



Newsletter – May 2020



www.ASIF.info

World AS Day 2020

TOGETHER – axSpA and mental health

#together #axSpA #mentalhealth
www.asif.info/worldasday

ASIF is grateful to its industry partners:



Dear Member,

First and foremost, the Trustees of ASIF hope that you are all surviving well during these very difficult times. There are many questions around axSpA, the taking of biologic medicine and COVID-19. The SAA and ASIF are behind a global survey for people with axSpA which we hope will go some way to answer some of those questions. We cannot encourage you enough to invite your members to take part in this survey (more information and links below).

We were saddened to have to cancel the ASIF Council Meeting scheduled to take place on 1 and 2 June in Frankfurt. We plan to rearrange it in 2021, possibly in Paris – watch this space. We still must hold an Annual General Meeting (AGM) and that will take place online. We will be in touch in the next couple of weeks to let you know exactly when and how you can join it and to invite you to submit your nominations for Trustees.

ASIF has been approached by pharmaceutical companies with offers of help available to patient associations specifically for projects addressing problems caused by the pandemic, so if you are experiencing difficulties or you have such a project that you are seeking funds for and would like to be put in touch with a potential funder, please contact Jo at office@asif.info

This coming Saturday 2 May is [World AS Day](#). This year we have created a campaign. The theme is **Together – axSpA and mental health** and together we can spread the word and raise awareness about Axial Spondyloarthritis. We need your help to spread the message as far and wide as possible. Visit our [website](#), download the [tools](#) and use them, follow [ASIF's facebook page](#) and repost World AS Day posts on [facebook](#), [Instagram](#) and [Twitter](#).

As part of World AS Day we encourage you to join a team for [Walk Your AS Off](#) and to register for the [Global Spondyloarthritis Summit 2020](#).

This is your community, together we are stronger.

More details on all these items below.

ASIF Committee

ASIF is grateful to its industry partners:





World AS Day

Saturday 2 May 2020

[A Message from Zhivko Yankov, President of ASIF](#)

ASIF has launched a [World AS Day website page](#) for you! Visit now to download a range of resources to help celebrate and recognise World AS Day.

The website includes a [toolkit](#) for you to use in your own World AS Day awareness campaign. The toolkit explains the themes and includes ready-made images to post and posts you can add your own messages to, in your own language, such as these.



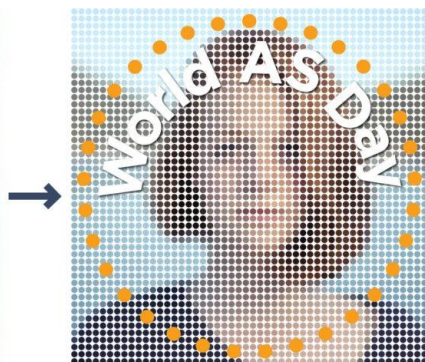
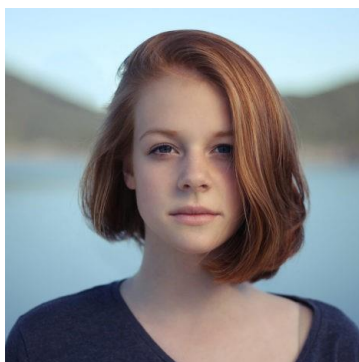
#together #axSpA #mentalhealth
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The [World AS Day Website Page](#) also has a Special [Dot photo tool](#) for you and your members to use. We encourage you to have as many people as possible use this profile for World AS Day and to creatively use the orange dots to emphasize our theme and key messages.



Profile Image for World AS Day

This year's World AS Day theme is **TOGETHER – axSpA and mental health**

Our aim is to raise awareness of how the disease affects patients' mental health. According to research data from Europe, 6 out of 10 people living with axial SpA will experience mental distress.

Key messages:

ASIF is grateful to its industry partners:



- People with axSpA often have mental health support needs.
- Physical and mental health services need to work together for axSpA patients.
- Living well with axSpA involves friends, family, employers and colleagues.
- Together we can support people to live well with their axSpA.

We believe that in this time of crisis, it is more important than ever to support and build our patient communities.

We recommend you follow ASIF on [Facebook](#), [twitter](#) and [instagram](#) and re-post our messages as they are posted up to and including 2 May - World AS Day - and beyond throughout May.

If you are planning your own campaign or online event for World AS Day - please do let us know by emailing office@asif.info so that we can add it to the website and let everyone know about it through social media.

Please visit our [World AS Day website page](#) now and let us know what you think of it and how you are using the resources for World AS Day activities and awareness by emailing office@asif.info

Two great events taking place for World AS Day which your members can take part in are Walk Your AS Off and the Global Spondyloarthritis Summit - More information below...

Please share these events with your members.

ASIF is grateful to its industry partners:



Walk Your AS Off 2020



Walk Your AS Off is happening again this year, from May 1 until May 31

Walk Your AS Off is an annual challenge run by [Walk As One](http://www.walkasone.org). ASIF fully supports this initiative.

