



## Newsletter – December 2020



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

### **A Seasonal message from Zhivko Yankov, President of ASIF**

Dear Members,

The Covid-19 pandemic has affected every aspect of everyone's life in 2020. Individuals and businesses have suffered and life has been far from normal. Despite this, ASIF has had a good year. Although we had to cancel our Council Meeting that was scheduled in Frankfurt immediately before the EULAR conference in June, and we missed being at the EULAR, PANLAR and the American College of Rheumatology congresses, we were able to forge ahead with our projects and grow the organization.

Early in the year we welcomed Valeria Tassi as an Administrative Assistant to help Jo Davies, our Executive Support to the Board, with her increasingly heavy workload as we pressed ahead with two major projects, Delay to Diagnosis and the International Map of Axial Spondyloarthritis (IMAS) survey. Both projects have enormous scope, so in September, we welcomed Jo Lowe as a project manager to manage them.

With thanks to our sponsors, we were able to hire an agency to help with our campaign leading up to World AS Day 2020. As a result, we offered social media graphics and videos to you to use in your World AS Day awareness campaigns, as well as run a very successful campaign ourselves on our social media platforms. Both the global events run by ASIF members for World AS Day that we promoted, the Spondylitis Association of America's Global Spondyloarthritis Summit and Walk AS One's Walk Your AS OFF, were judged to be successful. We look forward to promoting these events again in 2021 and of seeing more members participate in them.

This year has seen all our sub-committees being very active. These are Communications (which replaced and took on more responsibilities than the Social Media sub-committee), Delay to Diagnosis (to oversee and give direction to the Delay to Diagnosis project), IMAS (to build the partnership with Novartis and the University of Seville on IMAS, and to oversee and define ASIF's responsibilities within that partnership with a view to ASIF taking a more significant role in future), Membership (responsible for growth of membership and in providing services to members; more of this later), and World AS Day (responsible for promoting awareness around the day and providing members with campaign materials).

In terms of growth, we welcomed three new member organizations, but sadly had to say goodbye to two members, those from Ireland and Italy. Because of the lessons learnt in the dissolving of these organizations, I have given a new and larger mandate to our Membership Committee to create more engagement with you, our members, and to provide you with webinars on topics that you will find valuable, such as fundraising, business and succession planning, governance, use of social media, growing your membership, running educational forums, etc.

Your Trustees meet online every month to address policy and operational issues. I am pleased to report that a lot of attention is being paid to risk management, governance and policies, and budget matters to ensure the continuing and sustainable success of ASIF.

Without a doubt our biggest success this year was the two forums on Delay to Diagnosis that were run in October and November on a virtual conference platform. These brought together patients, rheumatologists, physiotherapists and other health care specialists from around the world to examine the reasons for the lengthy global delay to diagnosis and look at a possible solution.

Elsewhere in this newsletter you will find more detail on all the above subjects I have mentioned. I hope you will share the articles with your membership. And please do not hesitate to contact us if there is anything you think ASIF should be doing for you that we may have overlooked.

However, you celebrate, I wish you and yours all the very best of the Season. I, and I am sure, everyone at ASIF, sees you as part of our global axSpA family, so please enjoy the Season responsibly, stay safe and keep well. We hope to meet in 2021!

Sincerely

**Zhivko Yankov, President, ASIF**

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## New Members

We have welcomed 3 new members to ASIF this year. Fondation Enyarthrite Algérie, Algeria (FEAS), Stand For AS, India, and Arthritis Consumer Experts, Canada.



**Fondation Enyarthrite Algérie** - Algeria (FEAS). A group that was started by young patients in a country where 54% of the population is under 30. FEAS now has over 1500 members. You can see their facebook page [here](#).



**Stand for AS** is the second Association to join ASIF from India. Set up and run by Dr Shashank Akerkar to help AS Warriors understand their disease and to provide accurate scientific information and education.

