



## Newsletter - May 2019

## World AS Day Edition



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[www.ASIF.info](http://www.ASIF.info)

Dear Member

If this newsletter looks a lot like our previous one, it is because it is intentional. We want to impress upon you how everyone everywhere can participate in World AS Day. This newsletter may look the same, but there is new information on how to participate and create awareness about Ankylosing Spondylitis and Axial Spondyloarthritis. Please read on and please be sure to follow us on our social media platforms!

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ASIF is grateful to its industry partners:



World AS Day is here!

On May 4, 2019 we encourage all members to help celebrate World AS Day by creating awareness of Ankylosing Spondylitis/Axial Spondyloarthritis and by participating in World AS Day events. Most importantly, spread the word to your members so that individuals living with AS can be part of World AS Day.

We need to hear from you as to what is happening on World AS Day and throughout the month of May. Please let us know by sharing updates in our Members' Forum (more below) or emailing Jo at [office@asif.info](mailto:office@asif.info). We will post your updates on our social media, so be sure to Like and Follow us on [Facebook](#), [Instagram](#) and [Twitter](#). And, of course, check in on our website for news too.

Please read and share the following with your members!

ASIF Committee

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## Global Spondyloarthritis Summit

**Presented by Spondylitis Association of America.**



The poster for the Global Spondyloarthritis Summit 2019 Virtual Event features a central image of a human spine with a highlighted section. Text on the poster includes: "Global Spondyloarthritis Summit | 2019", "May 3 - 5, 2019 Virtual Event", "REGISTER FOR FREE", "PANEL OF EXPERTS", and the Spondylitis Association of America logo with the website "spondylitis.org". Below the main text are six small portrait photos of the panel of experts: Dr. Reveille, PT Papachristos, Dr. Overbaugh, Dr. Kiltz, Dr. Norton, and Dr. Fisher.

Everybody everywhere can participate in the Global Spondyloarthritis Summit presented by Spondylitis Association of America (SAA) from May 3 until May 5. All they have to do is register [here](#).

Here's how the Summit works. Everyone has to register (for Free!) to access the Summit. Once you are registered, you will receive an email from SAA with instructions for the log in page and the following information:

The program will start on **Friday, May 3rd, at 9:00 AM Pacific Daylight Time (PDT)** at which time the

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first two presentations will be made available for streaming.

The following day, **Saturday, May 4<sup>th</sup>, at 9:00 AM Pacific Daylight Time (PDT)** two additional presentations will be made available (with the two previously released presentations remaining online.) On the final day of the Global SpA Summit, **Sunday May 5<sup>th</sup>, at 9:00 AM Pacific Daylight Time (PDT)** the final two presentations will become available (and you will continue to have access to the previously released presentations.)

Your free access to these presentations will end at **8:59 AM Pacific Daylight Time (PDT) on Monday, May 6<sup>th</sup>** (unless you are or become a member of SAA).

You may register up to and including until May 5, but allow yourself enough time to watch the videos. Each video is about 20 minutes.

This is **an interactive event**, and you are encouraged to pose your own questions to the presenters, who will be checking in throughout the day of their segment airing to answer your questions. Everyone is asked to keep their questions general in nature, as specific medical advice for anyone's condition cannot be given through this forum.

Get Social! Interact with SAA and other Summit virtual attendees on Twitter with hashtag **#SpondySummit** and don't forget to follow SAA at [@spondylitis](https://twitter.com/spondylitis).

The topics of the Summit and the order in which they will be presented are:

- Comprehensive Approach to Pain Management - Rob Overbaugh, MD
- Complications & Related Conditions - Uta Kiltz, MD
- Physical Therapy and Exercise - Angelo Papachristos BSc, BScPT, MBA, ACPAC
- Diet & Nutrition for SpA - Mark Fisher, MD
- Latest SpA Research - John Reveille, MD
- Navigating Medical Management of SpA - Hillary Norton, MD

**SUMMARY:** To participate, you **MUST register**. To register, click [here](#).

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# Walk Your AS Off<sup>®</sup>

Walk Your AS Off returns May 1 – May 31.

ASIF endorses Walk Your AS Off and wants everyone to participate!

Is there a Team from your country?

If not, register one now at [www.walkasone.org](http://www.walkasone.org) and encourage all your members to get involved.

Let's see how many countries we can get to participate. Our goal is to have every ASIF member organization have a team, which means we should have 39 countries represented.



What is Walk Your AS Off? Recognizing that exercise is very important for AS patients, and that walking is an excellent form of exercise, Walk Your AS Off is both an exercise challenge and an AS awareness campaign. It can also be used as a fundraiser.

