

## ASIF Newsletter: December 2021

### Message from the President of ASIF

Dear Members

The pandemic continues to affect us all. We hope that you are all keeping healthy.

2021 has been another good year for ASIF. As we continue to grow, we welcomed five new members into our community:

ASWS, Ankylosing Spondylitis Welfare Society, the third association to join from India

AI Arthritis, The International Foundation for Autoimmune and Autoinflammatory Arthritis

ELEANA, Greece

ANMAR, Italy

Arthritis Ireland



We now have over 50 Members in over 40 countries, and we are working hard to continue to expand.

ASIF's staff team is also growing, we recruited Joanne de Bry as our Communications Manager. Amongst many other tasks, she will be seeking to create a network of communications people across our membership. Jo has already worked wonders on the website and she works closely with Jo Davies, Jo Lowe and Valeria managing all ASIF's Communications.

Due to the pandemic, we had to cancel our meeting in Frankfurt in 2020 and we held virtual council meetings in 2020 and 2021. Hopefully, we will be able to meet live in 2022. We plan to hold the ASIF 14th Council Meeting and Annual General Meeting on 29-31 May in Copenhagen, Denmark. This is immediately before EULAR 2022 which is also taking place in Copenhagen on 1-4 June 2022. We hope that this will mean that many of you will be able to combine both meetings. We would love to make this the biggest and best attended ASIF Council Meeting to date. We realise that there remains some uncertainty with regards to travel restrictions. We will keep an eye on that and we will make the meeting hybrid if necessary – to accommodate those who are unable to travel. More information about the proposed meeting below.

World AS Day was an enormous success in 2021 with over 12 million people reached on social media. We are working on the theme for 2022 - please help us to make it even bigger and better in 2022 by engaging with the campaign and sharing posts and materials.

ASIF's projects continue to provide resources and campaign materials for your use. The Delay to Diagnosis produced an excellent report in 2021. It was the subject of ASIF's first accepted abstract at EULAR and it was featured in articles in EFCCA and EULAR's newsletter and in the Irish Medical Times; and a presentation on it won 3rd prize recently at the EULAR PARE Best Practice Fair. In 2022 and beyond, we are going to build on the success of that report and work with our members and other stakeholders to find a way to actually reduce the global delay to diagnosis.

We are working on producing a set of resources for members about axSpA and about forming and developing a patient association. This is led by our Membership sub-committee who are also working on other ways to support members.

If you would like to join one of our project sub-committees, please do get in touch.

At the AGM, we explained ASIF's succession plan. We are aware that Andri and I both step down as Trustees in 2024 and we want to plan now for our replacements. Please let us know if you know anyone in your organisation, you think might have the potential to be the next President or Secretary of ASIF. You will find more about the nomination and election process below. Ideally, we will find someone to become a Trustee in 2022 who will work alongside me for a couple of years before then being elected President as my replacement. Please get in touch if you would like to talk about this further.

We extend to you all our very best wishes for the holiday season. We also wish you all good wishes and hope for the very best for us all in 2022.

*Zhivko Yankov*  
President of ASIF

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## Our Projects



### 27 countries have contributed to IMAS

Twenty-seven countries across five continents have now taken part in the International Map of Axial Spondyloarthritis (IMAS) - the biggest ever survey of

people living with axSpA. IMAS collects information about the impact of axSpA on all areas of life and is now in its final stages.

So far, almost 4,500 people worldwide have responded to the survey. In 2022, we will have a set of data that represents the experiences of people living with axSpA around the world. IMAS gathers and shares data on how people with axial spondyloarthritis (axSpA) experience their disease physically, psychologically and socially.

We thank our members that have supported the IMAS survey; without you, it would not be possible to collect this vital information.

Find out more about [IMAS \(https://asif.info/imas\)](https://asif.info/imas).

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## New Global Campaign!