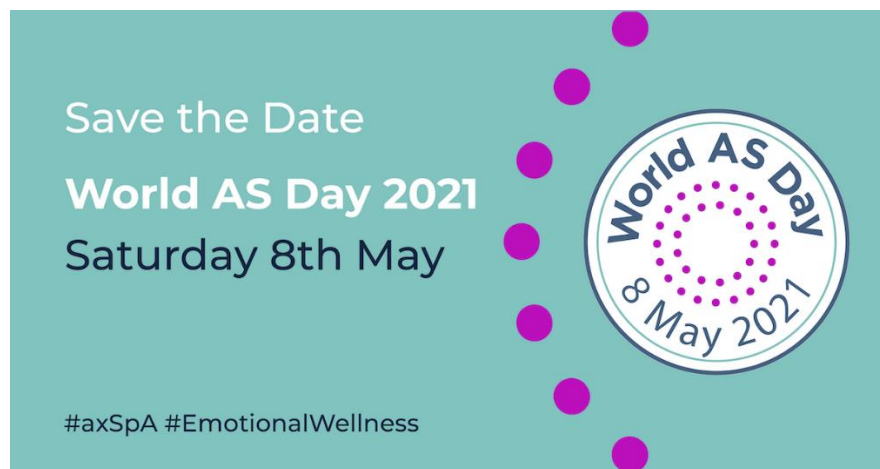
You can see their facebook page [here](#).



**Arthritis Consumer Experts** (ACE) is a Canadian, patient-led organization that provides free, science-based information and education programs in both official languages to people with arthritis. Founded and led by people with arthritis, [ACE's JointHealth](#)™ family of programs and the Arthritis Broadcast Network reaches more than 350,000 Canadians each month. Visit ACE's Website [here](#).

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## Save the Date - World AS Day Saturday 8 May 2021



**Save the Date!**

We will be celebrating World AS Day on Saturday 8 May, 2020. Continuing from the 2020 theme 'Together', this year's theme will be **'Together - axSpA and Emotional Wellness'**

Please join in by using our campaign materials and letting us know what your organization is planning for World AS Day 2021. You can download Save the date templates and the World AS Day logo [here](#)

In 2020, our World AS Day campaign reached a phenomenal number of people around the globe. The Global Spondylitis Summit had registrations in an amazing 71 different countries. Walk Your AS Off teams logged over 96 million steps and our Facebook posts reached over 4 million people.

With your help, we can reach even more people in 2021.

We will launch the full campaign early in 2021 and everything will be available on a dedicated website page. We also intend to hold a webinar (or two to allow for time differences) for members to tell you all about the campaign and how you can use it, share it and encourage your members to take part. We will send you an invitation to that event early in the New Year.

We really would like to hear from you about your plans for World AS Day in 2021, please email Jo Davies on [office@asif.info](mailto:office@asif.info)

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## Walk Your AS Off 2021



Once Again Walk Your AS Off will be back in action in May 2021.

Walk Your AS Off is a walking and exercise campaign to encourage people to be more active. There are teams from all over the world. You can participate as an individual or join or create your own virtual team and count and log your steps throughout May.

All you need to know to participate, join or lead a team will be available through [ASIF's website](#) World AS Day page (going live early in 2021) and social media as well as at [WalkAsOne](#).

We would love to see teams from all ASIF Member organizations take part this year. We will provide full details in our next newsletter.

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## Online Surveys

This year there have been more surveys than normal. But it is important that we take part in them.

The more respondents a survey can attract, the more robust the data is. And we can learn a lot from the analysis of this data - which is intended to help us all.

ASIF and the SAA's survey on COVID-19 and SpA is the only longitudinal survey tracking the effects of the pandemic on the [#spondylitis](#) community. If you are not currently participating, we invite you to be part of this groundbreaking research which could help so many. We are especially looking for household members to participate as well.

You and your household members do NOT have to have contracted COVID-19 to take part. The survey is available in many languages.

