

Message from the President

Dear friends,

Over the last few years ASIF has grown as an organisation. We have undertaken new and important projects and provided real value to its members. This work is largely thanks to our amazing ASIF team. I am excited that we are currently recruiting for an Executive Director to take ASIF to the next level. For more information about the role and application process please see below.

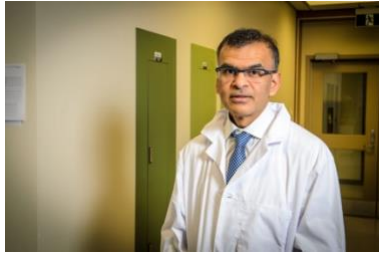


If you are interested in helping to create global change for people living with axSpA, please consider becoming an ASIF Trustee. Having been a Trustee for six years, I can honestly say it is one of the most rewarding roles I have taken on. The commitment our Trustees make to ASIF is invaluable to the global axSpA community – as well as being hugely rewarding on a personal level. If you would like to know more about becoming a Trustee please contact Jo Davies on office@asif.info. We will invite nominations in 2023 - we will have three vacancies - in the meantime, in order to find out more about how ASIF works, we recommend that you volunteer to sit on one of our sub-committees.

I was delighted to see so many of you at the Council Meeting at the end of May. Michael Mallinson has written an excellent report on the meeting, which you can find below, thank you Michael, for putting this together.

Best wishes,

Zhivko Yankov
President of ASIF



Member Webinar Series

We are excited to invite our members to our next Member Webinar on Precision Medicine in axSpA with Dr Proton Rahman MD FCAHS.

Topic: Precision Medicine

Speaker: Dr Proton Rahman MD (Memorial), FRCPC, Associate Dean, Clinical Research and Professor of Medicine (Rheumatology)

Date: Thursday 3 November 2022

Time: 19:00-20:00 GMT

The session will be interactive, with a question and answer session following Dr Rahman's presentation.

Please RSVP by Thursday 27 October to Jo de Bry at communicationsmanager@asif.info.

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

Future webinars will cover topics, including the latest research, fundraising, emerging treatments, membership, advocacy and others. If there are other topics that you would like to see covered, please email Jo de Bry.



ASIF IS RECRUITING AN EXECUTIVE DIRECTOR

ASIF has grown considerably in the last 5 years and whilst we are very happy with the success to date, we are now seeking an Executive Director – a new role – to take ASIF to the next level. To increase ASIF's knowledge, capability, credibility, and reputation. Our Executive Director will provide inspirational and values-led leadership to our organisation. They will guide us to achieve our strategic vision to increase stakeholder and public awareness and to disseminate knowledge of the disease around the world.

For more information about the role and details about how to apply click [here](https://asif.info/asif-is-recruiting-an-executive-director/).
(asif.info/asif-is-recruiting-an-executive-director/)



ASIF Members at the Council Meeting

ASIF Council Meeting, Copenhagen 29-31 May 2022

A full report on the 14th Council Meeting has been prepared by Michael Mallinson. This comprehensive narrative includes details from each session.

Click [here](https://bit.ly/3ATu73s) to read the report (<https://bit.ly/3ATu73s>).



*Dr Pramod Palekar - Physiotherapist
& Guest Speaker, Pune Seminar 2018*

Member Spotlight:

Ankylosing Spondylitis Welfare Society

Ankylosing Spondylitis Welfare Society (ASWS), a patient-led organisation was established in 2020 to support fellow AS warriors and their caregivers across India. Being patients, we realised that mostly patients consult their local doctors, Orthopaedic Surgeons or focus on alternate therapies rather than visiting a Rheumatologist due to lack of awareness about Ankylosing Spondylitis and Rheumatology, in general. This leads to delay in diagnosis amongst the patients causing mobility issues, permanent disability and mental health problems.

We aim to create a referral pathway so that various specialisations can help patients identify AS early and guide them to a Rheumatologist who can guide them in the right direction and help them deal with the disease effectively.

To create awareness about the disease amongst the general population we are taking efforts to collaborate with various schools/colleges/offices/corporate houses/hospitals. We are also organising various seminars, webinars with various medical faculties and using social media to help us spread the word. We are hopeful that this will help in early diagnosis so that AS does not remain an invisible illness, as it currently is.



