



Newsletter - January 2018

We are working on plans for **World AS Day**, which this year is on Saturday 5th May. We will again be collaborating on walkyourasoff with Walk AS One. We will be in touch with you in February/March with promotional materials. We want as many people to take part world wide as possible.

WATCH THIS SPACE!

The whole ASIF Executive Committee is attending EULAR in Amsterdam in June. We will have a booth, if you are there, please do come and join us. We will also arrange an informal ASIF members meeting during the congress. Watch this space.

In 2018 we hope to approve at least 8 new country members, beginning with [South Africa](#), Colombia and Chile.



ASIF Scientific Adviser

We are pleased to announce the appointment of ASIF's new Scientific Adviser.

Dr Uta Kiltz is the Senior Rheumatologist at the Rheumazentrum Ruhrgebiet, Herne, Germany. She is a member of ASAS and her main area of interest is in the field of spondyloarthritis, focusing especially on patient-reported outcomes.

We look forward to working with Dr Kiltz, she will be able to keep us up-to-date with the latest in scientific developments.



ASIF 13th General Council Meeting

Guangzhou, China

10-13 October 2018

The ASIF Council meeting will take place in China this year, kindly hosted by Dr Gu and the Association of Chinese AS Patients and Medical Advisory Board of Chinese Health Promotion Foundation.

The meeting is from 10-13 October. The programme is still being finalised but will in part focus on raising awareness.

Speakers will include:

Jennifer Visscher from Walk AS One, a very successful online campaigner

Souzi Makri, Honorary Chair AGORA, who will talk about personalised treatment and shared decision-making

Dr Tuncay Duruöz who will talk about the new criteria for axial and peripheral spondyloarthritis.

We really want to hear from our members at this meeting so there will be plenty of opportunity for you to take part in workshops and we will invite each country attending to give a short presentation about something of note - a recent success story or triumph - or even something that did not go so well. So that we can all learn from each other.

We hope to have presentations from up to 8 new member counties.

There will be a welcome dinner on Wednesday 10 October, Thursday, Friday and Saturday morning will be talks and workshops. On Saturday afternoon our hosts are planning an excellent trip out for us to see some points of interest.

We will be staying at the Guangzhou Southern Congress 1 Station Hotel. I will send out more details along with invitations and registration booking forms in February. For those who want to get ahead booking their flights, the nearest airport is Guangzhou Baiyun International Airport.

We really hope that as many of you will come to the meeting in China as possible.



ASIF Represented at ACR 2017

In November, 2017, we were represented at the American College of Rheumatology Annual Meeting in San Diego, California, by ASIF volunteer Michael Mallinson.

Michael's role is to encourage Ankylosing Spondylitis patient organizations who are not members of ASIF to become members, and to encourage the formation of AS patient societies where none exist. In this role, Michael was able to speak to rheumatologists from many countries and particularly those from the Arab world and Latin America, both areas where we do not have any members. As a result of these conversations, we are hopeful of attracting new members from both regions within the next year.

Michael reports that during the poster sessions, there were gratifyingly larger numbers of posters about Spondyloarthritis than the previous year. These covered a large number of topics and some were included on the poster tours. There were also quite a few more of lectures on various aspects of Spondyloarthritis than at the previous meeting.

The Great Debate at ACR was titled "Biosimilars..to Switch or Not to Switch". Speaking for switching was Dr. Roy Fleischmann and against was Dr. Johnathan Kay. Both agreed that biosimilars show little to no clinical differences to the original biologic, which is good news for patients. Dr. Kay argued that biosimilars are only useful if they are of lower cost to the patient and then demonstrated that in the case of the U.S.A., they are not. However, in Europe and other countries they are cheaper to the patient and society and therefore a switch is warranted.

News from our Members



New CEO at NASS, the UK's National Ankylosing Spondylitis Society

Dr. Dale Webb joined NASS as CEO in early November. He brings 25 years' experience of working in health-related areas - having spent time in the NHS, in health research and in health charities. Dale believes passionately that third sector organisations can help transform people's health and well-being.

2018 will see many developments at NASS. In June we will launch a new website; it will include a redesign of all our patient information to reflect the new national clinical guidelines published in late 2017 by the UK regulator NICE. It will also include a database of all rheumatology services in the UK. And we will update the exercises contained on our Back to Action App. In 2017 we developed the ASOne website which is aimed at younger people with AS and in 2018 we will develop more content.