You can read about the initial results of the survey below.

[Click here to take part](#)

Professor Laurent Arnaud from the French National Reference Centre for Auto-Immune disease invited us to share with you the newly launched VAXICOV survey. This survey is about the expectations and potential concerns related to the COVID vaccine for patients with autoimmune diseases and their families.

This survey takes 5-10 minutes, is anonymous and has been approved by the Strasbourg Ethic Committee.

[Click here to take part](#)



# Delay to Diagnosis



ASIF's Delay to Diagnosis project focusses on the unacceptable delay in receiving a diagnosis that most patients with axSpA must endure. Through the project, we aim to better understand why the delay to diagnosis occurs; how this affects patients, their families and friends and healthcare systems. Crucially, we must decide collectively what ASIF can do raise awareness and to support our members globally in tackling this burden that axSpA patients face.

The project, which launched early in summer this year, has achieved a lot in a short space of time. Most notably, we hosted two international Global Forum events in the autumn, which were a huge success, and we are very pleased to have received positive feedback from everyone involved. The events brought together patients, researchers, rheumatologists, physiotherapists, and other healthcare professionals to discuss the delay to diagnosis around the world. We were delighted to have participants from Argentina to Australia – and many countries in between! In total, we welcomed 48 delegates from 23 countries across five continents. We thank, in particular our Asian and Australian representatives who had to stay up very late!

Dr Dale Webb, CEO of NASS (the UK patient group) gave a presentation on the existing research evidence and what it tells us about the delay to diagnosis. Included in this is data from the IMAS project, evidence collected directly from patients about living with axSpA. We held break-out discussions during which we collectively explored the reasons that the delay to diagnosis occurs - almost without exception - around the world. In understanding the reasons for the delay, we can start to identify ways to tackle it. We heard time and again from patients of the suffering they had endured in waiting for their diagnosis. But, we also heard about some positive steps taken in certain parts of the world where small projects or schemes had led to some success in reducing the delay.



***Dr Dale Webb presents at the ASIF axSpA Global Forum event on 13 October 2020  
(Click picture to play video)***

We will launch dedicated webpages on the ASIF website very soon, where you can read in more detail about the project and keep up to date with developments. There you will also find resources on the delay to diagnosis, including links to the existing research, videos and infographics that can be tailored to your requirements.

During this initial phase of the project, we have also asked our member organizations to tell us more about the delay to diagnosis in their country and have collated and reviewed the existing research. We are now producing our final report from this stage of the Delay to Diagnosis project; this will be the definitive report on the impact of axSpA globally. We will highlight - most importantly - the burden on patients who wait too long for their diagnosis. This burden statement will be launched in spring of 2021 and we will use the knowledge gathered during this phase of the project to agree what work is most needed in the next phases of the Delay to Diagnosis project.

Stemming from ideas and discussions at the Global Forums and from existing research, we will explore ideas on how to take forward the project. We could look at how to support our members with better messaging to policymakers; we might develop a toolkit that can be tailored by countries to international or regional campaigns; we could help by making videos about the disease symptoms to raise awareness in the general public and alert people to the possibility that they have axSpA.

We will consider a range of ideas and explore how we build a project or program of work around them. Most importantly, we will consult with our members to find out what would be most useful and how they can get involved in the ongoing project. For now, ASIF would like to say a huge thank you to everyone that has been involved so far and we look forward to continuing this essential work. Together, we can – and must - create a better experience for axSpA patients.

We have heard throughout the Global Forums how many barriers we face in reducing the delay to diagnosis. Here at ASIF, we understand that this project should develop and grow to support our members in tackling these obstacles. We thank you again for your participation and look forward to working with you to achieve our goal.