Patient Audience, Pune Seminar, 2019

AS not only causes joint pains but also leads to other co-morbidities as well. Many people are unaware that AS requires a multi-disciplinary approach. We are trying to make people recognise various manifestations of the inflammation so that they are better able to understand their illness through other symptoms than just aches and pains.

As India is a very diverse country with various cultures, economic disparity, role expectations and demands, we want caregivers to realise the depth of the disease and the changes – both physical and psychological – that a warrior faces. At the same time, we understand that it is not easy for the caregivers to accept this sudden change in their “healthy” loved one and want to provide a listening ear to them as well so that they have someone to share their concerns and fears. We aim to help the family and the patient deal with the disease jointly and understand that no obstacle is hard to overcome if we are in it together.

Also, we want to provide a platform for female AS warriors to be able to share openly, with us, about their intimate problems – be it family expectations, marriage, work, conception, pregnancy, child care, periods, mood swings, or, being told that women don’t get AS and they are exaggerating or lying about their symptoms. We want them to know that they have a reliable confidante in us and they can share all their concerns uninhibitedly and seek guidance in any matter of their concern.



ASK the Experts
Live Webinar
10th Nov 2020 | 11:30 AM

Dr. Shashank Akerkar
Consultant Rheumatologist

Dr. Pravin Patil
Consultant Rheumatologist

Register now

Dr Shashank Akerkar - Rheumatologist & Guest Speaker, Dr Pravin Patil - Rheumatologist, Founding Member, Trustee & Medical Advisor ASWS, Webinar, 2020

In India, specifically in rural areas, one of the biggest problems that warriors face is not being able to afford even NSAIDs to suppress their pain to a bearable limit. Many patients are diagnosed, yet, are helpless as they can’t afford basic medical treatment. Their families helplessly watch them deteriorate gradually. AS is not covered under any insurance in India, pushing many into dark oblivion. We want to fight for this basic human right so that most have the opportunity to fight this illness and not have their financial condition determine their destiny. Until we are able to achieve this, we want

to facilitate support through various other charitable and funding sources to help them achieve their treatment objectives.

Overall, ASWS strives to provide AS warriors with proper guidance and support during this difficult process so that they don't suffer due to Ankylosing Spondylitis being an invisible illness. We wish that ASers are treated with respect, compassion and empathy by general public and medical professionals around them so that they are able to live a respectful and fulfilling life.

For more information visit: aswelfare.org

Contact Jo de Bry to have your organisation featured in our Member Spotlight section.

Nagaraja's Ironman Triathlon



The Founding Member and Secretary of Ankylosing Spondylitis Welfare Society (ASWS), Nagaraja Suryanaranappa (pictured left and below), has just completed his first Ironman Triathlon, in 15 hrs, 25 min and 34 sec. This mega event took place in Nur-Sultan, Kazakhstan on 14 August 2022.

An Ironman Triathlon is one of a series of long-distance triathlon races organized by the World Triathlon Corporation (WTC), consisting of a 2.4-mile (3.86 km) swim, a 112-mile (180.25 km) bicycle ride and a marathon 26.22-mile (42.20 km) completed in that order. It is widely considered one of the most difficult one-day sporting events in the world.

Nagaraja was diagnosed with AS in 2012, after suffering for 13+ years. His journey to running/fitness started in mid-2017 when the pain due to AS intensified again. Despite not being into sport as a child, he took up running, along with other regular exercises, with consultation from a Rheumatologist. After 6 months of practice, he completed his first 10km run in October 2017. From there, he built up his strength and completed his first full marathon, (42.2km) in January 2020.



Determined not to let the three-month lockdown affect his fitness, Nagaraja ran indoors, clocking up 767kms. In 2022 he participated in his first multi-sport event, the Kolhapur Bergman Duathlon (Running-Cycling-Running). He became inspired to learn to swim and in less than two months swam 3km. In May 2022 he registered for the Kazakhstan Full Ironman.

In the Ironman, he finished the 3.8km swim in 01:52:17, 180km cycle in 07:28:36, and 42.2km run in 05:41:01 – with a total time of 15:25:34.

His journey is inspirational – don't let AS limit your dreams!