We will extend our reach into health care professional communities - our Back Pain Plus project will now include nurses and physiotherapists. We have a new pilot project that will work with osteopaths and chiropractors to ensure that they have a good understanding of AS and can make appropriate referrals.

Fundraising is key to our future and so in May we will run our Mighty Orange Mashup fundraising campaign. We are a membership organization and in June we will launch a revised set of offerings for our members.

Finally, in November we will hold a reception at the UK Houses of Parliament to raise awareness of AS among politicians and to thank all of our supporters.

To find out more you can email Dale: dalewebb@nass.co.uk, Follow him on Twitter: @NASSchiefexec or look at our website: www.nass.co.uk



New CEO at the Spondylitis Association of America (SAA)

Cassie Shafer joined the Spondylitis Association of America (SAA) as the new CEO in late September 2017. Cassie brings with her a unique set of skills that she acquired over her many years of experience with national US healthcare nonprofits, where she has distinguished herself as a nationally recognized staff leader. Over the past 30 years Cassie has held executive and management positions in health care with organizations such as American Heart Association, American Lung Association, National Kidney Foundation and most recently the American Diabetes Association. Her focus has been on setting vision, driving performance management through best practices and benchmarks, revenue forecasting and budget optimization, developing program strategy, coaching staff and volunteers, and community organization and board development.

“I am so excited for this opportunity to join the SAA,” Shafer said. “I look forward to working with our Board of Directors, Medical Advisory Board and the staff to take the SAA to the next level in terms of patient support, fundraising and research of the disease.”

2018 marks the 35th anniversary of SAA. Many great and notable accomplishments have been made over this period of time. Cassie looks forward to leading SAA in the continued fight to improve the lives of patients and families who have experienced the devastating consequences of ankylosing spondylitis and related diseases. She is also excited to expand support for essential research projects, launch an e-advocacy platform, develop new programs to reach Primary Care Physicians (and other key healthcare providers) to improve early identification of axSpA among patients with chronic back pain, and create a more robust social media exchange around [#backpainmatters](#).

[SAA Website](#)



Changes at the Canadian Spondylitis Association

The Canadian Spondylitis Association underwent many changes in 2017. In June, Michael Mallinson retired as president of the Canadian Spondylitis Association, having held the position since the first officers and directors of the Association were elected on its founding in 2007. The newly elected president is Gerald Major. In addition, to strengthen and continue growing the organization, Wendy Gerhart was hired as the Executive Director. In addition to

Gerald moving into the role of President, the organization welcomed six new board members.

In 2018 the Canadian Spondylitis Association will be focused on Awareness and Education to general public, patients and healthcare professionals, and Strengthening National and International partnerships.

[CSA Website](#)



Sculpture Exhibition "Disease of Young People or Life with Pain" in Moscow

From 4 to 13 December, the Ankylosing Spondylitis Association of the Russian Federation created a sculpture exhibition in Moscow. Nine transparent sculptures of humans with luminous red spines, showing the stories of pain and suffering. The aim was to draw the attention of the public, the media and the authorities.

[Website](#)



AISpA
Associazione
Italiana
Spondiloartriti - Onlus



On 11 November 2017 AiSpa (Spondyloarthritis Italian Association) organized an important seminar on the topic of "Back pain" in the historical room of Auditorium S. Filippo Neri in Bologna.

Doctors and patients discussed together about the painful symptomatology that appears in the first days since the appearance of ankylosing spondylitis (back pain in the early morning): therefore it's important to know how to make a differential diagnosis. They also pointed out that an early diagnosis is necessary to improve quality of life in ankylosing spondylitis patients.

[AISpA Website](#)

[Link to conference programme](#)



Ankylosing Spondylitis Group of Victoria

A successful year is reported by Annie McPherson

[See Full Report](#)

Other News and Articles



Inspired by **patients**.
Driven by **science**.

UCB's CIMZIA[®] approved for potential use in women with AS during breastfeeding and pregnancy

The European Medicines Agency (EMA) has approved the label change for UCB's CIMZIA[®] (certolizumab pegol), making it the first anti-TNF for potential use in women with Ankylosing Spondylitis during both pregnancy and breastfeeding.

