

## Message from the President

Dear Members,

I am delighted to welcome our newest member, APMARR from Italy. You can read more about their work below and on their website. We are looking forward to working with them.



We are excited that at the end of May, many of us will meet face-to-face at the ASIF Council Meeting in Copenhagen. If you haven't registered already, we hope you can join us. Find out more below.

Our Talk to be Heard campaign has encouraged people around the world to talk about their axSpA. Conversations have been taking place across social media, including in many closed Facebook groups, where people feel safe discussing their experiences.

World AS Day is less than two months away and preparations are going well to ensure that together we raise more awareness than ever before. There are lots of ways our members and the axSpA community can get involved. We look forward to sharing the impact with you at the Council Meeting.

Finally, I want to say that living with axSpA is challenging enough without having to deal with conflict or a global pandemic or devastating natural disasters. Our thoughts, as ever, are with all those experiencing troubles in the world. ASIF is an apolitical charitable organisation and will continue to support member patient organisations around the world, including Ukraine and Russia.

Best wishes,

Zhivko Yankov  
President of ASIF

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## Our Projects

### World AS Day 2022



#### **Raising awareness of axSpA**

By working together, we can raise global awareness of axSpA this World AS Day. Last year we reached more than 12 million people through ASIF's social media. This year, with your help we can reach even more people.

Visit [asif.info/worldasday](https://asif.info/worldasday) to read our key messages, watch the supporting videos, and download resources. Please use the downloadable materials as templates; they can be adapted and translated to work for your association. There is also a flyer which you can share with rheumatologists and other health care providers, explaining what World AS Day is and how they can support it.

Thank you to everyone who attended the World AS Day webinars. A recording of the webinar is available to download on the webpage for those who couldn't attend. The webinar explains the campaign and how you can make it work for you and your members.

#### **Leave Your Footprint**

Leave your Footprint is an opportunity for people affected by axSpA to leave messages about their experience of axSpA, it could be what they are hoping for, what they wish they'd known at the start of their journey, where they gained support, what they are grateful for, something that they've learnt - the possibilities are endless.

The page will become an inspiring and hopeful place to visit, full of positivity from people living with axSpA to others living with axSpA.

Messages can be written in any language. Please leave your message and encourage everyone impacted by axSpA to do the same. [Find out more.](#)



### Walk Your AS Off

Walk Your AS Off is a virtual walk event encouraging everyone to get moving and raise awareness about axSpA.

We know exercise benefits people living with axSpA and walking is a great way to keep moving - but if walking isn't your thing, you can convert swimming, cycling, yoga or even gardening into a step count!

You can participate as an individual or create your own virtual team and start logging your steps. We know that COVID-19 restrictions in some countries may make it challenging to go for a long walk, but even walking around the block counts!

Download our social media assets and information sheet from the Resources section on [asif.info/worldasday](https://asif.info/worldasday) and encourage your members and colleagues to participate.



### Global Spondyloarthritis Summit – 6-7 May 2022

Please encourage your members to register for this free virtual education programme for anyone impacted by SpA and those on their diagnostic journey. The Summit is a series of virtual educational videos played over 2 days that anyone can register to log in and watch for free. You can also ask questions direct to the experts. Hosted by the Spondylitis Association of America (SAA), ASIF is proud to support the translations of the presentations into 12 languages, to enable more patients to access this valuable information. Translations will include Arabic, Bulgarian, Czech, French, German, Greek, Hebrew, Hindi, Italian, Japanese, Norwegian, Russian and Spanish (Latin American and European).

The programme features renowned rheumatologists and other experts from around the world, covering topics including the medical management of the Spondyloarthritis; behavioural therapy for pain management; intimacy, stress, depression and nutrition. [See programme.](#)

Download and use our social media assets to promote the Global Summit to your members.