Look out early next year for our new global 'Talk to be Heard' campaign! The campaign builds on the video released earlier this year for World AS Day, featuring people from around the world talking about the impact of axSpA on their emotional wellbeing. This video will be refreshed and will be released alongside three new videos of people talking about what they would like to achieve in the future; how axSpA affects their relationships, and the effect on their working life. The videos show people in nine countries from five continents talking in eight different languages about how axSpA affects them.

#AxSpATalkToBeHeard aims to encourage people to talk about their condition, and how it affects their life beyond their physical symptoms. We hope the campaign will inspire people

around the world to talk more about their disease and that they will find confidence in being part of a global community. We will also run a global social media campaign, encouraging people to respond on a week-by-week basis to different questions about their axSpA journey. The campaign can be engaged with on Facebook, Twitter and Instagram, as well as other on and off-line channels. We hope the campaign will encourage people to have conversations with their loved ones and doctors.

The campaign will be hosted on a new ASIF webpage hub. We will also provide a discussion guide to support people in having conversations about axSpA. This guide will serve as a tool to help patients openly discuss their experiences and help to define how axSpA affects them and what is important for others to understand. It will aim to promote meaningful discussions with loved ones and more effective discussions with rheumatologists.

Many ASIF members participated in webinars in November, during which we shared details of the campaign. With 23 members signed up to run the campaign and materials being made available in 13 languages, Talk to be Heard will be truly global and will highlight the strength and support of the international axSpA community. We are very excited to launch the campaign in February!

If you would like to run the campaign, it's not too late to get involved. The materials will be available in: English, Bulgarian, Czech, Danish, French, Greek, Hindi, Lithuanian, Norwegian, Russian, European Spanish, Latin American Spanish and Tagalog. Please contact [Jo Lowe](mailto:projectmanger@asif.info) ([projectmanger@asif.info](mailto:projectmanger@asif.info)) to find out more.

Talk to be Heard is part of the [IMAS](https://asif.info/imas) (<https://asif.info/imas>) Project.

Talk to be Heard has been developed through a collaboration between Novartis and ASIF.

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### **World AS Day – 7 May 2022**

We are developing the World AS Day 2022 campaign with guidance and input from our Sub Committee, made up of representatives from our member organisations.

The campaign will focus on general awareness raising, rather than focusing on one impact of axSpA.

We look forward to sharing more detail with you in the new year.

The first set of World AS Day assets for the 2022 campaign will be emailed to you, they include the logo, three Save the Date assets (sized for Facebook, Twitter and Instagram), along with a blank template that you can insert translated copy into.

Please share the images on your social channels to raise awareness of the upcoming campaign.

Please use the hashtag:

**#WorldASDay2022**

in all posts/tweets so that we can track engagement.

We will run webinars for our members to introduce the campaign, as we did last year. I look forward to inviting you to these events in the new year.

## The Global Summit

The Global Summit, hosted by the Spondylitis Association of America (SAA) will take place from 6-7 May. As a supporter of the Summit, ASIF will fund the translation of the presentations in a variety of languages again this year.

Zhivko Yankov encouraged members of the Bulgarian Association to attend the summit. He commented, "Having the presentations available with Bulgarian subtitles made the Summit content accessible to our local axSpA community. The sessions contained really interesting and beneficial information. I will be encouraging our members to attend again next year, and urge you to do the same."

Last year the sessions were translated into languages including: Bulgarian, French, German, Greek and Russian. Please contact us if you would like to have the presentations translated into your language.



## Walk Your AS Off

We hope to increase participation in Walk Your AS Off this year. The annual walking challenge encourages participants to get moving through the month of May. We know that walking can be of great value to people living with axSpA, but sometimes it can be hard to make time to go for a walk. Walk Your AS Off helps to motivate people to count their steps – whether it is going for a walk in the countryside, getting off the bus a stop earlier and walking that extra distance into work, or walking to the local shop instead of driving there. Other forms of exercise can be converted into a step count, for example swimming, yoga or even doing housework! Registration will open in April for this fun and active event.

Thank you to the members of the subcommittee who are helping develop this year's campaign.

