

## ASIF Newsletter: December 2022

### Message from the President

Dear friends,

As the end of the year approaches, I look back with pride at what we have achieved as a global community.

It was ASIF's busiest year, starting with the Talk to be Heard campaign in which 22 of our members participated across 19 countries. The campaign, available in 13 languages, ignited conversations on social media and between people living with axSpA, their loved ones and their rheumatologists.



World AS Day raised awareness with 12.5 million people through ASIF's social media alone – in reality the number is much bigger when we consider our members' social media activity and events, and individuals' posts and tweets.

IMAS closed with 5,557 participants from 27 countries. Understanding more about the impact of axSpA on people's lives will help us educate healthcare providers, advocate on behalf of people living with the disease, and raise awareness with the wider population.

The ASIF Council Meeting was attended by representatives from 23 Members. The presentations, workshops and connections made were invaluable.

Over the last few months, the team has begun planning for the second phase of our Delay to Diagnosis campaign. We are looking forward to telling our members more at the Webinars on 7 December. If you haven't yet confirmed your attendance, please email Jo Lowe ([projectmanager@asif.info](mailto:projectmanager@asif.info)).

Our new Member Resources webpage will be launched early next year. This library of resources includes a series of booklets on axSpA, organisational guides, and information and videos about exercise.

In October most of the ASIF Trustees met in person in Bulgaria. We undertook training on good governance to improve the way we govern ASIF. Our role as an advocacy organisation was discussed, focusing on how best we can add value to our member organisations. We explored the services we offer to members and what more we can, and should, be doing. The Trustees and staff spent time

discussing the Strategic Plan and what we want to have achieved by 2028. Our Trustees also presented ideas for future projects – we have a lot to consider. There is so much to be done, and meeting face-to-face gave us the opportunity to spend quality time focusing on ASIF.

ASIF has welcomed two new members this year bringing our total membership to 51. Bringing so many associations together to focus on improving the lives of people living with axSpA is incredible. The spirit of collaboration is strong and I am excited to build on what we have achieved. I know that together we can have even more impact in 2023.

Wishing you all a healthy and safe end of the year.  
Best wishes,

Zhivko Yankov  
President of ASIF

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## Our Projects



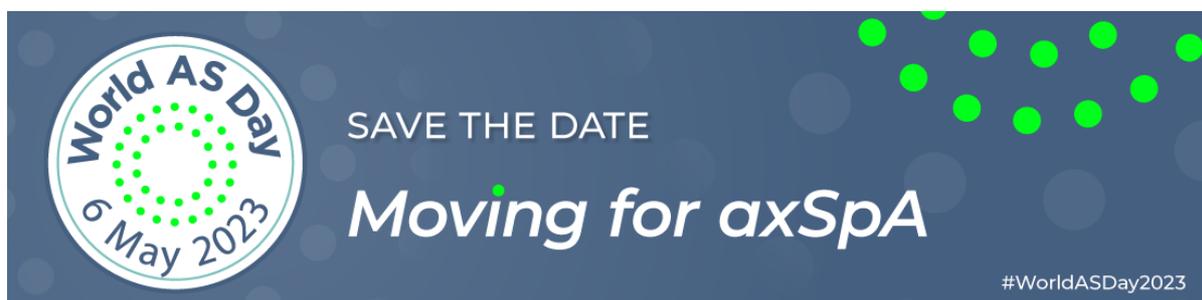
## It's All Connected

It's All Connected is a campaign encouraging people living with axSpA to talk to their healthcare providers about of their symptoms – even if they seem unrelated to their disease. It also aims to raise awareness with people who are undiagnosed, and encourage them to discuss all their symptom with their doctor, in the hope it will lead a diagnosis.

In February, 12 ASIF members, using eight different languages, will run the campaign.

It's All Connected is primarily a social media campaign using a powerful 90 second video, along with three 15 second videos for social media. These videos were created by Lilly, and we are excited that Lilly offices around the world will also run the campaign through their social media channels, increasing the campaign's reach.

## World AS Day 2023



This year's theme is movement!

Save the date social media assets are available for download from our website ([asif.info/worldasday](https://asif.info/worldasday)). Look out for more information coming soon!