We encourage and challenge your organization and every member of ASIF to join or create a Team!

What's involved? Walk Your AS Off is a walking and exercise campaign to encourage people to be more active. You need a Team leader to register personally and create a team at www.walkasone.org. Once the team has been created the leader and your organization should encourage your members to sign up and participate.

Participation is easy. Each team member also registers at www.walkasone.org. Each participant can walk when they want and how they want or do whatever exercise or movement works. The only important thing is that they should track their steps and log them through their personal page at www.walkasone.org throughout May. Most smart 'phones have step tracker apps, but you can also buy inexpensive pedometers. Walk Your AS Off allows everyone to participate at their own rate, however they like. If people are swimming, cycling, practicing yoga or using the gym, they can participate and log their steps using the downloadable [Step Conversion chart](#). You can even convert household chores to steps.

You may think that it is difficult with the restrictions of social distancing, and isolation to measure your activities. Walk Your AS Off has come up with creative tips and handy hints to keep exercising whilst isolated and physically restricted - see these handy New Ways to Step guides

ASIF is grateful to its industry partners:



NEW WAYS TO STEP
COVID-19 Social Distancing Options

USE YOUR WORK

1. If you are working from home, set a timer and stand up and walk in place every so often.
2. If your job requires phone time that does not require you to be at a desk/computer, walk around your room during the entire call or as much of it as you can.
3. Use your breaks to walk around your house or yard. Make laps.
4. Pick a certain word or task and every time that word or task comes up during the work day stand and walk in place for so many steps.

Walk your A.S. off

NEW WAYS TO STEP
COVID-19 Social Distancing Options

While Watching TV

GET CREATIVE

1. During commercial breaks, stand up and walk in place. Or roll backwards and forwards in wheel chair.
2. Other options are to do sitting leg lifts and raising arms over head or out in front of you. Convert the movement to steps using our step conversion chart.
3. When watching streaming services with no commercials, set a timer for every 8-10 minutes and repeat for as long as you are watching TV for 5 minute intervals each time.
4. Stand up and sit down, if able, as many times as you like while watching TV.
5. Watch and follow along to dance videos, exercise videos or other active shows. Example : Shadow box to Rocky during fight scenes.

Walk your A.S. off

NEW WAYS TO STEP
COVID-19 Social Distancing Options

EVERYDAY LIFE

1. Count every step. Don't rely on just your phone. Many of us walk while not carrying our phones.
2. Convert all activities to steps. Household chores, showering, dressing, and everything in between can be converted to steps. If you burn calories you can count a step.
3. Do you have a basketball hoop or other recreational spot at your home? Utilize this area for activity if you do.

1. Join the Facebook group for encouragement support and more ideas.
2. Accountability from board members and team captains
3. Q and A
4. It's more important now then ever in order to protect our mental health.

KEEP ON STEPPING

Walk your A.S. off

NEW WAYS TO STEP
COVID-19 Social Distancing Options

SOCIAL DISTANCING

1. Use FaceTime, Zoom, Skype or other video chat software to hold a social walk and talk around your home, yard or neighborhood while respecting social distancing.
2. Have a watch party via Facebook or Netflix to exercise videos or action movies that you act out.
3. Have a Facebook watch or video chat dance party.
4. Check your local Y, many are offering free online live classes right now.
5. Join a virtual 5k or walk. There are many that exist.

Walk your A.S. off

Everything you need to know about Walk Your AS Off can be found on the [WalkASOne website](#) And please note that one of the objectives of Walk Your AS Off is to collect enough steps to reach to Mars! Your Team can help!

ASIF is grateful to its industry partners:





Global Spondyloarthritis Summit 2020

[Registration is now open!](#)

The 2020 Global Spondyloarthritis Summit is the Spondylitis Association of America's 7-day virtual event focused on addressing some of the most important topics impacting the axSpA community today.

Now in its second year, this free educational program provides attendees the opportunity to hear from some of the most renowned rheumatologists, researchers, and other healthcare professionals as they discuss the latest treatment options, case studies, research and recommendations for people impacted by spondyloarthritis. Access to the Summit is free. New presentations for each day will be released beginning at 9am Pacific Time. All video presentations will remain open 24/7 for the full duration of the Summit, 1-7 May 2020.

ASIF is grateful to its industry partners:



ASIF is a partner for the Summit and this year subtitles will be available in French, Italian, Russian, Chinese, Bulgarian, Spanish and Ukrainian.

