



## Newsletter – September 2019



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

Dear Member

It is an exciting time for AxSpA and for ASIF. It was clear at EULAR that awareness and interest in AxSpA is increasing. With your help we can continue to push AxSpA up the health agenda in every country in the world. We have new tools you can use to help to raise awareness. This newsletter is full of articles we hope you will find interesting and with information we hope you will pass on to your members.

At the Annual General Meeting in Madrid on 12 June 2019, Members and Trustees voted to change the name of our charity to Axial Spondyloarthritis International Federation. We launched the first results from IMAS (International Map of Axial Spondyloarthritis), a project run with Novartis and CEADe and lead by Professor Marco Garrido Cumbreña, University of Seville.

The survey results revealed many interesting findings, for example that people living with AxSpA face uncertainty and worry for their future, with 74% reporting difficulties finding a job due to the condition. The survey is now expanding into the rest of the world and we are very excited to see the next set of results.

We recently produced two new infographics with help from UCB. One explains the terminology, the difference between Axial Spondyloarthritis and Ankylosing Spondylitis and another that addresses how the disease affects women.

**STOP PRESS!** We hope to be able to arrange the 14th ASIF General Council Meeting in Germany on 1 and 2 June 2020, the two days immediately before EULAR 2020. We will let you know as soon as we can confirm this.

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At your request, we have begun to set up sub-committees manned by Trustees and Member representatives to deal with specific topics. So far we have one dealing with Social Media and another dealing with World AS Day. This has proved to be a great way to brainstorm ideas, share expertise and to increase worldwide impact. We are now setting up the next two and we are asking for volunteers again. Please get in touch if you would like to be involved.

This is your community, together we are stronger.

More details on all these items below.

## ASIF Committee

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# ASIF Changes its Name!

## Axial Spondyloarthritis International Federation

Morbus Bechterew      *Marie-Strümpell Disease*  
*Rheumatoid Spondylitis*      **Bamboo Spine**  
**Seronegative Spondyloarthritis**  
Bekhterev's Disease      **Undifferentiated SpA**  
**Spondyloarthropathy**  
*Ankylosing Spondylitis*      Axial Spondyloarthritis  
**Non-radiographic Axial Spondyloarthritis**

At the Annual General Meeting of ASIF, held in Madrid and by telephone conference during EULAR in June, the majority of members voted to change our name to Axial Spondyloarthritis International Federation from Ankylosing Spondylitis International Federation.

The name change was subsequently approved by the Charity Commission in the United Kingdom. ASIF is a registered charity in the UK.

Why the name change? In many ways the name change was driven by progress in technology. Before MRI was developed in the late 1970s, x-ray had been used to see into the body, and one

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of the criteria to help diagnose ankylosing spondylitis (“AS”) was an x-ray of the spine showing inflammation and sacroiliitis. The problem is that x-rays cannot detect sacroiliitis until about seven or eight years after onset of the disease.

Once MRI was developed, it was realized that you could detect sacroiliitis as early as 18 months after disease onset. This gave rise to the condition of Non-Radiographic Axial Spondyloarthritis (“nr AxSpA”). Assuming that people with nr AxSpA (that is, without evidence by x-ray) progress to radiographic AxSpA means that the two diagnoses are the same disease. Consequently, the term axial spondyloarthritis (“AxSpA”) covers the full spectrum of the disease from early onset to advanced AS.

The term Axial Spondyloarthritis has been in use for about 30 years. In 2005, ASAS (Assessment of Spondyloarthritis International Federation) defined two stages of AxSpA, the non-radiographic stage where there is back pain and sacroiliitis seen on MRI, and the radiographic stage, where there is back pain and radiographic evidence of sacroiliitis, plus, eventually, syndesmophytes (bony growth on the spine). In 2009, ASAS reaffirmed these stages when it introduced new classification criteria for axial spondyloarthritis. In other words, it has been almost 15 years since ASAS stopped using the name ankylosing spondylitis in defining and classifying inflammatory back pain.

Interestingly, there are differences between nr AxSpA and r AxSpA/AS (see the downloadable poster on Axial Spondyloarthritis in Women in this newsletter). But there is no doubt that the disease burden in nr-axSpA is substantial and similar to that of AS, with both groups of patients experiencing inadequate disease control and the same symptoms. And, we might add, the same pain.

In the interest of giving a voice to and support for those people who are being increasingly diagnosed with nr AxSpA, the Trustees of ASIF thought it best to open our umbrella further and change our organization’s name to include all those living with AxSpA. The majority of members agreed.

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## ASIF Sub Committees Call for volunteers

At the General Council Meeting in China, Members proposed that ASIF create sub-committees to deal with certain issues. So last year we started with two, one on World AS Day and one on Social Media. These are up and running and already starting work on a campaign for World AS Day 2020.

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Now we are going to set up two more sub-committees and we are looking for volunteers to sit on them. They are:

1. **Delay to Diagnosis** – this is a broad topic but one we think we will be able to attract a substantial amount of funding for;
2. **New and Potential Member Development** – this sub-committee will concentrate not only on attracting new members but also on developing those who have newly joined. It will especially help new associations to develop.

