

#### Newsletter - April 2019 World AS Day Edition



Dear Member

World AS Day is on 4 May, 2019. We listened to your views about the Day at the last Council Meeting. We are pleased to advise that to improve the visibility of World AS Day and create more awareness about Ankylosing Spondylitis/Axial Spondyloarthritis and events around World AS Day, we formed two sub-committees, the World AS Day Committee and a Social Media Committee.

Both committees have been hard at work. This newsletter reports on the events we are promoting for World AS Day and lets you know how you and your members can participate. We are also excited to share local events that you, the ASIF members have come up with, and provide a means whereby you can tell everyone about your World AS Day.

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We'll be promoting World AS Day through our social media. Please ensure you follow us on <u>Facebook</u>, <u>Instagram</u> and <u>Twitter</u>, by clicking on the icons below and Liking or Following us. And, of course, there'll be news on our website. Please read and share the following with your members!

**ASIF Committee** 

### **Global Sponyloarthritis Summit**



#### Presented by Spondylitis Association of America.

To register, click <u>here</u> The first Global Spondyloarthritis Summit will be held on 3-5 May inclusive and consists of six lectures of topical interest you can view at your leisure. ASIF's Scientific Adviser, Dr. Uta Kiltz, is one of the speakers. Here's how the Summit works.

Everyone must register (for Free!) to access the Summit. Once you are registered, you can log in to the website any time and as many times as you wish during May 3 to May 5 and choose which presentations you would like to view. That's it!

You will also have the opportunity to participate in a Question and Answer session with the expert speakers.

The presentations are in English. Some members took advantage of the opportunity we offered you to translate sub-titles into your own language. If you did not ask us for the transcripts to do this, keep it in mind for next year!

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The topics of the Summit 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 <u>here</u>

## Walk Your AS Offo

Walk Your AS Off returns in May this year bigger and better than ever.

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. It includes all sorts of exercise. If swimming or yoga is your thing, you can still participate.



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.

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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. What we would really like you to do is form a team or teams in your country. Then teams can compete against each other as to the number of participants, number of steps or can compete between participants. But, competition is not the chief objective. The objective is to get people moving.

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. 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 and we'll post them on our website.

To register for Walk Your AS Off go to <u>www.walkasone.org</u>. You can create your team after you have registered, or join an existing team. To follow news about Walk Your AS Off, go to <u>www.walkyourasoff.com</u>



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. To learn how to register, watch this short video

And Send ASIF your Success Stories and pictures.

#### World AS Day Facebook Frames and Social Media Covers

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 on the <u>ASIF Facebook page</u>.

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SUMMARY: Please follow us on Facebook, Instagram and Twitter to access the frame and cover.

#### **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.

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 (seee below) or email Jo at 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

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# Website update - Members' Forum

We are about to launch the Members' Forum on the ASIF website.

Jo will contact each member association, by email, with instructions as to how to create an account.

The idea is to share information, publications and projects. We hope that it will lead to some interesting and fruitful collaborations. We have a lot of knowledge to share between us.

SUMMARY: keep your eye out for the email from office@asif.info inviting you to set up an account. And join the conversation.

# 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 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





Is there a Health App that you use and like?

Let us know by mentioning it on the Forum or email Jo at <u>office@asif.info</u> 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 <u>Rheumafit</u>, developed by the Swiss AS society, SVMB.

Rheumafit is currently available in German and French. It will soon be available in English.

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### **Other News**

### Newsflash!

On March 28, 2019 the U.S. Food and Drug Administration approved certolizumab pegol (Cimzia®) for use in patients with non-radiographic Axial Spondyloarthritis.

It is the first time that a biologic drug has been approved for nrAxSpA. Read the full FDA Press release.



Driven by science.

#### **Dr Muhammad Asim Khan - New Publication Axial Spondyloarthritis**



Focusing on the key essentials you need to know, Axial Spondyloarthritis provides a quick, expert overview of axSpA from a clinical perspective. This concise resource by Drs. Philip Mease and Muhammad Khan presents practical recommendations and guidelines for the diagnosis, management, and treatment of spondyloarthritis impacting the axial skeleton alongside an overview of epidemiology, special populations, and patient education.

Boehringer

Ingelheim

Further details can be found here.

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