As a walking challenge, the idea behind Walk Your AS Off is to get everyone moving! It applies equally to those who want to start an exercise program and those who exercise regularly. We especially want to promote exercise in people who are not currently exercising. Approximately 56% of patients were not exercising at diagnosis according to a U.K. study. Walk Your AS Off and Success Stories (more below) want to change that figure.

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How does Walk Your AS Off work? It is a virtual walk, so that participants can walk when they want and as much as they want. All they have to do is count their steps and log them. Beyond that they could challenge themselves to walk a bit more, a bit further, each day or week of the month of May.

What happens to the steps? Walk Your AS Off is walking to Mars! Although Walk Your AS Off has already collected over 2.2 billion steps, it needs to get 316 billion to get to Mars! Every step counts. And if you swim or practice yoga or some other form of exercise, you can convert your exercise into steps with a conversion chart.

What makes Walk Your AS Off exciting? This year you can register as an individual, but continuing the tradition of previous years, it is more fun to be part of a team where everyone can encourage each other.



ASIF endorses Walk Your AS Off© and would like to see Teams from each and every Member. Register your Team today!

SUMMARY: To register for Walk Your AS Off and create a team for your organization, go to [www.walkasone.org](http://www.walkasone.org).

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## Success Stories

Because it is important to get people moving we are encouraging all participants in Walk Your AS Off to send us success stories about how Walk Your AS Off got them moving or moving more.

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We would love to hear your stories about starting to exercise and the benefits you have derived from it, or about how you have challenged yourself to go that extra step such as run further, lift more, or swim longer.

Send your success stories and photos to [office@asif.info](mailto:office@asif.info) and we'll post them on our website.

Walk Your AS Off is a great way for people who want to exercise to get started by setting themselves walking or exercise goals for each day and week during the month of May. We love hearing success stories of how Walk Your AS Off motivated someone to start and continue an exercise plan and the benefits they derive from it.

SUMMARY: Ask your Walk Your AS Off team members to send their success stories and photos to Jo at [office@asif.info](mailto:office@asif.info).

Please keep success stories short (no more than 250 words).

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## World AS Day Facebook Frames and Social Media Covers



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ASIF is grateful to its industry partners:



To help promote World AS Day and AS awareness, we have prepared a Facebook frame and a social media cover or banner for your members to use. These are available now.

SUMMARY: Please follow us on [Facebook](#), [Instagram](#) and [Twitter](#) to access the frame and cover.

You can find the Facebook frames [here](#).

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## Local Events

We know quite a few of you put on your own events for World AS Day.

We would like to hear about them and share them with other members so that they too are inspired to hold a local event.



NASS in the United Kingdom is doing #ASfamousAS. What is #ASfamousAS? It's simple! [Walk Your AS Off](#) to your town's most famous landmark.



#ASfamousAS  
#CantonTower

Take a selfie or have someone take your photo with the landmark clearly visible in the image.

Share it on social media using the #ASfamousAS hashtag as well as a popular hashtag for your landmark (eg. #Stonehenge, #EdinburghCastle, etc.) so many more people will see it. Here's an example post:

"It's #WorldASDay today so we are making #axialSpA #ASfamousAS #TowerBridge to raise awareness!" Learn more here: <http://bit.ly/WhatisaxialSpA>

[Antardhwani](#) has planned an event for the patients. Highlights of the event:

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- Focus group session for patients
- One on One with Doctor panel
- A common platform for patients to meet & exchange information and experiences with each other
- Get latest information about the disease
- Discuss symptoms, medicines used and their effects /side effects
- Understanding importance of support group.

Active participation and support from patients for way forward of Antardhwani group.



[ASHAD](#) in Turkey is holding a patient seminar and social event.



[SAA](#) in the USA is *Going Blue* for the month of May and is also lighting up landmark buildings.

What are you doing? Share it in our Members' Forum on our website (see below) or email Jo at [office@asif.info](mailto:office@asif.info) we will help promote it as well as motivating other members to get involved in World AS Day activities.

**SUMMARY: Share your World AS Day activities with us by emailing them to [office@asif.info](mailto:office@asif.info)**

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# ASIF Website update

## Members' Forum

[www.asif.info](http://www.asif.info)

We want to ensure this is a real asset to members where they can share information, ideas, materials and where collaborations can be formed. So that it does not become too unmanageable, we are allowing just one log in per member organisation.

To register click [here](#), complete your details and submit. Once your registration is approved, you will be sent an email to verify your account.

You can then log in and join in or start a conversation. You will see there are 3 main categories under which there are topics. You can start a new topic or reply to an existing topic. You can attach pictures and insert links.

Remember to tick the box to 'subscribe' to a conversation before – so that you receive notifications when others join in.

Posts and images/photos that you share to the Forum may be posted by us on our social media if the matter is of interest to all members and the general public.