## Few axSpA-patients infected with COVID-19

**Despite concerns of possible risk factors, very few patients with axial spondyloarthritis have been infected with the coronavirus so far.**

***“This is very good news. It looks like axSpA-patients have been protecting themselves, adhering to the advice of the health authorities and taking the risk of infection seriously,” ASIF-president Zhivko Yankov says.***

*By Trine Dahl-Johansen*

COVID-19 has caused global disruptions in the management of chronic illnesses like axial spondyloarthritis (axSpA). The extent to which patients with axSpA have been affected by the coronavirus needed to be established, and Axial Spondyloarthritis International Federation (ASIF), The Spondylitis Association of America and survey company Any-3, developed the international COVID-19 axSpA-survey, which opened in April.

The preliminary results show some of the effects of the pandemic for this patient group and are based on answers through the questionnaire for the period of 3rd April to 31st October 2020. There are 4900 patients across 72 countries who have answered the patient survey. 93 % have completed all the questions.

### **The good news**

Easy interventions like keeping distance, isolating from other people, washing hands, using antibacterial liquid and face masks etc. in public are essential to avoid infections like the coronavirus. Only 4 % of the total survey population report they have had the coronavirus. This is good news, but many of the respondents have not been tested to confirm it and are self-diagnosed. A lot of the symptoms of COVID-19 are very similar to those of an ordinary cold or flu, like fever, fatigue, sore throat and continuous cough. Therefore, it is almost impossible to know for sure if you have Covid-19 without being tested.

Despite the low COVID-19 testing, the low numbers in coronavirus patients amongst the axSpA-group is probably due to many taking the risk of viral infection seriously and doing what they can to protect themselves from such an infection. As chronically ill, many axSpA patients are used to taking illness seriously and making changes when life presents challenges. The ability to adapt to fluctuations in the disease throughout life probably leads to people coping with such a pandemic situation better than many feared.

*"It is still amazing that so few with rheumatic diseases are infected with COVID-19 during this period,"* Zhivko says.

### **Adapting to the situation**

Many might also easily adapt to the rules of isolation and less social activity because they already are limited due to their health challenges in everyday life. For example, those who live with a lot of pain, fatigue and impaired mobility are accustomed to pacing their activities, and many already have a limited level of activity and social life. For many people with axSpA activity regulation is important, so they are able to accomplish the most necessary things.

*"Our members are used to accepting periods where you cannot do everything you want. Many have probably adapted well to the pandemic restrictions and have good skills when it comes to taking care of their own health,"* Zhivko elaborates.

Response to the global coronavirus pandemic has resulted in major changes to how people go about their daily lives. A study presented at ACR 2020 shows that individuals with axSpA with higher levels of stress and anxiety, had significantly higher disease activity levels. [\[1\]](#)

### **Good recovery status**

The low frequency of testing for the coronavirus is a well-known situation internationally, due to variable test capacity worldwide, which leads to a very different situations for each country represented.



Although patient-reported outcomes have limitations, especially regarding the accuracy of self-diagnosis of COVID-19, the current results from the survey may add to more knowledge on potential risk factors and the course of this coronavirus infection in axSpA-patients.

Several international data show there are very few patients with rheumatic diseases who have contracted the virus, and few have been hospitalized or died because of infection. This is the same trend as the axSpA-survey.

Now it is crucial to get more responders to answer the axSpA-survey, *especially* those who have been tested for COVID-19, regardless of whether they have a positive or negative test result. It will provide the survey with better data and higher credibility.

*"I encouraged all ASIF-member organizations to invite more people to respond to the survey,"* Zhivko says.

**The following link allows new participants to self-register:**

[Click here to take part](#)

### **Similar risk factors**

The risk factors for people with autoimmune diseases are the same as for the general population. Those who also have cardiovascular disease and get infected with the coronavirus often have a tougher course, and are at higher risk of death, but they are not at a higher risk of getting infected overall compared to the normal population, according to The COVID-19 Rheumatology Alliance. [2]

This is supported by more studies released during the digital EULAR-congress in June.