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## Report on the ASIF Council Meeting

We were delighted to see so many friends at the ASIF Virtual Council Meeting on 11 September. Jo Davies, Executive to the Board, welcomed everyone and introduced ASIF's President, Zhivko Yankov. Zhivko's presentation highlighted the work that ASIF had completed over the last year. Joanne de Bry, Communications Manager, welcomed ASIF's newest members who proceeded to introduce themselves by video and shared a little about their organisations. [Watch video \(https://vimeo.com/657813167\)](https://vimeo.com/657813167).

ASIF's Treasurer, Thierry Vannier presented the 2020 Report and Accounts. As ASIF's income has grown, it has been necessary to engage with an auditor/accountant with specialist knowledge of UK charity accounting and law. The members voted and approved the appointment of John Gordon as the Independent Examiner of ASIF's accounts in 2022. Justino Romao was thanked for his many years as ASIF's auditor.

Yuki Zeniya stepped down as Trustee and was thanked for his contribution to ASIF. We are starting a campaign to recruit more Trustees in the next few years – please see below

Jo Lowe Project Manager, Lillann Wermskog, Spafu Norge and Wendy Gerhart, CSA, provided an update on ASIF's projects.

We were delighted to see so many members at the meeting, but know that nothing really compares to meeting face to face. We hope that 2022 will allow us to do that – we will look at hybrid options if travel remains a problem for members

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## Register for the ASIF Council Meeting 2022

Scandic Hotel, Vester Søgade 6, 1601 København V,  
Denmark  
29 – 31 May 2022

Registration is open for the ASIF Council Meeting 2022.

The programme will include talks and workshops covering the latest in scientific developments around axSpA, and developments in treatment and the patient journey. We will provide more information about the results of the IMAS study and will invite participants to share information about what is going on in your countries.

We will circulate the full programme as soon as it is finalised.

ASIF is delighted to host this face-to-face Council Meeting, after two years of virtual events.

If the global pandemic prevents some or all of our members traveling to Copenhagen, we will have the option to hold the meeting as a virtual or hybrid event.

### Registration fees

The price per person to register for the Council Meeting is as follows:

Delegates (maximum of 2 per member organisation):	€300
Additional Delegates if not sharing a room:	€500
Extra delegates/observers sharing a room:	€250
Family members	€200

If you need a personal assistant/carer to travel with you, they can register at no charge.

The registration fee includes 3 nights' accommodation, breakfast and lunch each day, two dinners. Arrival date 29 May, departing 1 June 2022. The conference and accommodation will be at the Scandic Hotel, Vester Søgade 6, 1601 København V, Denmark.

Extra nights before 29 May will be charged at €200 per night per single room bed and breakfast. Extra room nights on 1 June and after will be charged at €200 per night per single. If you would like to stay extra nights, and you need help to book those rooms, please let Jo Davies know when you register. You will pay for extra nights direct to the hotel.

### Flights and transport

The nearest international airport is Copenhagen, Kastrup. There are also good train connections to Copenhagen. The train from the airport to the hotel is 19 minutes and the drive/taxi will take less than 15 minutes.

ASIF are not covering the cost of transfers for delegates.

If you require a visa to travel to Denmark and it would help to have a letter of invitation, please email Jo Davies at [office@asif.info](mailto:office@asif.info)

### Payment

Once you have registered, you will receive an email with the breakdown of registration details, price and bank transfer details so that you can make the payment.

All registration fees must be made 31 March 2022.

### **Special offer to apply for financial assistance to attend**

ASIF would like to offer those member organisations that have never been represented at an ASIF Council Meeting before – and who have trouble in finding the financial resources to do so – to cover of the cost of one delegate to attend Copenhagen 2022. That will include a flight and transfer costs and we will also waive the registration fee for that delegate. There is an [application process](https://bit.ly/3rKg3VH) (<https://bit.ly/3rKg3VH>) for this and we ask you to meet some simple criteria. Trustees will approve applications on a case by case basis. If you are interested in taking up this offer, please contact Jo on [office@asif.info](mailto:office@asif.info).