[Full Press Release](#)



Intimacy and AS

Michael Mallinson has lived with AS for over 35 years. He developed this content as a consultant to Novartis Pharmaceuticals Canada Inc. No payment was received.

Let's not hold back on this. You've got Spondyloarthritis and your back and some of your other joints hurt, a lot. You've also noticed that you've lost some flexibility and simply can't get into the positions you used to be able to. Furthermore, what with the fatigue and bouts of depression, you don't feel like doing 'it'. But you are still young and you know it's healthy for couples to have regular sexual intercourse. What's to be done?

[Full Article](#)

Did you know that BACK PAIN can be caused by AXIAL SPONDYLOARTHROSIS?
Do you suffer from chronic back pain?

This questionnaire¹ can help assess if your back pain is characteristic of inflammatory back pain – the major symptom of axial spondyloarthritis.^{1,2}

Approximately 5% of individuals with back pain are considered to have axial spondyloarthritis.^{2,3}

You may have inflammatory back pain if your pain has persisted for more than 3 months and you answer 'yes' to at least 4 of the 5 following questions.⁴

1. Did your back pain start before the age of 40 years? YES NO
2. Did your back pain begin slowly and develop gradually over time? YES NO
3. Do you have back pain at night, which improves upon getting up? YES NO
4. Do you find there is no improvement in your back pain when resting? YES NO
5. Does your back pain improve with exercise? YES NO

If you have identified the possibility of inflammatory back pain, you may wish to visit your primary care physician and seek a referral to a rheumatologist for further investigation.⁵

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Ankylosing Spondylitis (AS)

AS is a chronic inflammatory disease, predominantly involving the spine and sacroiliac (SI) joints.^{1,2} Patients with AS have clearly defined structural damage of SI joints on X-ray.³

Onset and diagnosis
Affects young people: mean age of symptom onset = in mid-20s.⁴ Average delay of **8.5 years to diagnosis⁵**

Prevalence
Global prevalence (%) of AS⁶

Estimated prevalence of AS in adults aged 18 to 44 years is **0.35%⁸**

Patients may experience additional disease-related manifestations^{9,10}

- INFLAMMATORY BACK PAIN
- DISTURBED SLEEP
- STIFFNESS
- FATIGUE
- REDUCED MOBILITY

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Axial Spondyloarthritis (axSpA)

axSpA is a chronic inflammatory disease, predominantly involving the spine and sacroiliac joints.^{1,2}

Onset and diagnosis
Affects young people: mean age of symptom onset = in mid-20s.³ Average delay of **8.5 years to diagnosis⁴**

Disease spectrum^{5,6}

axSpA → AS → Ankylosing spondylitis (AS)

Global prevalence (%) of AS⁷

Estimated prevalence of axSpA in adults aged 18 to 44 years is **0.70%⁸**

Patients may experience additional disease-related manifestations^{9,10}

- INFLAMMATORY BACK PAIN
- DISTURBED SLEEP
- STIFFNESS
- FATIGUE
- REDUCED MOBILITY

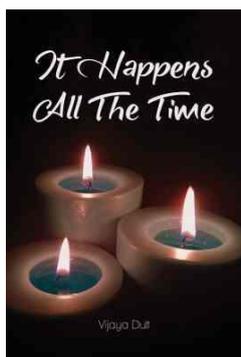
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UCB have developed these infographics - useful for diagnosis and raising awareness. You are welcome to download and use these. If you would like assistance in translating them into your language, please email Jo at office@asif.info

Our friends at [AGORA](#) are in the process of getting these translated into a number of languages and for others we may be able to help you get them translated for distribution in your country.



Book Review by Michael Mallinson

'It Happens All the Time' by Vijaya Dutt, published by Austin Macauley, 2016.

This novel includes a character with Ankylosing Spondylitis.

Author Vijaya Dutt was born in India and spent her childhood in Wales before the family moved back to Delhi. She later married and moved to Kolkata but now lives once again in Delhi.

Her life is the basis of the novel, which follows the life of Divya, born in 1959, the second daughter of a Bengali doctor and his Punjabi wife.

[Read the full review](#)

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