*"The study shows that most patients with rheumatological conditions recover from COVID-19, independent of the medication they receive,"* professor Dr. John Isaacs, Chair of the EULAR Scientific Committee stated in a press release. [3]

### **Some concerns**

The preliminary results of the axSpA-survey also enhance some worries regarding some patients discontinuing their medications during these months, often without consulting their rheumatologist. Amongst the patients with more severe disease measured by BASDAI the percentage of those discontinuing their medications also increases. The data show that amongst those who measured between 6 and 10 on the BASDAI-scale from 1 to 10, 19-28 % had changed their medication in fear of COVID-19. This is a big concern because this might lead to flare-ups that requires a doctor's appointment in a health system already overloaded.

In total 17 % of the 4900 respondents report they have changed their medications due to the concern of COVID-19. In the age groups 20-29, 30-39 and 40-49 more than 20 % have done this. Type of spondyloarthritis diagnosis does not seem to influence this decision. Neither do other diagnoses believed to affect the coronavirus, like high blood pressure, chronic lung disease, diabetes, heart disease and heart failure, systemic lupus or cancer.

The answers about changing medication reflect the huge worry many with axSpA faced when the pandemic was a fact in the beginning of 2020 and when there was little information about

immunosuppressive medications and the risk of contracting the new virus. Both rheumatologists and patients were in doubt of what to do regarding medications, and this continued for several months.

An American based survey, answered by rheumatologists, was presented at the ACR Convergence congress in November 2020. A third of the respondents indicated that at least 10% of their patients had self-discontinued or reduced at least one immunosuppressive medication to mitigate their risk of COVID-19. [4]

*"In the early months of the COVID-19 pandemic, patients with RA, PsA, AS, and SLE frequently avoided office visits and laboratory testing. (...) Participants often stopped medications without the advice of a physician, and medication interruptions were more common in participants without access to telehealth",* another ACR-abstract reveals. [5]

### **Knowledge is key**

Even some rheumatologists were uncertain if patients should sustain their treatment because there were no recommendations due to the brand-new virus.

*"There is considerable uncertainty about the drug management in the context of rheumatic conditions,"* EULAR-president professor Dr. Iain B. McInnes explained in a press release in June.

According to another poster session at ACR, a national American sample of rheumatologists answered a survey in the period of April to August this year. It revealed there are still variations regarding perceptions of patients' risk of COVID-19, and how to manage medications such as NSAIDs, biologics and steroids during the pandemic. [6]

After many months and several studies, it is now well established there is currently no evidence to suggest that there are grounds for stopping or slowing down ongoing immunosuppressive therapy, i.e., treatment that suppresses the immune system, including disease-modifying medications (DMARDs) such as methotrexate and TNF-inhibitors. [7] [8]

In hindsight studies show that both the HLA-B27 gene and the use of some biological medications (bDMARD) might in fact be protecting axSpA-patients from contracting the virus and lead to a less difficult course of the disease for those who do become infected. The majority of patients do not require hospitalization, even if they use immunosuppressive drugs.

*"It is reasonable that patients with inflammatory diseases treated with b/tsDMARD (biologic, targeted disease modifying anti-rheumatic drugs) continue their treatment during the COVID-19 epidemic. The different rates of hospitalization based on the diagnosis or DMARD may be due to comorbidity, confounding by indication and other bias,"* one ACR-abstract concludes. [9]

If you do get infected with COVID-19, standard procedures for other types of infections apply. You should discontinue or postpone the medication until you recover from COVID-19, consistent with guidelines on the management of patients with active infections on biologic therapy. [10]

The SAA's initial findings from the survey data can be found on the [SAA Website](#)

[1] <https://acrabstracts.org/abstract/disease-activity-in-an-axial-spondyloarthritis-cohort-during-the-covid-19-pandemic/>

[2] <https://rheum-covid.org/epidemiology-and-outcomes-of-novel-coronavirus-2019-in-patients-with-immune-mediated-inflammatory-diseases/>