### **Country Presentation**

We invite each member/country to prepare a 5-10 minute presentation to be given at the conference. You can talk about any particular successes or things that perhaps did not work so well.

### **Conference booklet**

We will create a digital booklet which tells a little about each participating organisation. Once the format is decided, we will be in touch to ask you to provide some basic information.

### **Registration**

Please follow these steps:

1. Click on this [link](https://bit.ly/3tUXocr) (<https://bit.ly/3tUXocr>).
2. Please complete one form for each person attending. Be sure to hit Submit for your form once you have completed it.

If you have any questions, please contact [Jo Davies](#).

We look forward to seeing you in Copenhagen.

Very best wishes

*ASIF Trustee Board*

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## **Trustee recruitment**

Charity trustees are some of the most important people in a charity. ASIF's members are dependent on our trustees to make good decisions and lead well. We look for a wide range of skills from our trustees, we need a trustee board that can challenge one another and the status quo, that bring different experiences, knowledge and ideas and are able to work constructively and enthusiastically as a team.

ASIF is seeking to appoint one Trustee at the AGM in May 2021. There will be a further 2 trustee posts vacant in 2022.

We are very conscious that Zhivko Yankov and Andri Phoka will both be stepping down in 2024 – following eight years of great leadership. We would like to start preparing for that now. We are aiming to appoint Trustees in 2022 and 2023 who would be interested in taking on the role of Chair or Secretary in 2024. This would provide those elected trustees time to learn about ASIF and how it operates by working alongside Zhivko and Andri for 1 or 2 years before taking over those important roles.

All this would be dependent on being elected. Any person nominated needs to be elected as a trustee and they would also need to be elected by the members into the role of Chair or Secretary. However, we think it still sensible to plan as well as we can and it is in the interest of all members that we have a good and robust succession plan.

Being a Trustee of ASIF is very rewarding – Andri Phoka, current Secretary said:



When I became an ASIF trustee, I met passionate trustees who wanted to raise awareness globally for axSpA, visionaries for a global organisation who can help big and small organisations to improve the situation in their countries, and even help countries without a patient organisation to start one. Having served ASIF for 5 years now, I believe it was one of the wisest decisions I made to become a trustee. I have learnt a lot about axSpA, I empower my knowledge and I share it in my national organisation, I share my opinions, my ideas, and my knowledge with others. I see ASIF becoming a bigger and stronger global organisation day by day and

I am part of it. In addition, I have learnt about people around the world: scientists, rheumatologists, advocates, patients, people from the industry. I have participated in lots of conferences and I feel like I gain much more than I give. I would truly recommend becoming a Trustee of ASIF.”

If you or anyone in your organisation is interested in learning more about the role of Chair or Secretary with a view to being nominated to stand for election at the 2022 or 2023 AGM, please contact [Jo Davies](#) for further information. She will arrange for you to have an informal chat with Zhivko and Andri in the New Year.

You can find out more about becoming a Trustee of ASIF [here \(https://bit.ly/3qWDRpT\)](https://bit.ly/3qWDRpT).

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## Highlights from conferences

### IMAS at EPIS

In November, ASIF Secretary and Chair of the IMAS sub-committee, Andri Phoka, presented the IMAS project at EPIS. EPIS is the European Patient Innovation Summit and, this year, was in the form of a virtual webinar series between September and November. The 2021 summit focussed on matters relating to health data and explored the value of health data to patient communities.

Andri presented the IMAS case study as part of a session on ‘what patient organisations can do to empower patients around health data’. During the presentation, she talked about the different ways that IMAS data has been used with a range of stakeholders. Speaking to an audience of around 200 people from across Europe, Andri demonstrated why this type of health data is crucial in providing evidence to underpin patient advocacy work.

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## Highlights from EULAR PARE

- **Get the information out there: monthly webinars - Ingrid Hennes, ReumaNet vzw**

ReumaNet vzw in Belgium improved and updated their IT and used Teams for their webinars. Ingrid explained that there were lots of interesting topics and with no travelling time, it was easier to secure good speakers. The webinars were free and had 60-70 participants. Questions were asked through the chat function. The sessions were recorded and put on You Tube after the live event. Post COVID-19, ReumaNet vzw will continue to run webinars.