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## BritSpA

The Annual Scientific Meeting of BritSpA was held in September. Michael Mallinson attended and has provided a comprehensive report from the sessions. Thank you Michael!

[Download report.](https://bit.ly/3PfUYgU) (<https://bit.ly/3PfUYgU>)

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## Why I'm an ASIF Trustee



Lillann Wermskog, tells us why she chose to become an ASIF Trustee.

"I am the leader of Spafu Norway and I started writing for the member magazine before I joined its board. It is important to me to make a difference to other people, so I am passionate about sharing my experience with AS and spreading accurate information about the disease.

"I am an academic educated in art history and history of ideas from the University of Oslo. In the job I do as head of Spafu Norway I use a lot of what I learned when I studied the history of ideas, where we looked at all the factors in society that influence our decisions and where freedom of expression and

freedom of the press are two of the most important things a society has. This is something I take with me by working against discrimination, for justice and being able to contribute to a better quality of life for people with disabilities.

“For many years, I have written from rheumatology congresses such as EULAR and ACR and see the importance of sharing this knowledge, particularly when working for a better quality of life for patients. In 2018, we got the results of EMAS (the predecessor of IMAS, world's largest survey about axSpA), where patients from many different countries shared how they live with this disease. Through the work I did with EMAS and IMAS, I understood how important it was that we stand together to address the big questions about axSpA and try to achieve a better quality of life for patients around the world.

“Being a board member of ASIF provides an opportunity to do this important work globally and meet an incredible number of great people from different countries. I have discovered that we are not so different from each other and many have the same challenges in the different countries.

“My driving force is to make a difference for people, but I believe that the more people that stand together the more we achieve.

“Remember, together we are stronger.”

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](mailto:office@asif.info).

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

(Photo by Morten Korgvold)

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## Member Spotlight: AFS



Fabienne Lacombe, Director of AFS, provides an insight into their work.

### About AFS

The France Spondyloarthritis Association (AFS) is an association of people with spondyloarthritis. It is run by patients, for patients and their relatives, regardless of their geographical location.

The AFS is approved by the Ministry of Health, and its membership of ASIF enables it to represent France on an international stage. It strengthens its relations with other associations in the interest of patient members.

### **Spondylitis in France**

The number of people in France affected by spondylitis is estimated between 200,000 and 300,000. This disease affects young people, with the average age being 28, and unfortunately does not spare children. Currently, the average diagnostic delay in France is between 3 and 6 years.

### **AFS' goals**

The AFS is above all a place of exchange of knowledge and experiences for a whole community of people with Spondyloarthritis. As such, it organises medical conferences throughout the year and writes reports intended to deepen the knowledge of each of its members through magazines and its website. AFS raises awareness of the disease and its difficulties, and provides daily support to its members.

The association is an essential link to the medical profession and research. It shares information from member surveys with doctors, and collects donations to finance research programs on spondyloarthritis.

### **AFS' mission**

The AFS has set itself the mission of helping, within an ethical framework, patients suffering from spondyloarthritis to resolve the difficulties they may encounter in their daily lives, on a medical, social and professional level. It also aims to support each patient and ensure that all patients, regardless of their social or geographic situation, benefit from the same therapeutic treatments.

### **Conclusion**

AFS' existence and functioning are essential in supporting men and women who suffer and whose daily journey remains a real ordeal. The information they receive will always be insufficient in the face of the many questions that challenge them (significant difficulties in family or professional life, the maze of administrative procedures to ensure or maintain their future, the doors that close in the face of projects, the entourage that moves away because of illness, etc). The will of our Association is directed above all towards the patient by bringing him reliable and precise information on this disease which is often not correctly and sufficiently known.



## [Paye Ma Douleur](#)

The AFS created Paye Ma Douleur to help parents and health professionals understand the pain of children with chronic inflammatory rheumatism, but also those suffering from other conditions that cause pain because they are often under-evaluated. AFS wanted to find a way for the child to be better understood and heard.

The platform includes three age groups from 3 to 18 years old. It allows children and teenagers with pain to describe it throughout the day. Paye Ma Douleur is not just a simple online application, it is also a real means of communication with those around them and with doctors, it allows them to put words to their pain.