**SUMMARY:** You need to [Register](#) first and then log on to our Forum.

Please make sure that there is always someone from your organization who is registered for access to the Members' Forum.

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## Health Apps

Health apps are a great way for patients to track their medications, doctor appointments, how they are feeling, and the number of steps they walk during Walk Your AS Off. They have the added benefit of providing an accurate tracking of

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how a patient's health has been between doctor appointments, so that when the patient sees the doctor, the doctor can read what has been happening and is better able to assess the disease condition and the effectiveness of the patient's treatment.

Some apps also help you with an exercise plan. Here are some Health apps that are widely available through Google Play and The App Store:

*AS Health Storylines*  
*MySpA*



**SUMMARY:** Is there a Health App that you use and like? Let us know by mentioning it in our Forum: Share with us at [www.asif.info/Forum](http://www.asif.info/Forum) and we'll let all our Members know.

A great way for patients to design and implement a customized exercise plan that is just right for them is to use [Rheumafit](#), developed by the Swiss AS society, SVMB.

Rheumafit is currently available in German and French. It will be available in English by the end of May 2019.



## EULAR 2019

EULAR 2019 takes place from 11-15 June in Madrid. If you are attending please do let Jo know ([office@asif.info](mailto:office@asif.info)) and be sure to come and visit us at our booth in the EULAR village.

ASIF is holding its Annual General Meeting (AGM) at EULAR on Wednesday 12 June at 11.30am - all members are invited to attend. The official Notice of the meeting and the agenda will be circulated next week along with joining details if you want to join by telephone.

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## IMAS Event Invitation

The steering committee for the International Map of Axial Spondyloarthritis (IMAS) are delighted to invite you to participate in an open dialogue on how the IMAS survey results can be used to improve care and quality of life for people living with axSpA during EULAR 2019.

The International Map of Axial Spondyloarthritis (IMAS) is a research initiative assessing the impact and burden of axial spondyloarthritis (axSpA) from the patient's perspective.

Professor Marco Garrido Cumbreira, University of Seville, Spain led this exciting project with assistance from ASIF and Novartis Pharma AG. More details can be found on the [ASIF website](#).

This is an informal and public gathering intended to bring together and share opinions among patient group leaders and healthcare professionals from around the world. For this purpose, refreshments and finger food will be served at the venue.

**Date:** 13 June 2019

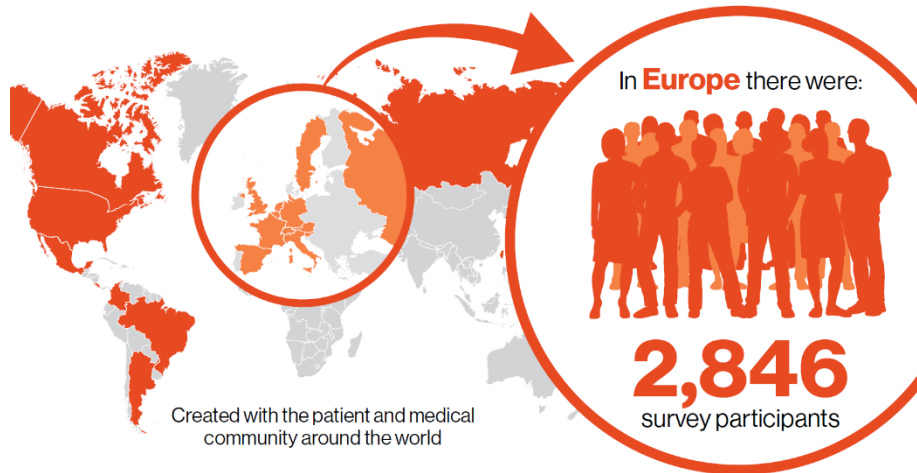
**Time:** 19:00-20:30

**Location:** Hotel Novotel Madrid Campo de las Naciones

**Important:** This event is organized and sponsored by Novartis Pharma AG. Please note that this is a voluntary gathering for those who will be in Madrid for the EULAR 2019 conference and cannot be compensated by Novartis.

If you would like to register for this event, please email Jo on [office@asif.info](mailto:office@asif.info)





## Images

### ASIF needs photographs of AS patients!



So we would like all our member organizations (this means you!) to send us two or three photographs of you and or your members for us to use.

The photos may be of individuals or groups, seated or standing or involved in an activity.

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We want to show that AS is everywhere and affects everyone, so we need photos of women, men, teenagers, children from every continent in the world. Send your photos to Jo at [office@asif.info](mailto:office@asif.info)

Lastly, enjoy World AS Day and don't forget to let us know what you did to celebrate it.



[www.ASIF.info](http://www.ASIF.info)

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