- [3] [https://www.eular.org/sysModules/obxContent/files/www.eular.2015/1\\_42291DEB-50E5-49AE-5726D0FAAA83A7D4/eular\\_press\\_release\\_covid\\_registry\\_final.pdf](https://www.eular.org/sysModules/obxContent/files/www.eular.2015/1_42291DEB-50E5-49AE-5726D0FAAA83A7D4/eular_press_release_covid_registry_final.pdf)
- [4] <https://acrabstracts.org/abstract/geographical-variations-in-covid-19-perceptions-and-patient-management-a-national-survey-of-rheumatologists/>
- [5] <https://acrabstracts.org/abstract/concerns-and-behaviors-of-patients-with-common-autoimmune-rheumatic-diseases-in-the-united-states-early-in-the-covid-19-pandemic/>
- [6] <https://acrabstracts.org/abstract/geographical-variations-in-covid-19-perceptions-and-patient-management-a-national-survey-of-rheumatologists/>
- [7] <https://diakonhjemmetsykehus.no/nyheter/korona-informasjon-til-pasienter-med-inflammatorisk-revmatisk-sykdom#er-det-spesielle-forholdsregler-hvis-du-far-infusjonspreparater>
- [8] <https://spondylitis.org/research-new/covid-19-and-spondyloarthritis-your-questions-answered/>
- [9] <https://acrabstracts.org/abstract/use-of-biologic-treatment-and-risk-to-be-admitted-for-covid-19-infection/>
- [10] [https://www.jaad.org/article/S0190-9622\(18\)33001-9/fulltext](https://www.jaad.org/article/S0190-9622(18)33001-9/fulltext)

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# IMAS

International  
Map of Axial  
Spondyloarthritis

The International Map of Axial Spondyloarthritis (IMAS), a patient experience survey, continues to be a hugely important project for everyone involved in the axSpA community.

The project has produced a wealth of information, which is being used globally to raise awareness, support our advocacy efforts and, ultimately improve the lives of people living with axSpA. The IMAS team have been working hard on disseminating information on the issues identified through the data. They have so far produced a variety of reports and papers on issues ranging from psychological distress; the impact on work and social life; how people manage their disease and, of course, why it takes so long to diagnose axSpA.



Whilst the project was running in Europe (EMAS), 2840 patients from 13 countries completed the survey. We eagerly await the full report of EMAS, which is due to be published early next year.



As well as the European countries, the survey has also now closed in Canada, Taiwan and South Korea – with responses from a further 800 patients.

And IMAS continues to grow! The survey is currently open in Turkey and four Latin American countries, Mexico, Colombia, Argentina, and Costa Rica. We are working hard to maximize the number of people who complete the survey in these countries; and are looking to make sure as many axSpA patients as possible know about IMAS.



On top of these countries, IMAS is expanding further into



six new countries; USA, Philippines, India, South Africa, Algeria and Lithuania – ensuring that this is truly an international project that delivers robust global data to everyone involved in the fight against axSpA.

Patients in these six new countries will be invited to complete the survey from early 2021. IMAS will also be

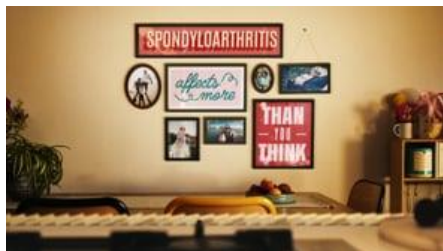
relaunched early next year in the UK, where the aim is to significantly improve on the number of respondents from the first round of the survey.

Alongside the survey itself, the IMAS team continue to work hard on disseminating information gained from the data. Early in 2021, we will invite all the Patient Organizations involved in IMAS to a meeting to discuss how we can best use the data to support their work and what work we can do that will be of most value to ASIF's members. With this in mind, we are already beginning some IMAS sub-projects; one is to identify the most powerful public affairs messages, so that we can support our members with information and statistics to lobby and approach policymakers. Another project will bring to life some of the IMAS data through patient videos; we will ask patients to talk about their personal experiences of axSpA, viewed through a particular lens - such as how the disease has affected their career or how they coped with their diagnosis.