You can watch the webinars here: <https://www.youtube.com/user/Jorien99/videos>

- **An oRAnge button as sign of involvement & raise awareness for the RA campaign in Belgium - Mireille Verscheure, RA LIGA**

RA LIGA in Belgium have integrated an oRAange button throughout their awareness activities, including World Arthritis Day and WALK Family Day. The oRAange button is featured on their website and used as a lapel pin. Mireille explained how this simple tool draws attention to Rheumatoid Arthritis.

- **Digital Friends - best practice: challenges and solutions - Karina Krichau, The Danish Rheumatism Association**

The Danish Rheumatism Association recruit volunteers with RMD to be part of their Digital Friends programme. The volunteers telephone others with RMD who are lonely or who want to share the ups and downs of the condition with someone who truly understands. Volunteers are matched when they sign up, depending on what they want to get out of the programme. The matching can be based on age, location, or type of RMD. The Association plan to continue running programme post COVID-19.

- **COVID-19: The Challenges we faced as a patient organisation and how we overcame them - Nadia Malliou, Hellenic League Against Rheumatism**

The challenges faced by the Hellenic League Against Rheumatism during the pandemic included: extensive lockdown, social distancing/isolation and fear of the unknown.

To overcome the challenges, they focused on online engagement with their members. They found this to be an inclusiveness solution as anyone with a computer or phone could join virtual conferences or access content on demand. They utilised the interactive environment of social media and nurtured a sense of community and support. Their members also utilised their helpline.

- **Role of general practitioners (GPs) in the management of Ankylosing Spondylitis - Ugo Viora, ANMAR Italia**

The delay to diagnosis is unacceptable. Ugo stated that rheumatologists are involved too late in diagnostic process. The red flags have been changed on the intranet platform used in two selected Italian regions by GPs to manage their patient data with the aim of identifying patients sooner. ANMAR Italia send a weekly newsletter to GPs. They monitor how many



patients were sent back to GP after seeing rheumatologist and how many patients suffering back pain underwent the red flag analysis.

- **Keynote presentation: Patient organisations in the 21st century – how to best use digitalisation and related developments to benefit the development of the organisation - Marnie Webb, Techsoup, US**

Techsoup surveyed community service organisations (CSO) at a global level and despite the size organisations had similar problems. The biggest barrier to digital tool use includes cost of adopting tools, staff training and culture change.

CSOs who believe digital tools would improve data efficacy say progress is delayed by lack of money, expertise and training.

What four things organisations can do:

1. Take control of technology planning and strategy
2. Assess
3. Decide
4. Act
5. Measure

Then....create Centres of excellence (this can be just one person in your organisation who is responsible for the IT/systems), Communicate the progress the IT development is making with the team, re-evaluate regularly to ensure your system is meeting the needs of your organisation.

Use project management tools to ensure you meet project timelines and crucially, be clear about what your goals are.

- **Establishing a youth group during the pandemic - Mary Vella and Jagoda Beltrani-Cordina, Arthritis and Rheumatism Association Malta (ARAM)**

During the pandemic, ARMA developed a youth section. They set up social platforms, including WhatsApp and updated their website. They began receiving phone calls from non-members asking for support and advice. Mary invited a patient, Jagoda, to be the ARAM youth representative. She recruited young patients and participated in medical webinars and training conferences. She hopes that these patients will grow with the association and continue to support each other. This group has helped to reduce the stigma around the condition in younger people.

- **Keeping senior members involved**

Harnessing skills of older members (65yo +) can be a valuable tactic. Many senior people are using the internet and are relatively tech savvy.

Older and younger people want both digital and face to face connection. A project called ReSurf teaches older people about online safety. It was found that WhatsApp groups seem to be popular with older people. Groups can be established based on age or interest, it's important not to dismiss certain interests across different age groups. Being able to offer training on using digital tools during pandemic was valuable to people, not just from a rheumatologist disease perspective, but also in connecting families and friends.