The first step of each sub-committee will be to decide its own scope. We will have at least one ASIF Trustee on each sub-committee in order that they can report back to the Executive so that plans can be centralised.

If you are interested in sitting on (or proposing someone from your association to sit on) either of these two new sub-committees, or the first two World AS Day or Social Media – please email Jo at [office@asif.info](mailto:office@asif.info)



## World AS Day – A Global Success

World AS Day was celebrated on Saturday 4 May and in terms of worldwide participation and events, was a great success! The ASIF sub-committee on World AS Day worked hard to identify and promote events, while the work of the Social Media sub-committee spread the word to create awareness of the day and encourage members and individuals to participate.

Three events were promoted by ASIF and in addition, ASIF produced Facebook cover photos and photo frames which everyone could use to show their support for the day.

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The first event that ASIF promoted was the first Global Spondyloarthritis Summit produced by the Spondylitis Association of America. Over the course of three days, people who had registered for the summit were able to log into the SAA website and view six videos of expert speakers on topics of interest to everyone living with Spondyloarthritis. Over 2,000 people from 30 countries tuned in and there were more than 2,400 page views. The expert speakers were great, providing lots of valuable information. If you didn't register for the Summit and missed the presentations, you can still see them by becoming a member (a membership fee applies) of the Spondylitis Association of America ([www.spondylitis.org](http://www.spondylitis.org)).

Be sure to register for the second Global Spondyloarthritis Summit, which will take place in May, 2020 with an expected 12 expert speakers. Follow us on social media or check [www.asif.info](http://www.asif.info) for when you can register and full particulars of the Summit.

The second event was this year's edition of Walk Your AS Off, presented by Walk AS One, a US registered charity run by Ricky White. For those not aware of Walk Your AS Off, it's a challenge to get yourself walking or moving that runs for the month of May each year. You log the number of steps you walk each day through Walk AS One, adding them to the team you have joined or created. This year there were 72 teams and 2,111 participants from 22 countries! For the month of May, 100,907,844 steps logged, to bring the total number of steps since Walk Your AS Off began in 2012 to 2.37 billion!

Walk Your AS Off has circled the globe, walked to the Moon and is now walking to Mars – some 316 billion steps, which means that we need many more teams from many more countries to participate in 2020 and beyond. Follow us on social media or check [www.asif.info](http://www.asif.info) for Walk Your AS Off 2020 details and when and how you can register, join or create a team.

The third item ASIF promoted was local events. Not very many of you told us about local events, so we could not promote them. An exception was [NASS](#), the National Axial Spondyloarthritis Society in the UK. NASS started a social media awareness campaign, #ASFamousAS, where people took selfies together with famous landmarks and posted them on social media with the #ASFamousAS hashtag.

We would be interested in knowing more about any local events so that we can share them with other members and also help promote them in the future.

There are two other aspects of World AS Day to report. ASIF arranged for cover photos and Facebook frames promoting World AS Day to be made and distributed. There was a widespread take-up of these, all of which helped create more awareness of AxSpA. The other aspect was the amount of social media posting we did around World AS Day, reaching tens of thousands of people through Facebook, Instagram and Twitter.

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The sub-committees on World AS Day and Social Media will be meeting regularly to bring you an even bigger and better World AS Day in 2020!

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## EULAR 2019



The annual EULAR congress was held in Madrid, Spain, June 12-15, 2019. All the Trustees of ASIF were there for a business meeting, the Annual General Meeting and to staff a booth where they could meet rheumatologists and allied health professionals and spread the word about axial spondyloarthritis. We were also pleased to see several members attending the congress. Also at EULAR was Dr Uta Kiltz, Scientific Adviser to ASIF. Dr Kiltz attended many sessions as well as presenting in some, Dr Kiltz' full report can be downloaded [here](#).

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## IMAS

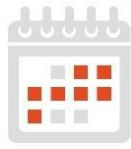
### International Map of Axial Spondyloarthritis

During EULAR 2019 in Madrid we were pleased to launch the European [IMAS](#) survey results. IMAS is a research initiative assessing the impact and burden of axial spondyloarthritis from the patient's perspective.

Developed by patients, for patients, the aim of this collaboration is to generate insights into the real-life experiences of people living with axSpA.

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Many waited **over seven years** on average to be diagnosed with axSpA<sup>1</sup>



On average, women waited **two years longer** than men to be diagnosed<sup>1</sup>



1. ASIF (2017) International. The International ASIF Survey Report 2017. ASIF, 2017. Available at: [www.asif.info](http://www.asif.info)



**46%** reported that their **disease influenced their job choice**<sup>1</sup>



AxSpA caused patients to worry for their future but... **over 1 in 3** ...had never discussed their treatment goals with their doctor<sup>1</sup>



**74%** had **difficulties finding a job due to their condition**<sup>1</sup>



1. ASIF (2017) International. The International ASIF Survey Report 2017. ASIF, 2017. Available at: [www.asif.info](http://www.asif.info)



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### Key findings from the IMAS survey included:

- *people living with axSpA suffer a delay in diagnosis of over 7 years*
- *74% of people surveyed living with axSpA reported difficulties finding a job due to the condition, 56% were forced to take sick leave and 45% had difficulties in fulfilling their working hours*
- *on average, people surveyed living with axSpA began experiencing disruptive and debilitating symptoms at around the age of 26*
- *1 in 3 people surveyed living with axSpA had never discussed their treatment goals with their doctor*

There are a whole set of tools which you are welcome to use to share data with your members. Please email [office@asif.info](mailto:office@asif.info) for more information.

