



Newsletter - January 2019



ASIF Members at the top of the Canton Tower, Guangzhou, China, October 2019

Dear Member

In October 30 delegates from 18 countries met in China at the 13th ASIF General Council Meeting. The first time in its history that ASIF has held its General Council Meeting outside Europe. We are very grateful to Dr Jieruo Gu and her team for looking after us so very well. Also, a special thank you to the speakers for some excellent talks.

We held 2 sessions of workshops in which delegates took part enthusiastically, the outcome of those will feed into ASIF's plans for 2019. You can read more about this in the full report which can be found below.

For the first time we invited each member country to give a talk about their work. This proved extremely popular and it is something we will expand on at the next General Council Meeting. Clearly members are keen to share information and this is something that ASIF are keen to encourage.

We continue to collect publications and educational material to share on the ASIF website and to hold in our library. If you have publications you are happy to share this way, please email them to Jo at office@asif.info alternatively if you want to send hard copies, please send to:

ASIF is grateful to its industry partners:



ASIF, c/o Jo Davies, 5a Quernmore Road, London N4 4QU

What to look forward to in 2019

Sub-Committees

At the General Council meeting members agreed to set up a few sub-committees to work on specific areas or issues.

Trustees, having met, suggest that two initial sub-committees are set up. The first to discuss World AS Day Activities and the second, Use of Social Media. If you want to take part, please let Jo know by emailing office@asif.info. You are welcome to nominate anyone from your organization to take part in one or other or both sub-committees. Jo will email with more information about this shortly.

Website updates

We plan to launch the members' area of the ASIF website in February. This will be an area that you will be able to log in to and share information. Watch this space.

We are also working on translating parts of the website and will enlist your assistance with this task.

2019 AGM and EULAR

ASIF is now a charity registered in the UK and as such must hold an Annual General Meeting every year. We have decided to hold this year's AGM in June during EULAR 2019. The AGM will be on the morning of Wednesday 12 June 2019. If you are planning to be at EULAR this year, we hope you will join us at ASIF's AGM. Further details to follow.

ASIF plans to have a large booth in the EULAR village. Please feel free to make the ASIF booth your base whilst you are at EULAR.

Name change

I am sure the new ASAS classification criteria for Axial Spondyloarthritis has not escaped your notice. The new term has a much broader reach which includes non-radiographic AxSpA as well as radiographic AxSpA, which includes Ankylosing Spondylitis.

ASIF will remain ASIF but members will be invited to discuss in June at the AGM whether we should consider becoming the Axial Spondyloarthritis International Federation.

If you have any thoughts on this that you would like to share in advance of the meeting, please let us know by emailing office@asif.info.

ASIF 14th General Council Meeting 2020

We are still seeking a volunteer organization/country to host the 14th General Council Meeting in 2020. It is a great opportunity to welcome members to your country and to showcase what you are doing. We can help to raise any necessary funding and we will organize the programme.

If you think you could welcome us to your country in 2020, please email office@asif.info.

ASIF Committee

ASIF is grateful to its industry partners:



New Trustees

A huge welcome to our three new Trustees who were elected at the meeting in China to join the ASIF Trustee Board. They are:

Yuki Zeniya, Japan



Cassie Shafer, USA



Cassie serves as the CEO of the Spondylitis Association of America (SAA) and currently manages a staff of 12, a governing board and a medical/scientific advisory board. She brings with her 30+ years of non-profit healthcare management having served in senior leadership or executive roles with American Heart Association, American Lung Association, National Kidney Foundation, and American Diabetes Association

Aleksei Sitalo, Russia



Aleksei is the Founder and President of the Bechterew's Disease Mutual-Aid Society in Russia since 2012. In order to set the society up, he studied the law and incorporation procedure from the ground up.

Aleksei has had a lot of success raising awareness of the disease in Russia. You can learn more about Aleksei's story [here](#).

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New ASIF member – Ukraine



In November the Trustees approved the application from the Ankylosing Spondylitis Organization of Ukraine ASOU "Ankylosis.net"

This is a very new organisation set up by Irina Bublik and her colleagues and formalised only in July 2018.

Irina was diagnosed 8 years ago. She is a Pilates teacher and has studied the effects of exercise in rehabilitation for AxSpA patients.

We look forward to working with Irina, and her colleagues at ASOU.



ASIF 13th General Council Meeting Guangzhou, China 10-13 October 2018

We had a packed programme over 2 and a half days. Speakers included Ricky White from Walk As One, USA, who talked about how best to using social media.