For more information on IMAS, you can visit the [IMAS page on the ASIF website](#) or you can contact [Jo Lowe](#), ASIF Project Manager.

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## It's All Connected



This film helps us to see the knock-on effect of untreated SpA symptoms and how they can increase the burden of the disease for patients. This highlights the need for Healthcare Providers to work together with patients to recognize untreated SpA Symptoms and help to reduce their impact.

[\(Click picture to play video\)](#)

It's All Connected is a multi-channel campaign for Health Care Providers and Patients.

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It aims to re-frame the conversation around SpA (Axial Spondyloarthritis and Psoriatic Arthritis) in order to drive a better standard of patient care.

The campaign was co-created with Lilly and an associated steering committee of Healthcare Providers and Patient Representatives.

If you would like to use this video locally, to add a translated voice over or subtitles and to ensure that local rules and regulations are met before you launch the campaign locally, please contact Jo at [office@asif.info](mailto:office@asif.info) and she will put you in touch with your local Lilly representative.

There will be more material to go with this campaign available soon – infographics and social media material. [Watch this space!](#)

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## News from South Africa and a name change

Being part of a patient support arm has never been more important than this year. The constant isolation created a bigger need for patient support and education.



South Africa has been in lock-down since March this year. This has no doubt been a topsy-turvy year for us all, creating more anxiety and fears among our members.

Being the new kid on the block, we have had to do a lot of groundwork to see any movement. With no financial support in any shape or form, and no awareness of AxSpa in our country, this will be a long journey.

This journey is reaping rewards as we are being noticed not only by top specialist in our country, but we will also become part of local studies at Universities.



*(Click picture to play video)*

We are proud to announce the registration of our new name, and our association. To celebrate this moment, we had a live interview with Michael Mallinson, which was also a first for our association to have international live collaboration. He explained in amazing detail the reason for the name change and shared his knowledge with our members.

***Maranda van Dam asks Michael Mallinson to explain why we are using the term Axial Spondyloarthritis***

We have seen a steady increase in our membership throughout the year. Social media remains our preferred mode of communication. This pandemic has brought a lot of people to their screens a lot more, which gave us a fantastic platform to work from. We will see an increase in Zoom platforms starting in 2021.

Following the Delay to Diagnosis Forum, we asked our members to fill out some basic questionnaires; more than 90% of our members requested emotional support. This leads us to believe that our role as Patient Support is becoming more and more important.

Our overwhelming theme for 2021 will be the Voice of the Patient. We will be having various live interviews with our members and encouraging open and free communication to talk about the great emotional burden that is part of this disease. Together- AxSpa and Emotional Wellness will be our main focus for the new year.

With only the second country in Africa that has this support, we hope to become a leader in our continent, and set a fine example to create awareness and support our members.

A special note of thank you to Jo Davies, Jo Lowe and Michael Mallinson, who have been in constant contact. Starting out a new association from ground zero could become daunting but has been a lot easier with this support.

Wishing you all a lovely Festive Season.

**Maranda van Dam, Leader, ASAS**



## From Stretching to Baking, NASS has done more online in 2020

As we come to the end of 2020, everyone would agree that Covid-19 has changed our lives beyond recognition. One positive thing is the way that many people have adapted to new ways of working and socializing with friends, using technology in ways that are new and innovative. From online Zoom quizzes to remote working, technology is now part of our lives in a way that would have been unimaginable just 12 months ago.

Things during 2020 have been no different here at National Axial Spondyloarthritis Society (NASS). At the beginning of lockdown in the Spring we quickly realized that we would need to change how we provide support and advice to thousands of people living with axial SpA (AS). With many NASS branches unable to meet in person and some people not feeling confident about stepping-outside, we quickly adapted to a new world. We are particularly proud of [My AS My Life](#), a hub of online self-management resources that anyone can use to help them take control of their axial SpA (AS).