*“Having the Global Summit presentations translated into Bulgarian enabled our members to access the valuable information that was shared. We promoted the Global Summit and the translated presentations on social media, via email, in our newsletter and on our website, a few weeks before the event and encouraged our members to register. We advertised it again during the Summit to encourage anyone who hadn't yet registered to do so. We got some great feedback from our members and we are delighted that ASIF will translate the presentations again in 2022. We want to enable even more Bulgarians to benefit from watching the presentations this year! This is an important set of resources that ASIF's members can provide to their non-English speaking communities.”*

– Zhivko Yankov

Bulgarian Ankylosing Spondylitis Patient Society and President of ASIF

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## Talk to be Heard

In the first five weeks of our Talk to be Heard campaign, which launched on 7 February, we received over 53,000 clicks from the social media posts to our webpage hub. The first of the campaign teaser videos has been seen by around 3 million people worldwide! With the campaign running in 19 countries and being supported by 22 patient organisations in 6 continents in 13 languages, our global axSpA community has the chance to really show its power. Through the campaign, we aim to support people in talking more openly about the disease, particularly with their doctors and loved ones.

During the campaign, we have been promoting the four main themed videos; these are self-filmed footage of people living with axSpA, talking about the emotional impact of the disease and how it affects their work, relationships, and their personal goals. We are also asking people to respond to questions about living with axSpA; there have been some fantastic discussions, many within closed Facebook groups, as well as incredibly honest admissions:

*“I was struggling to recognize myself in the new reality.”*

And powerful sentiments:

*“Remember me for what and who I was before...accept me for what and who I am now. I'm still wild at heart, it just takes me longer to get there.”*

You can find the videos, and our discussion guide to support people in having conversations about the disease, on our dedicated [campaign webpage hub](#).

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## **Delay to Diagnosis**    **Delay to Diagnosis**

The launch of our Delay to Diagnosis [Global report](#) last summer was a significant milestone for ASIF. The report was well received and we managed to spread the message far and wide; we presented the report at EULAR, at the Indian Rheumatology Conference, recorded a podcast about it and had an article in the Irish Medical Times. But, we need to get the message to policymakers, healthcare leaders and anyone with a role in axSpA diagnosis and treatment.

And so, now we are moving the project onto this crucial next stage. We are delighted to announce that a new global Steering Group has been formed to help us decide the strategic direction of the project and how best to tackle the barriers we identified in the report. The Steering Group is made up of ASIF members and people living with axSpA, world-leading axSpA healthcare professionals and patient advocacy and public affairs experts.

Our first meeting was held on 3 March; it was a lively affair, with lots of discussion and engagement from everyone on the group. We discussed which barriers are most urgent to tackle and where we might have the most impact on the diagnostic delay. Broadly, the group felt that awareness of the disease for those with symptoms, the general population and in primary healthcare, were crucial to reducing the delay. We are now working to develop these ideas further. Look out for our presentation at the ASIF Council Meeting, where there will also be an opportunity for all our members to share their thoughts on how the project can benefit your organisations.

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## **ASIF Council Meeting, Copenhagen 29-31 May 2022**

We are delighted that so many of our members have already registered to attend the upcoming Council Meeting – we are looking forward to seeing many of our friends and colleagues in person after so long.



The Council Meetings are the most important event in ASIF's calendar. It is an opportunity for member representatives to meet and to network with other Patient organisations from around the whole world.

The programme will include keynote speakers on topics including the latest advances in axSpA research. We will also hold some workshops so that we can get your ideas and opinions on what ASIF is and should be doing.

We have not met 'in person' for a few years due to the pandemic and we have had many new members join ASIF in the last few years. I encourage you to consider sending someone to join us in Copenhagen if you can. If you have not yet registered and plan to come, please do so before the end of March.

You can register [here](#).

We are able to help with letters of sponsorship to support visa applications, please contact [Jo Davies](#) for assistance.

We already have around 40 delegates from over 20 countries signed up.

The full programme will be emailed to registrants in April, but we've included an overview below.

### **Programme**

Sunday, 29 May - 18:00-21:00

Welcome Cocktail Reception for delegates and guests

Monday, 30 May

Two guest speakers and a selection of our members will give presentations during the day. ASIF representatives will provide updates on our projects and priorities.