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## Highlights from ACR

The American Congress of Rheumatology (ACR) again took place virtually, but the exchange on new findings was lively as usual in the SpA community. ASIF's Scientific Advisor, Uta Kiltz attended the congress and provides an insight into the sessions through her personal highlights.

- The assessment of treatment response in axSpA patients relies heavily on the assessment of pain. Therefore, the question of how concomitant fibromyalgia symptoms affect patient reported outcomes is relevant. Baraliakos et al. have now investigated this question and published their results as a poster. The main finding is that clinical symptoms in axSpA and fibromyalgia partially overlap and that response pattern of PROs is not different between axSpA and fibromyalgia. However, so-called composite scores such as the ASDAS discriminate between axSpA and fibromyalgia. Consequently, the assessment of disease activity by the ASDAS has long been recommended by the international expert association ASAS.
- The influence of patient and disease characteristics on global functioning and health in patients with AxSpA is incompletely understood. In the early axSpA cohort DESIR, this analysis has now been performed based on the ASAS Health Index. In this so-called Bayesian network analysis, global functioning was shown to be influenced by disease activity and physical functioning as well as comorbidities, but largely independent of structural damage in the spine. The consequence of these study results is that the process of coping needs to be better understood in order to better understand these apparent adaptive processes.
- In patients who are in remission with TNFi therapy, the question of whether the therapy could not be reduced repeatedly arises in clinical practice. A previous study with adalimumab suggested that this may be possible in some patients. However, the Ability 3 study only examined patients who received either adalimumab or placebo. The C-OPTIMISE study presented at the ACR examined continuation/reduction/discontinuation Certolizumab Pegol. Only patients who were in remission from prior therapy with certolizumab pegol were randomised. Patients continuously treated with CZP benefit from this treatment. The study showed that neither treatment discontinuation nor dose reduction produced similarly good results as continuing the approved dose.
- The development of bimekizumab, a monoclonal bispecific selective interleukin 17A and 17F inhibitor, is advanced in the study program. Bimekizumab shows sustained and clinically meaningful long-term improvements in health-related quality of life in patients with ankylosing spondylitis. Interim results after 3 years of treatment have been presented at the ACR with good results. Bimekizumab is already approved in the EU for skin psoriasis.
- At ACR, initial results were presented on a new mode of action using an oral, selective MK2 inhibitor with sustained multi-cytokine inhibition for the treatment of ankylosing spondylitis. Results of the Phase I study were presented with promising results and the information was shared that the Phase II study for patients with AS has been initiated.
- Assessment and monitoring of disease activity and function is of great importance for qualified treatment of patients with axSpA. Tight control strategies are beneficial in patient care, but are also time and personnel intensive. Strict monitoring enables

timely effective adjustment of therapy. However, due to lack of time and staff, intensive treatment plans are often not feasible, even though they are superior to conventional approaches. Health apps are increasingly used to record Patient Reported Outcomes (PRO). To date, however, good data for this strategy in axSpA patients are lacking. The aim of a study presented by R. Kempin was to collect data on the practicality and adherence of a commercial health app. The app could be used by most patients, but adherence was poor over the course of six months. Interestingly, older patients had higher adherence, as did patients with high disease activity. The authors conclude that a digital app is feasible for axSpA patients with high disease activity in order to direct them to more rapid therapy initiation.

Thank you to Uta for this informative summary.

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## Scandinavian Rheumatology Congress Features Key IMAS Findings

For patients living with axSpA, the burden of the disease can impact all areas of their life. The survey results from the International Map of Axial Spondyloarthritis (IMAS) demonstrate the varied ways that people are impacted by this disease. IMAS brings together researchers, rheumatologists and patient organisations to deliver evidence of the disease burden, ensuring that the patient perspective is better understood.