SAVE THE DATE
World AS Day
Saturday 6 May 2023



Research Corner: Understanding Our Members' Relationship with Physical Activity

What supports people with axial spondyloarthritis to do physical activity? What hinders them? Lauren Angelil (physiotherapist, health coach and vice-chairperson of Axial Spondyloarthritis Association South Africa, pictured left) is asking these questions. She's doing her masters in Physiotherapy with a specialisation in Behavioural Medicine. She's interested in the psychology of putting health information into practice.

The axSpA challenge we're seeing

When diagnosed with axSpA, the gold standard to manage the condition is medication, physical activity, and education.

But, few patients with axSpA meet the general exercise recommendations (Haglund et al., 2012¹), and few perform vigorous aerobic physical activity (Fongen, et al., 2013²).

The question is - what happens with physical activity?

The unique benefits of physical activity in axSpA

The benefits of physical activity on health and wellbeing in axSpA are significant. It is one of the cornerstones of disease management.

The reasons are as follows:

- It positively impacts pain experience, spinal mobility, physical function, and cardiovascular health
- High intensity exercise is well tolerated and associated with reduced axSpA disease activity

But, there is a mismatch between the recommendation and the action.



The additional axSpA challenge

Getting started and keeping up with these physical activity guidelines is a challenge.

What's more, following an exercise plan without axSpA is known to be hard. Having a disease affecting your physical and mental health makes it even more difficult.

But, following all the axSpA treatment recommendations can make a huge difference! It's possible to achieve much lower levels of disease activity or have low levels of disease activity. The question remains - what happens with physical activity?

Where to from here

We have limited research available to understand what supports or hinders physical activity. What's more, barriers and facilitators are not only related to

disease symptoms. They include psychological state, and environmental and social support, or the lack thereof.

The research will help us understand the gap between exercise recommendations and action.

What we can all do

I encourage everyone reading this to spark conversations about physical activity in their patient groups.

The World Health Organization (WHO) recommends:

- At least 150-300 minutes of moderate intensity physical activity or 75-150 minutes of vigorous intensity physical activity exercise per week or a combination and
- Two strength training sessions a week



Find out from your members:

1. What do they enjoy about exercise?
2. What are the challenges?
3. Who or what supports them in their exercise?

Encourage members to post about their experiences and hold each other compassionately accountable to their goals.

Exercise can be really challenging - it takes time, effort and it can be uncomfortable. Sparking conversations with an air of curiosity and compassion can go a long way.

If you're interested in hearing more about the research or sparking conversations, reach out to Lauren at healthcoach@laurenkimwellness.com or find her and the South African Axial Spondyloarthritis Association team on Facebook.

¹Haglund E, Bergman S, Petersson IF, Jacobsson LT, Strombeck B, Bremander A. Differences in physical activity patterns in patients with spondylarthritis. *Arthritis Care Res (Hoboken)*. 2012;64:1886–1894.

²Fongen C, Halvorsen S, Dagfinrud H. High disease activity is related to low levels of physical activity in patients with ankylosing spondylitis. *Clin Rheumatol.* 2013;32:1719–1725.



IMAS Update

The IMAS survey has now closed with a total of 5,557 participants from five continents. The data are now being analysed and the first results have been shared with the IMAS sub- and scientific-committees.

Our members have been invited to a meeting on 22 September to discuss the results, how they will use them within their own organisations, and the key messages shown. This meeting is an opportunity for our members to have their say on how the IMAS results could be presented and used. If you haven't yet registered for a session, please email Jo Lowe (projectmanager@asif.info) stating which session you will attend – 08:30-10:00 BST or 16:30-18:00 BST.

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



Global Spondyloarthritis Summit 2022

Carrie Kellenberger is a Canadian living in Taiwan with axSpA. She has written a great review of the SAA Global Spondyloarthritis Summit, held in May this year. You can read her Event Recap [here](#):

www.myseveralworlds.com/2022/05/31/saa-global-spondyloarthritis-summit-event-recap

Dates for your Diary - 2022/23

7 - 9 September - International Congress on Spondyloarthritides, Ghent, Belgium

14 - 15 September - BRITSpa, Birmingham, UK

15 - 17 September - AFLAR, virtual

10 - 14 November - ACR, Philadelphia, USA

23 - 27 November - IRACON, Indore, India

6 - 9 December - APLAR - Hong Kong

13 - 14 January 2023 - ASAS, Athens, Greece

ASIF is grateful to its industry partners



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Visit us at www.asif.info

Contact us at office@asif.info