Dinner

Tuesday, 31 May

Two guest speakers will follow the ASIF Annual General Meeting and election of Trustees. Members will have the opportunity to share ideas and feedback during workshop sessions

Delegates and guests are invited a sightseeing activity in the afternoon, followed by dinner.

## Posters

All members have been invited to submit a poster about one or more projects or their organisation generally. The posters will be displayed during the Council Meeting and delegates will have time view them. Six will be selected from the posters submitted to give a 'live' presentation to the delegates during the Council Meeting.

Posters should be submitted to [admin@asif.info](mailto:admin@asif.info) or [office@asif.info](mailto:office@asif.info) by 22 April.

Please find the poster template and [instructions](#) on how to complete it on our [website](#).

Please contact Jo Davies with any questions.

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## Welcome to APMARR

Welcome to our newest member APMARR.

APMARR, Italian National Association of People with Rheumatological and Rare Diseases, is a Social Promotion Association founded in 1984 to protect the right to care of people (adults and children) suffering from rheumatological and rare diseases.

Its mission is: "to improve the quality of assistance to improve the quality of life".

Rheumatological diseases are still "unknown" today and above all "not recognised" at a social level. The primary objective of APMARR is to ensure that these pathologies find the just dignity and bring attention to public opinion and the policymakers.

APMARR operates on multiple fronts promoting:

- awareness campaign,
- psychological support
- health care assistance
- social and human right,
- rheumatology research,
- early diagnosis and early access to treatment





A competent and organised volunteering activity can give answers to needs of people who are feeling alone with their pathology.

APMARR trains its volunteers so that they can develop non-specialist “transversal” skills, with particular attention to interpersonal relationships, communication, empathic listening, as well as the ability to enhance the experiences and skills of others.

APMARR, through advocacy actions, encourages initiatives aimed at promoting socio-health policies in Italy, which facilitate the achievement of an early diagnosis, which allows access to equal treatment without disparity.

Find out more at [www.apmarr.it](http://www.apmarr.it)

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### **Member Webinar Series**

We are excited to invite you to our new Member Webinar Series. The webinars will cover topics, including the latest research, fundraising, emerging treatments, membership, advocacy and others.

The webinars will be held every few months and we will vary the day and time to enable as many of our members to attend live. They will be recorded for those who cannot attend the live session.

The sessions will be interactive, with a short presentation from one or more speakers, and time for questions and or panel discussions. You are welcome to submit your questions early to me or ask them live.

Our first webinar will feature Dr Matthew Brown (pictured) and his research on the potential to treat axSpA via the gut microbiome.

Topic: The potential to treat axSpA via the gut microbiome

Speaker: Matthew Brown MBBS MD FRACP FAHMS FAA, Director, Guy's and St Thomas' NHS Foundation Trust and King's College London NIHR Biomedical Research Centre

Date: Monday 11 April 2022

Time: 17:00-17:45 GMT

Link: <https://meet.goto.com/JoannedeBry/asif-member-webinar>





Please RSVP by Tuesday 5 April to Jo de Bry at [communicationsmanger@asif.info](mailto:communicationsmanger@asif.info).

Please share this invitation with your colleagues who may be interested.

We look forward to seeing you at our first Member Webinar.

If there are topics that you would like to see covered in future webinars, please email Jo de Bry.



## **EULAR PARE PODCAST**

Listen to the Podcast featuring our Delay to Diagnosis project on:

Spotify: <https://t.co/4GhYeS4DxF>

iTunes: <https://t.co/ei2400USmE>

The podcast features ASIF's Jo Davies and Jo Lowe, who talk with Peter Boyd about our Delay to Diagnosis project and report.

Thank you to everyone who voted for the ASIF Poster at the PARE Best Practice Fair. Our prize was to be featured in the Podcast! We hope you enjoy listening! Thank you EULAR PARE!

Read the [Delay to Diagnosis Report](#)

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## **ASAS Annual Meeting - Report**

Patient representatives from ASIF were invited to attend the ASAS (Assessment of Spondyloarthritis International Society) Annual Meeting, held virtually on 13-15 January, 2022.

