivko Yankov, President of ASIF, shared ASIF's Strategic Plan for the upcoming five years. He closed the meeting by thanking all ASIF's members, for their passion and dedication to improving the lives of all those living with axSpA. We are stronger when we work together.

Look out for our full Council Meeting Report coming soon!

[Watch](https://bit.ly/3P8Q84k) Professor Denis Poddubny's Presentation (<https://bit.ly/3P8Q84k>)

[Watch](https://bit.ly/3z8jc6w) Doctor Victoria Navarro-Compán's Presentation (<https://bit.ly/3z8jc6w>)

Visit our [website](https://asif.info/asif-council-meeting) to see more photos (<https://asif.info/asif-council-meeting>).



New Trustee

ASIF is delighted and honoured to welcome Maranda van Dam from South Africa, to the ASIF Board.

Maranda understands only too well the impact axSpA can have. In 2008 Maranda began experiencing symptoms; however, it took her almost 8.5 years of dead ends and frustration before she finally got a diagnosis.

Knowing that she didn't want others to go through what she did without support, two years later, Maranda set up the Axial Spondyloarthritis Association of South Africa (ASASA). The organisation began as a Facebook group that reached out to people living with axSpA. Four years on, the private Facebook group has become a vibrant community with 243 members who ask advice, post information and share experiences. Maranda says that the most important role of the Facebook group is to be a safe place where AS survivors, as she calls them, can be themselves. ASASA now has a newsletter and anticipates growing at around 50 members per year.

Shockingly, South Africa has just 85 rheumatologists for a population of 60 million people. This is one reason why ASASA is so important, as for many people living with axSpA, seeing a rheumatologist is a once in a lifetime experience.

Maranda is passionate about advocating for people living with axSpA and sees the value in working as a global community. Over the last few years Maranda has been increasingly involved in ASIF's work, sitting on sub-committees and providing input into key projects.

A unanimous vote at the ASIF Council Meeting in Copenhagen on 31 May 2022, secured her place on the ASIF Board.

Maranda commented, "Giving a voice to a silent disease has changed my life forever".

As well as her work with ASASA and ASIF, Maranda is a successful business owner and a single parent to two wonderful boys. She enjoys an active lifestyle that includes riding her mountain bike, playing tennis and Pilates. Early in 2022, she completed a gruelling trip with her motorbike for 3 weeks in the Himalayas.

Maranda's enthusiasm for life is contagious and she will not let her axSpA stop her from achieving her dreams.

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



Vale Margaret Lewington

It is with great sadness that we announce the passing of Margaret Lewington, physiotherapist of Brisbane, Australia in June. A true champion of Ankylosing Spondylitis management, treatment and advocacy in the Musculoskeletal (MSK) healthcare and professional community in Australia and Internationally.

Margaret played an integral role in the organisation and operations of the Ankylosing Spondylitis Group of Queensland for over twenty-five years. In addition to conducting weekly group hydrotherapy sessions for people with ankylosing spondylitis, Margaret played a core role in enhancing the social and education programs of the Group through her input in the newsletters, the organisation of speakers at the seminars conducted by the Group and in the organisation of many of the social activities (e.g., fun walks, dinners etc.).

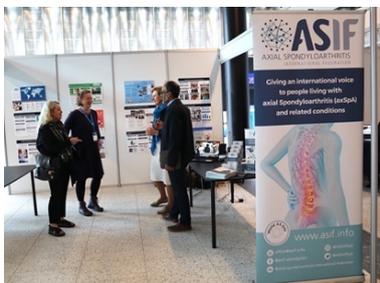
Marg was influential in establishing the AS Victoria peer support group in 2005 along with Greg Tate, formerly of Brisbane, Ankylosing Spondylitis Group of Queensland and joint editor of Australia's important national AS newsletter, AStretch.

In addition, Marg has been an AS advocate and activist in the professional MSK community, through active involvement with Arthritis Australia, professional Rheumatology (ARA) and Physiotherapy (APA) societies. Additionally, Marg had

long supported the international community, with Axial Spondyloarthritis International Federation patient and clinical networks.

Margaret was well-known and loved among ASIF's membership, she took an active part in ASIF's Council Meetings for many years, travelling to United Kingdom, Russia, Bulgaria and Turkey among other countries. She loved to feel connected to the world-wide community and was so dedicated that, due to the time zone difference, she regularly got up in Australia in the middle of the night to join ASIF's online meetings and webinars. Margaret was passionate about learning and sharing information and about the international community and how we could all help each other. In one of her last emails to ASIF, she offered to assist us to find a way to connect physiotherapists working in axSpA around the world which we agree is a great idea. Margaret will be sorely missed.

Graham Collins (AS QLD), Annie McPherson (AS Victoria) and Jo Davies (ASIF)



EULAR

We were pleased to have met rheumatologists, researchers and other health care professionals during our time at EULAR. Conferences like this provide an important opportunity to highlight axSpA and the challenges faced by people living with the condition.

We displayed the posters our members produced for the Council Meeting, enabling them to feature at this key rheumatology meeting.

We will share a report on some of the EULAR sessions soon.

ASIF Sub Committees

If you are interested in working more closely with ASIF, helping to guide the World AS Day campaigns, grow our membership and develop the ways we support our members, consider joining one of our Sub Committees!

World AS Day Sub Committee

Membership Sub Committee

Contact Joanne de Bry to find out more at communicationsmanager@asif.info

Dates for your Diary - 2022

30 July - Spondyloarthritis (SpA) Hybrid
International Congress, Taiwan

10-13 August - PANLAR, Florida, USA

23-26 August- SCR, Copenhagen, Denmark

14-15 September - BRITSpa, Birmingham, UK

15-17 September - AFLAR, virtual

10-14 November - ACR, Philadelphia, USA

23-27 November - IRACON, Indore, India

ASIF is grateful to its industry partners



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