Professor Marco Garrido Cumbreira PhD from Seville, talked about the survey EMAS, the European Map of AS. The data from this survey will be launched over the coming months. This is now being rolled out globally, if you are interested in your country taking part, please email office@asif.info. Dr James Chang-Chung Wei from Taiwan talked about Treat to target in AS. This is clearly a hot topic and was also a key discussion at the SpA conference in Ghent. Dr Uta Kiltz reports on that discussion in the article below.

Dr Muhammad Asim Khan, a founding member of ASA, SPARTAN and GRAPPA and author of many books and articles on AS. A rheumatologist and patient, Dr Khan has an enormous knowledge about the condition both its history and its treatment present day. Dr Khan gave a presentation about Emerging Therapies in AS.

Souzi Makri, President of ENFA, EUPATI Fellow, Vice-President of Cyplar and Honorary Chair of Agora talked about Personalised Treatment and shared decision-making. Prof Dr Tuncay Duruöz covered the new criteria for Axial and Peripheral Spondyloarthritis and co-morbidities.

Dr Dale Webb, Chief Executive of NASS talked about the importance of exercise and how NASS promotes it and Raj Mahapatra gave us 'his story'.

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The workshops ranged from social media campaigning to World AS Day, raising awareness, building relationships with pharma companies and to How ASIF can better help its members.

Dr Jieruo Gu and her team organised a full social programme of dinners and sight-seeing. All in all, it was a very successful meeting.

The full report can be found [here](#).

Comorbidities Common in AxSpA A theme at the 13th ASIF Council Meeting

Michael Mallinson

When the Canadian Spondylitis Association, collaborating with Self Care Catalysts Inc., formed a focus group to see what AS patients needed to track and what was of importance to them in the development of an AS App, it quickly became evident that most participants were dealing with more than one disease or condition. The fact that AxSpA patients live with one or more comorbidities and extra-articular manifestations emerged as a theme in presentations during the 13th ASIF Council Meeting.

The Canadian Spondylitis Association took the findings from the 2014 focus group one step further and surveyed its membership in 2018 about comorbidities. Over 50% of respondents reported chronic pain and mental health issues. A similar online survey undertaken by ASHAD, the Turkish AS patient organization, found that 88.5% of respondents had at least one co-morbid disease. The EMAS project has surveyed AxSpA patients in 13 European countries. While the full results have not been published yet, Dr. Marco Garrido-Cumbrera and Pedro Plazuelo-Ramos, who were presenters at the Council meeting, presented posters at the recent American College of Rheumatology Annual Meeting including one on [psychological distress in EMAS patients](#). That risk is over 57%.

At the end of his presentation on Treat to Target in AS, Dr. James Wei spoke of the importance of treating AxSpA holistically, including extra-articular manifestations and comorbidities.

In addressing Emerging Therapies in AS, Dr. M. Asim Khan discussed the complexities of treating AxSpA when there are so many associated manifestations and comorbidities, and stressed the importance of a multi-disciplinary approach to management of the disease.

Finally, Dr. Tuncay Duruöz presented on two topics, the second of which was Comorbidities, which he noted can contribute to the burden of disease, prognosis, morbidity and mortality. Like Drs Wei and Khan, Dr. Duruöz concluded that the assessment and management of comorbidities should become an integral part of the management of SpA with a multi-disciplinary approach.

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Scientific summary SpA congress in Ghent, October 2018, and ACR congress in Chicago, October 2018

Report by Uta Kiltz

The SpA congress in Ghent is unique as it combines hot topics from basic and clinical science. Three major topics in the field of axial spondyloarthritis (AxSpA) have been discussed during this meeting:

Treat-to-target approach (T2T): This approach is well recognized in other diseases and has been formally established in diabetes mellitus. The basic idea of this concept is that a pre-specified target should be met within a certain timeframe by adapting the treatment if the target is not met. T2T principles have been published for patients with spondyloarthritis (SpA). However, there is a debate about the optimal target for patients with SpA. This is thought to be “disease activity” but there is no unique single measure to assess the level of disease activity. In clinical routine, BASDAI or ASDAS is often used as a surrogate for the concept of disease activity in axSpA. In Ghent, two researchers debated about whether it is appropriate to implement a T2T strategy in patients with SpA. One “Pro-Speaker” summarized the evidence for a persistent low disease activity (less structural damage, increased quality of life, better employment rates). A “Contra-Speaker” countered the arguments by focusing on the limitations: population at risk for a progressive disease cannot be specified upfront, fluctuating disease, and difficulties in measuring the target correctly. The audience voted at the end of the debate in favor of the T2T strategy in patients with axSpA.