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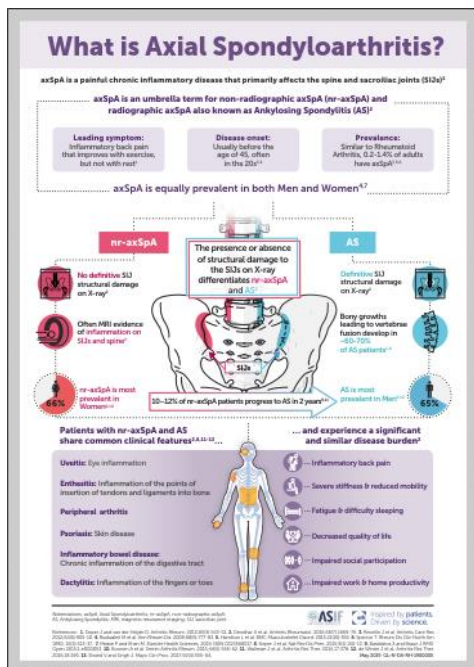
As part of the IMAS launch Novartis created some amazing spine sculptures, "I'm AS". People were invited to write on the pieces of 'spine'. They proved an impactful and engaging tool. We hope to use these again for World AS Day 2020 - watch this space.

## New Infographics Available for you to share

With assistance from UCB ASIF created two new infographics. One on the new terminology around AxSpA and another on Women and AxSpA. These are available to download from the [ASIF website](http://ASIF website).

We also have both of these infographics available in an editable format (in the programme, *illustrator*) so you can translate the text into your own language.

If you would like to take advantage of this offer, please email Jo at [office@asif.info](mailto:office@asif.info)



Click on the image to download it in pdf

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# Rheumafit

## Online exercise videos for AxSpA/AS and other arthritis patients

That exercise is important for people with AxSpA/AS and other rheumatic diseases is repeatedly confirmed in scientific studies. However, various studies have shown that many sufferers are unable to take part in a group therapy course due to time constraints and geographical reasons. The Ankylosing Spondylitis Association of Switzerland (SVMB) has now launched the Rheumafit platform in collaboration with the Zurich University of Applied Sciences (ZHAW). Rheumafit is ideal for use at home but can also be used in a group setting.

Rheumafit is now available in English as well as French and German!



### Découvrez les programmes d'exercices équilibrés

Des physiothérapeutes spécialement formés montrent les exercices contre la spondylarthritis ankylosante conçus par une équipe d'experts.



Various exercise programmes suitable for people with Axial Spondyloarthritis and other rheumatic illnesses can be found online at [www.rheumafit.ch](http://www.rheumafit.ch).

Each exercise comes with a video illustration and written on-screen instructions, plus important hints for training at home. Each exercise program indicates its purpose, the duration (most are under 20 minutes), the intensity, the targeted body parts as well as alternatives or variations to the main exercise.

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Filters allow you to select the duration and intensity of your exercise programme as well as on which part of the body you want to concentrate. Rheumafit can automatically suggest those exercise programs that best fit your profile. The programs can be accessed from any device connected to the Internet, be it a smartphone, a tablet, laptop or an Internet-capable television set (Smart TV). More than 20 exercise programmes are available. You can register for Rheumafit for free at [www.rheumafit.ch/signup](http://www.rheumafit.ch/signup).

Rheumafit's exercise programs were developed in close cooperation with Prof. Karin Niedermann, head of the masters' program in physiotherapy at the Zurich University of Applied Sciences (ZHAW) and consulting physiotherapist at the Ankylosing Spondylitis Association of Switzerland (SVMB). She encourages those living with AxSpA/AS to train with the help of online videos: "Rheumafit is an excellent support tool for individual training. It enables the patient to train for strength, endurance, mobility and coordination two to three times a week. This also corresponds to international movement recommendations, which are effective, safe and feasible for people suffering from rheumatism. If pain occurs during the exercises, you should talk to your physiotherapist to find a suitable selection of exercises."



## Eular PARE

World Arthritis Day is on 12 October this year. World Arthritis Day is a global awareness-raising day. More information about EULAR's campaign Don't Delay Connect Today – Time2Work can be found on the [EULAR/World Arthritis Day website page](http://EULAR/WorldArthritisDay)

If you want to take part, you can download a copy of the Don't Delay Connect Today – Time2Work toolkit [here](#).



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