This September, IMAS was once again present at a major rheumatology congress to present findings from the initial European phase of the project. Alongside IMAS partner, Spafo Norge of Norway, we presented four posters at the Scandinavian Rheumatology Congress (SRC) 2021. These explored the following different disease burdens.

One third of axSpA patients reported an inability to work or a recognised disability. One poster explores the factors associated with these situations and concludes that early access to effective treatments and flexible working environments are essential to keeping active and continuing to work.

A number of different factors are associated with physical activity, which is an essential part of axSpA self-care. Another poster emphasises the benefits of activity on disease management and mental health - as well as the factors associated with increased activity. The role of patient organisations in enhancing access to physical activity is also highlighted. The impact of axSpA on Spanish patients' close relationships was the theme of a third poster with almost 58% of people reporting a high functional limitation in intimate relationships and a decrease in sexual activity. Over 80% of people reported worsening relationships with their spouse. One conclusion is that healthcare providers can play a key role by improving communication about intimate relationships with patients and giving access to counselling on a healthy sex life.

The final poster explores gender differences in Norwegian axSpA patients. The different healthcare professionals visited by men and women on the path to diagnosis is examined. We also look at the differences in the way the genders experience symptoms of the disease, including spinal stiffness in different areas of the spine, functional limitation and which body areas are affected by inflammation. Although time from symptom onset to diagnosis has been reduced for female patients, their diagnostic delay is still longer.

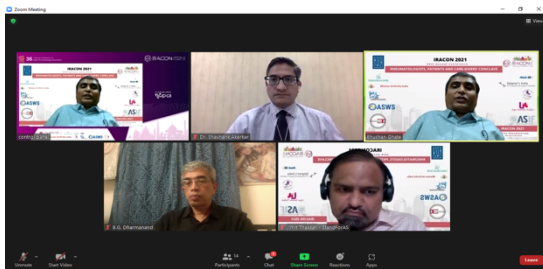
As well as the poster presentations, the data on fatigue from the European results were presented by the IMAS founder, Dr Marco Garrido-Cumbrera. The presentation explored the key factors associated with fatigue, showing poorer mental health and sleep disorders as the most common factors. Almost 80% of patients experienced severe fatigue with France and Belgium having the highest prevalence.

The IMAS objective is to ensure that the axSpA patient perspective is integrated into health policy and clinical decision-making. By presenting IMAS data at rheumatology congresses worldwide, we continue to highlight the patient perspective, engage clinicians who directly provide treatment to patients and keep the care of people living with axSpA in the spotlight.

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## India Rheumatology Conference

The 36th Annual Conference of the Indian Rheumatology Association (IRACON) took place between 9 and 12 December. As a prelude to the full conference, we were delighted to be invited to the 'Rheumatologists, patients and caregivers' enclave'. This was a series of sessions bringing together patients and doctors to focus on different rheumatoid diseases.



On 8 December, Dr Shashank Akerkar organised a session dedicated solely to axial spondyloarthritis, which was attended and introduced by the President Elect of the Indian Rheumatology Association, Dr B.G. Dharmanand. Dr Dharmanand spoke encouragingly about the Indian Rheumatology Association being a knowledge partner of the

patient associations, supporting them in their fight for insurance recognition and that he would like a coalition of rheumatologists and patient organisations to work together on the matters most important to patients.

The session focussed on the delay to diagnosis in axSpA, taking a closer look at the factors associated with diagnostic delay. We were pleased to be able to participate in the session, where all three of ASIF's Indian members also gave presentations. Bushan Gate from ASWS, Ashish Joshi from Antardhwani and Jimit Thakker from Stand for AS talked about some of the fantastic work they are doing. The Indian groups also talked extensively about the stigma associated with the disease, both for the individual, but also for their families. Patients in India are often made to feel that they are somehow to blame for their axSpA, are not doing enough to 'help themselves' or just need to be 'more positive'. Other common themes were supporting patients in managing their disease; advocating for their rights to treatment and insurance cover, and educating broader sections of the healthcare system.