Management of comorbidities: There is an increasing awareness that management of comorbidities is essential for patients with SpA in the long run. Especially, cardiovascular diseases, osteopenia/osteoporosis and infectious disease must be managed throughout the disease course. Although selection of disease types is quite clear, the way of managing the disease and implementing a standardized screening strategy is not clear at all. The individual barriers in health systems throughout the world are quite heterogeneous. However, research in this field starts to increase! One study presented during EULAR and ACR showed that it is beneficial to inform the patient about existence of comorbidities and appropriate screening strategies: patients randomized to the informed arm had more vitamin D intake (for preventing bone disease) and were more often vaccinated (for preventing infectious diseases) compared to patients who did not receive information about comorbidities after 12 months of follow-up,

Microbioma: The formation of all bacteria in the human digestive system is called microbioma. It is quite clear that the composition of the individual microbioma is associated with disease outcome in many different diseases. In Ghent, a summary of the knowledge about microbioma in patients with axSpA are presented. At the moment, no clear conclusion can be drawn from the research because the results did not show a clear picture. Especially, no direct consequence on daily routine can be drawn.

Website update

www.asif.info

Watch this space. We are about to launch the members area on the website.

ASIF is grateful to its industry partners:



The members' area will be pages that you can log into and hold discussions and share information with each other.

If you have any articles, videos or publications that you would be happy to share with other members, please email them to office@asif.info. We will ensure that you are credited with their creation and ownership.

We are grateful to Novartis for their sponsorship of our website project



World AS Day 4 May 2019

World AS Day logo

Please feel free to use it on your publicity material and websites.
You can download it here in difference formats

[.jpg](#) [.pdf](#)

ASIF will again be promoting WalkASOne, Walk Your AS Off and the Selfie Challenge in 2019.

Further details about ASIF's plans World AS Day 2019 will be announced soon.
This project and the development of the World AS Day logo is supported by our partners at UCB

EULAR 2019

The ASIF Executive will be at EULAR in Madrid 12-15 June.

ASIF hope to have a large booth in the EULAR Village. We already know that the CSA will join us and we hope that you will all feel free to base yourselves at our booth if you are attending EULAR.

There will be an ASIF Annual General Meeting on the morning of 12 June. The agenda will be circulated in good time and we will aim to enable remote access to the meeting.

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Finer details have not yet been decided but ASIF with Novartis hope to hold some sort of event to announce the EMAS project.

We will present the work of our members on a screen at our stand. If you have not already done so , please send Jo (office@asif.info) a couple of slides showcasing your work.

if you are attending EULAR, we look forward to seeing you there.

News from ASIF members



The SAA have announced an online event that will bring together medical professionals and people living with spondyloarthritis in presentations that will be broadcast on 3, 4 and 5 May 2019.

You will also be able to pose your own questions to the presenters. The whole event is free and open to the public – but you will need to register. Details about how to register will follow.

Follow the link below to find out more about the broadcasts and the speakers. **ASIF** is a proud partner of this event.

Opportunity to translate the videos into your language

The videos are currently all in English. ASIF members are to be given the opportunity to translate the text in advance of the broadcast, so that sub-titles can be added and your members will be able to access the broadcasts with the relevant sub-titles. The text will be made available on 1 March and will need to be returned before 29 March.

If you think you would be interested in organising a translation to your language, please contact [ASIF](#) as soon as possible to register interest. Please contact us even if you are unsure how to manage the translation, ASIF will do its best to assist – and of course there are some common languages among our members. Translations into those languages need only be done once.

Further details can be found [here](#).

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Michael Mallinson, the past President of the The Canadian Spondylitis Association and current ASIF volunteer, was presented with the 2018 Qualman-Davies Arthritis Consumer Community Leadership Award on November 21 in Toronto, Ontario, Canada at the Arthritis Alliance of Canada meeting.

This award was created in 2014 to recognize one person's contributions to helping Canadians living with the disease to be heard in decision-making processes that affect millions. That's what Ann Qualman and Jim Davies did as early pioneers in arthritis advocacy in Canada. Their tireless and selfless efforts helped millions of Canadians.



Michael's efforts over the last 25 years have made a difference for those living with Spondyloarthritis in Canada and globally. ASIF is lucky to have Michael continue his volunteer efforts, now focusing on encouraging and supporting the creation of patient support groups in countries where they don't currently exist.

I think we can all thank Michael and extend congratulations to him for his leadership, support, time and passion for helping truly making a difference to those living with Spondyloarthritis.