Find out more at: <https://payemadouleur.fr/>



## **Walk'athon**

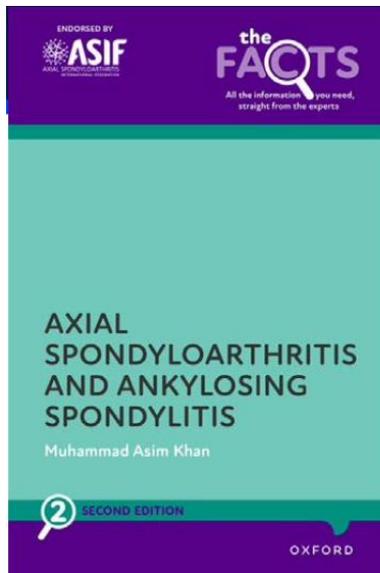
AFS' inaugural Walk'athon took place from 10 – 30 October. It reflected the World Day of Rheumatism's theme: physical activity and rheumatic diseases. The event aimed to involve patients in order to highlight the benefits of daily walking on the pain caused by SpA and all chronic rheumatic diseases.

Six other French and foreign associations joined us resulting in 287 teams, 1500 registered, and more than 100,000 km walked.

This formidable inter-associative challenge, with the collaboration of ASIF, allowed patients from all backgrounds to take up the challenge and demonstrate that even with rheumatism, sport can be beneficial against pain. This first Walk'athon was a real success! We are looking forward to next year's event being even better!

The AFS thanks its partners Kiplin and Héroïc Santé, the participants, the patient associations, ASIF, and our institutional partners Biogen, Amgen and Lilly France.

## New book: Axial Spondyloarthritis and Ankylosing Spondylitis



World expert in axSpA, Dr Khan, has published an update to his book Axial Spondyloarthritis and Ankylosing Spondylitis. Dr Khan is a Professor Emeritus of Medicine at Case Western Reserve University, USA, and has authored and co-authored seven books on AS-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 \(https://bit.ly/3ASE6qX\)](https://bit.ly/3ASE6qX).



### Member Webinars

#### Upcoming Webinar: Community/Direct Fundraising

We will hold our next Member Webinar in February. The topic will be direct/community fundraising, for example regular donations, bequests, fundraising/sponsored events etc.

This interactive Webinar will be designed for all our Members - whether your organisation doesn't currently fundraise from individuals; or you do, but you want to get more ideas and hear about what has

worked for others.

Is there an area of community fundraising that you are particularly interested in that you would like to discuss?

If you would like to share your organisation's experience in this area and join the panel, please contact Jo de Bry ([communicationsmanager@asif.info](mailto:communicationsmanager@asif.info)).

We are keen to know what topics are of interest to you. Please take 2 minutes to complete this [Google Form](#) - thank you!



### **Precision Medicine**

[Watch](#) Professor Rahman talk about how Precision Medicine could impact axSpA in our latest Webinar.

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## **News for Members**

### **Your social media**

Our Member's webpage signposts people living with axSpA to your website and social media channels. We know that we don't have links to all your channels on the page (and some may have changed), so please send us your handles.

You can check your page [here](http://asif.info/membership) ([asif.info/membership](http://asif.info/membership)).

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## **International Events Webpage**

We have created a new page on the ASIF website listing [Events and Conferences](http://asif.info/events) ([asif.info/events](http://asif.info/events)). If you have an event or conference that would be of interest to an international audience, please let us know by sending: date, name of event and link to event information.

If there are any events that you know of in your region that should be listed, please get in touch. The page is accessible from the home page and we hope will be an informative source of information.

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### 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](mailto:communicationsmanager@asif.info)

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## ASIF Office

Please note that the ASIF office will be closed from 22 December and will reopen on 4 January. The ASIF Team wishes you a happy and healthy 2023.

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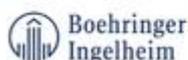
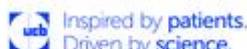
### Dates for your Diary - 2022/23

6 - 9 December - APLAR - Hong Kong

13 - 14 January 2023 - ASAS, Athens, Greece

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### ASIF is grateful to its industry partners



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## Follow us on Social Media

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axial-spondyloarthritis-international-federation 

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Contact us at [office@asif.info](mailto:office@asif.info)