We were delighted to be given the opportunity to present at the IRACON session and ASIF's Project Manager, Jo Lowe, gave an overview of the barriers to timely diagnosis identified in our Delay to Diagnosis report. Dr Akerkar, hosting the session, inviting attendees to discuss each of the barriers and what might be done to tackle them. Very encouragingly, Dr Dharmanand committed, as incoming President, to working with patients and patient associations to explore ways to reduce the time to diagnosis.

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## Raising the Patient Voice with ACR

Tiffany Westrich-Robertson from AI Arthritis (an ASIF member), has done some amazing work recently to persuade ACR (American College of Rheumatology) to consider ways that patient organisations and therefore patients can be more involved in and have better access to ACR Convergence which is their annual scientific meeting. EULAR has long respected the role of patients and patient organisations and provides ways for us to take part in their annual congress, but ACR is a little behind others in this regard.

It is important that scientists and medical professionals realise that patients need to be involved, included and/or consulted at all stages of research and that we bring added value. It is furthermore important that we have the opportunity to attend ACR convergence to find out the latest scientific findings and disseminate that information to the people it most affects.

ASIF fully supports this action. [Find out more \(https://asif.info/important-message-to-patient-organisations/\)](https://asif.info/important-message-to-patient-organisations/).

Thank you to all those who signed AI Arthritis' letter.

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### **AS features in The Good Doctor**

TV's The Good Doctor, featured a storyline about a 21-year old with ankylosing spondylitis undergoing a life-altering operation. With an average viewership of 8.16 million, this American TV series will have raised awareness of AS with a new audience.

Here is a synopsis of the episode:

*Dr. Glassman (Richard Schiff) introduces his medical team to a 21-year-old patient named Jeffrey Williams. He tells them how he fell in love with baseball when he was 5 years old and how he enjoyed playing the game. Glassman then shows them Jeffrey's spine, which is severely deformed.*

*Glassman says the young man has a condition called ankylosing spondylitis, which is a type of arthritis that can cause joint damage. He says Jeffrey's inflammation got so bad that the bones in his back began fusing together into one bone. Glassman must choose two doctors to be on his surgical team, so he goes with Dr. Alex Park (Will Yun Lee) and Dr. Asher Wolke (Noah Galvin).*

*The team is chosen, and Glassman is excited to get started on the surgery. However, Dr. Andrews (Hill Harper) thinks the surgery is too risky. He accuses Glassman of taking on a surgery no other surgeon will touch because he feels empty and he's looking for something to fulfil him.*

*When Andrews tells Jeffrey about the surgery risks, he becomes afraid and decides he doesn't want the procedure. Glassman comes to his room with discharge papers and tries to talk to him about his decision. He tells Jeffrey he doesn't think he's afraid the surgery won't be a success. He thinks he's really afraid the surgery will work. Jeffrey tells Glassman he doesn't know how to live a normal life. He's fearful of what life will be like once his spine is repaired.*

*"Say no to the surgery if that's the right decision," says Glassman. "But do yourself a favour. Don't say no because you're afraid to live your life."<sup>1</sup>*

<sup>1</sup> [www.cheatsheet.com/entertainment/the-good-doctor-one-of-our-favorite-season-4-episodes.html](http://www.cheatsheet.com/entertainment/the-good-doctor-one-of-our-favorite-season-4-episodes.html)

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### SARS-COV-2 Vaccinations in RMD patients

The EULAR Task Force on COVID-19 has updated the [EULAR View-points on SARS-CoV-2 vaccination in patients with RMDs](#) ([https://www.eular.org/eular\\_sars\\_cov\\_2\\_vaccination\\_rmd\\_patients.cfm](https://www.eular.org/eular_sars_cov_2_vaccination_rmd_patients.cfm)) (December 2021).

The information addresses questions, including considerations regarding vaccination effectiveness and safety, the third vaccination dose, booster vaccination, combination with Influenza and Pneumococcus vaccination, among other frequently asked questions by people with RMDs.

EULAR President, Prof Annamaria Lagnocco, invites you to share the link with your axSpA community.

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### 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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