Stichting Axiale SpA Nederland

The 16th International AS (Ankylosing Spondylitis) Volleyball Tournament of 2019 will take place on Saturday 30 March 2019 in Utrecht. The tournament has an international character with the participation of teams from home and abroad.



[Further details.](#)

NASS Launches Every Patient, Every Time Campaign at the Houses of Parliament



NASS was delighted to welcome 200 guests, including 11 MPs or their representatives, to a reception at the Houses of Parliament on Monday 3 December to launch their Every Patient Every Time campaign and hold their Patients' Choice Awards.

Announcements included the new All-Party Parliamentary Group for Axial Spondyloarthritis, which will oversee the implementation of the NICE Guideline and Quality Standard for Spondyloarthritis, and the Aspiring to Excellence programme which

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will encourage rheumatology departments around the country to share best practice and improve services in a collaborative manner.

CEO Dr Dale Webb says “NASS knows that not everyone in the UK gets the same standard of care for their AS – that’s why we launched our new campaign **Every Patient, Every Time**. The publication of the National Institute for Health and Care Excellence (NICE) Guideline in 2017 and Quality Standard in 2018 were huge landmarks for axial SpA (AS), but there’s much more work to be done. Our next goal is to ensure that the guideline and quality standard are both effectively implemented, so that every patient, every time gets the care and support that they need.”



The event culminated in honouring recipients of the 2018 Patients’ Choice Awards – given to health care professionals who had been nominated by their patients for their outstanding care during the year. [Click here](#) to learn about the full scope of Every Patient, Every Time and [here](#) to see who’s been honoured in the awards.

Antardhwani – India

“Antardhwani”, the first of its kind support group from India started in 2014 with a prime motivation to spread awareness about Ankylosing Spondylitis, manage pain and help patients to live a normal and healthy life. Apart from creating awareness about healthy lifestyle including diet and regular exercise it also serves as a common platform for patients to meet and exchange information and experiences. The journey of



Antardhwani, to manage this non-curable disease, has been challenging but promising. Some insights:

- 7 Rheumatologists joined the Antardhwani panel
- The celebration of World Arthritis Day every year – 1st of its kind Rheumathon in India with 500+ participants
- Signature Drive initiated with 3000+ signatures aimed to reach 10000+, as a collective voice to include AS under Insurance and government health schemes
- Yoga and Physiotherapy seminars for AS patients
- Patients get a discount of 20% on Arthritis tests done at selected pathology laboratories

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- Sponsor injections and discounted doctor consultation charges to the poorest of the poor who fit in the criteria

Further down the line; Antardhwani is focused on starting regular yoga groups for AS patients. Efforts are also made to get diagnostic tests at discounted rates.



Other News

Accomplishments of Heinz Baumberger PhD: a remarkable patient with ankylosing spondylitis for 72 years

An article by Dr Muhammed Asim Khan

This is the story of a remarkable Swiss patient - Heinz Baumberger, PhD - who was born in 1931 and has suffered from ankylosing spondylitis (AS) since 1943. He has survived many manifestations and co-morbid conditions associated with his disease and its treatment. These include severe episodes of acute anterior uveitis, osteoporosis with fragility fractures, and also post-traumatic spinal

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fractures on three different occasions. In addition, he has suffered from multiple basal cell carcinomas as a late complication of a 3-week course of spinal radiation in 1952, and another one in 1962. It was only in 1971 that Dr Baumberger for the first time met a fellow sufferer from AS, and he subsequently helped establish the Swiss AS patient support group, the second such national group in the world. He co-authored with his rheumatologist an excellent and well-illustrated book on AS for patients and their family members and for allied healthcare professionals. He travelled extensively around the globe lecturing and participating in various meetings and congresses in his zeal to spread

the idea of self-help organizations for patients with AS.

You can read the full article [here](#).

Nutrition to Fight Inflammation

It's the time of year when many people look at their diet.

Many AxSpA patients wonder if diet can help them manage their disease, and on the understanding that you are what you eat, try various diets and foods to alleviate their symptoms or even 'cure' their AxSpA. The truth is that there is very little scientific evidence for the curative effects of diets, foods and supplements, especially when they are fads that people sometimes turn to in desperation for something, anything, that may work.

While there is no magic bullet in diets, Lara Hamilton, Registered Dietitian, who spoke at a recent Spondylitis Association of America patient forum in Chicago on "Nutrition to Fight Inflammation: the role of diet in Spondyloarthritis", gave sound advice on which foods to avoid and which to choose to control inflammation.

You can find the full report [here](#).

For any further information please contact office@asif.info

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