ASAS brings together international experts in the field of spondyloarthritis to support and promote the study of axial and peripheral spondyloarthritis, with a mission to increase awareness and early diagnosis of the disease, the development and validation of assessment tools, and the evaluation of treatment modalities in order to promote clinical research with the ultimate goal to improve outcome of the disease.



The annual meeting, in addition to such usual activities as addressing fellowships and grants, membership and news, is a workshop to review current research projects and decide on future courses of action. The big workshop topics this year were Classification Performance, the SPEAR project and the ASAS Core Set.

There was also a review of ongoing studies and projects. These were:  
Y-ASAS, or Young ASAS, an initiative started in 2017 to involve younger (under age 45) members in ASAS and its projects.

CLASSIC (Classification of Axial Spondyloarthritis Inception Cohort) project which aims to test or validate the performance of the current ASAS classification criteria in a prospective cohort of patients.

AXIS, a joint project with GRAPPA (Group for Research and Assessment of Psoriasis and Psoriatic Arthritis) to study axSpA in PsA patients and to develop classification criteria and a unified nomenclature for axial involvement in PsA that would allow defining a homogeneous subgroup of patients for research. The project is recruiting 400 patients in 20 countries.

MRImagine, a project that aimed to investigate inter-reader reliability, the extent of detection of lesions, and frequency of cases with a positive MRI for structural lesions when using an “all slice” approach versus the SPARCC scoring of 5 central slices.

Imaging Reporting, a project to develop recommendations for the standardization of communication around imaging for diagnosing and assessing axSpA in clinical practice.

The workshop on SPEAR (a definition of early axSpA project) was to assess how to continue with work on a definition of early axial spondyloarthritis for research purposes. The objectives of the project are to:

First, identify all possible definitions employed in the literature for “early SpA”, including “early axSpA” and “early pSpA”.

Second, to summarize the evidence on the relationship between symptom duration or the presence of radiographic damage and clinical response in patients with axSpA treated with NSAIDs, bDMARDs or tsDMARDs.

Third, to summarize the evidence on the relationship between symptom duration or the presence of radiographic damage and burden of disease at the moment of diagnosis in b/ts/dMARD-naïve patients.

The project's working group has reviewed a few hundred publications, including studies, for a definition of early axSpA. About 60% of the studies had a specific definition. However, the definitions used varied between using mainly symptom duration and disease duration. As the workshop saw, coming up with a definition is not an easy task, but based on the working group's review, it recommended using symptom duration as the basis of an early axSpA definition for research purposes. The project is also looking at the possible benefit of early versus delayed treatment.

The Classification performance workshop looked at the challenges to the ASAS Classification Criteria and the evidence for their validity and applicability compared to the rheumatologist's diagnosis.

The ASAS Core Set workshop addressed an update to the ASAS-OMERACT (Outcomes in Rheumatology) core outcome set for Ankylosing Spondylitis into the ASAS-OMERACT core outcome set for axial spondyloarthritis (axSpA). At this time, 7 domains (pain, physical function, stiffness, disease activity, mobility, overall functioning and health, peripheral manifestations) were selected for the symptom-modifying therapies setting. For the disease-modifying therapies setting, 6 domains (physical function, disease activity, mobility, structural damage, extra musculoskeletal manifestations, peripheral manifestations) were selected.

Thank you to Michael Mallinson for this report.



## **International AS Volleyball Tournament**

The 17th International AS (Ankylosing Spondylitis) Volleyball Tournament will take place in Utrecht in the Netherlands on Saturday 25 June 2022.

Organised by Stichting Axiale SpA Nederland, they invite international players with AS, who are a

member of a patient organisation to participate.

[Read invitation letter.](#)

## Dates for your Diary - 2022

6-7 May - Global Summit (virtual)

7 May - World AS Day

29-31 May - ASIF Council Meeting, Denmark

1-4 June - EULAR, Denmark

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## ASIF is grateful to its industry partners



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