Topics to be covered:

- Thriving with a Chronic Illness: Discussing the Mental & Emotional Impact of Living with axSpA
- Exercise – General Physical Activity Recommendations
- Exploring Pain Management Options, with a Focus on Holistic/Psychological Approaches
- Medicinal Cannabis – An Overview of Current Clinical and Anecdotal Evidence
- Novel Treatments: Fact or Fiction?
- Understanding Spondyloarthritis Around the Globe
- Exploring Common Theories: Discussion Topics to Include, Triggers for Disease Onset, Leaky Gut, SpA Pain Burn Out, Klebsiella, and More
- Treatment in SpA: A Review in Case Studies
- Overview of the Full Family of SpA – Reviewing the Different Diseases in SpA, Their Symptoms, and Noting Treatment Differences
- Overview of Back Pain – A Review of the Types of Back Pain, Their Causes, and Treatments
- Diet & Nutrition – The Great “Evidence” Discussion
- Innovations and Progress in SpA Research, and New Treatment Options for SpA and Complications

Access is free but you need to register to see the videos.

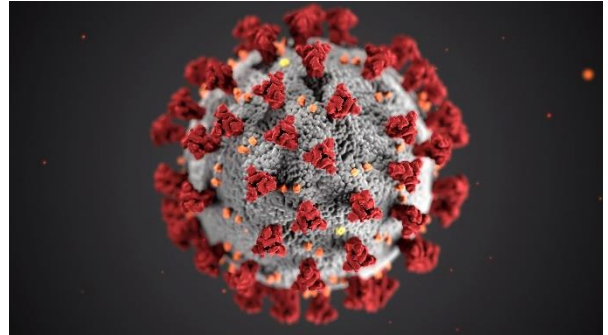
Do not miss this amazing event, please share the registration link with your members.

[Register Here](#)

ASIF is grateful to its industry partners:



ASIF/SAA axSpA and COVID-19 Survey



We need your help to track how COVID-19 is impacting our community, and learn more about any possible impact axial Spondyloarthritis, and medications used for spondyloarthritis, may have on COVID-19. Please, take some time now (10-15 minutes) and be a part of this important research.

The Spondylitis Association of America (SAA) in partnership with the Axial Spondyloarthritis International Federation (ASIF) are pleased to invite you to participate in a COVID19 in Axial Spondyloarthritis survey. SAA has worked closely with members of their Medical and Scientific Advisory Board and is spearheading research into the possible impact axial spondyloarthritis, and medications used for axial spondyloarthritis, may have on COVID-19.

To take part click [here](#) or point your phone camera at this QR code:



If you would like to invite your members to take part, please contact office@asif.info as soon as possible.

ASIF is grateful to its industry partners:



2020 COVID-19

News and Helpful Links



From NASS the National Axial Spondyloarthritis Society (UK)

- [How to assess your risk](#)
- [Medicines and Biologic therapies](#)
- [Mental health support](#)



From the SAA

- [Does having AxSpA put you at greater risk for COVID-19](#)
- [Your Questions Answered](#)

EULAR

EULAR's website has a [video](#) explaining guidance for patients with RMDs about COVID-19 outbreak





If resources are needed for Covid-19 related programs such as those below, Novartis will prioritize funding requests addressing immediate needs of patients stemming from the pandemic.

Novartis will consider proposals for programs that:

- Provide information on COVID-19 or related topics.
- Enable patients to access their HCP online or virtually, to ensure continuity of care and disease monitoring, remotely.
- Deliver support to manage incremental demand of calls related to COVID-19 and disease management (call centers enhancement).
- Facilitate digital approaches for patients and caregivers support and education as well as program that strengthen the community's digital capabilities to reach patients.

Please reach out to your local Novartis patient advocacy contact – if you need help to find out who that is, please contact Jo Davies on office@asif.info

If you wish to find more information about how Novartis is working during this time, please visit <https://www.novartis.com/coronavirus>



Boehringer Ingelheim have some helpful information for [patients and carers](#)



The UCB contact to use for any questions or concerns patients from your community may have, is provided through the UCB Cares service GlobalMI-Content@ucb.com

ASIF is grateful to its industry partners:



The ACR has developed clinical guidance for the care of adult patients with rheumatic diseases during the COVID-19 pandemic. You can find that guidance [here](#)

2020 EULAR

Considering the current situation and the necessary cancellation of EULAR 2020 in Frankfurt, EULAR are offering virtual congress experience. Starting from Wednesday 3 June 2020 and accessible on demand over a time frame of several months.

Registration is available [here](#)

Last but by no means least...

We are delighted to welcome three new members to the ASIF Team



Professor Marco Garrido Cumbreira

Marco Garrido Cumbreira is Professor at the Department of Physical Geography and Regional Geographical Analysis of the University of Seville.

ASIF is extremely excited that Professor Garrido Cumbreira has accepted the honorary position of Scientific Advisor to the Trustees. Many of you know him as the key driver behind the [IMAS](#) project. You can see a larger biography [here](#).



Christine Wilson recently joined ASIF in the role of Program Management Consultant. Christine has a background in leading emergency health programs across Asia, Africa and the Caribbean. She has a particular interest in resilience-building of health systems and the inclusion of affected groups.

Valeria Tassi is ASIF's new Administrative Assistant, one of her first tasks is to ensure that ASIF's membership database is up to date, she may have contacted you already. You can contact Valeria on admin@asif.info.



You can see the full ASIF team on the [website](#)



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