My AS My Life is home to a mix of videos, guides and blogs covering subjects as diverse as mindfulness, tips for managing remote appointments with healthcare professionals and managing neck and shoulder pain. There is also a suite of new videos on our [YouTube channel](#), where you can find playlists that cover topics from Pilates, to emotional well-being and stretches to help you with daily life.

One of the innovations we are most proud of are our hugely popular Facebook live sessions. Often run-in partnership with healthcare professionals, over the past few weeks we have run sessions on sleep, jaw pain and an introduction to HIT exercises. Keep an eye on our [Facebook page](#) for details of the session, that you can either watch live or watch on catch-up.



One of our most popular sessions live on Facebook, has been Great British Bake-Off's James Hillary's online sessions. To wrap up the year, James has kindly agreed to host a Christmas bake-along live on Facebook on Saturday 19th December, where you'll get the chance to bake his Chewy Amaretti Christmas Cookies, alongside the master. Anyone can join us for the session at 3pm, and don't forget to visit the event listing on the [NASS Facebook](#) page to get the ingredients list ahead of the session.

## Art Apple A Day

On October 1st this year, it was 10 years since Jennifer Visscher created her first **Art Apple for A.S.** You may know Jennifer as the founder of Walk Your AS Off and Walk AS One.

Her story is like so many who have axSpA. It's about the challenges faced when our health becomes compromised and severe pain and fatigue invades our bodies. As well as the struggle finding a diagnosis and treatment can be long and difficult.



Jennifer wondered how she could share her story to help others. Ten years is too long to be in such pain and basically disabled. She wanted to share about the disease, but she wanted to share hope most of all so she came up with the idea to use art as a way to focus herself and gain interest by others in learning about axSpA.

"Art Apple A Day" was created!

Each and every day for a full year, via her blog and social media, she created and shared a piece of apple art along with stories of challenges, thoughts, successes, and some days all she could manage was creating the artwork. Her apples became a vehicle to discuss difficult topics in a mostly positive manner and to her surprise she also found friendships online with so many amazing people who understood what she had gone through because they too had axSpA. Over the course of the year and since that first apple, the community of strong, courageous, and loving people become like family.



On the 10th anniversary of the very first apple, Jennifer is once again posting her thoughts looking back in a retrospective year of the “Art Apple A Day” project. She has new insights and is enjoying the reflection of the past as well as reconnecting with the community. Jennifer is also creating a new apple each month for a calendar she’ll be releasing for 2022 to help raise funds for the various axSpA non-profits like ASIF.

You can find Jennifer's apple posts [here](#), on [Facebook](#) at or on [Instagram](#) and she hopes you'll stop by and say hello!

## News from ACR Convergence

Dr Uta Kiltz, ASIF scientific Advisor, attended ACR Convergence, this year all virtual. Uta reported there were many interesting abstracts on axSpA and related diseases at the congress. Abstracts can be found on the [ACR Convergence website](#).



Some key topics to note were:

**Inheritance:** [M Khan et al: Genetic influence on occurrence of axial SpA:](#)

Based on data from a Swiss Study conducted over 35 years of patients clinically diagnosed and their first-degree relatives. Research showed a high recurrence rate in first degree relatives. HLA-B27 positive mothers are more likely than fathers to have affected children.

**Extraspinal and extraarticular manifestations:**

[C Lopez-Medina: Identification of the clinical phenotypes in patients with axial SpA, peripheral SpA and PsA according to peripheral musculoskeletal manifestations:](#)

The international PerSpA study showed that the pattern of peripheral manifestations is very heterogeneous. Patients with psoriatic skin manifestations have a higher risk to have peripheral arthritis.

[G Fitzgerald: Time dependent analysis of incident extra-articular manifestations:](#) Research from Canada showed that presence of uveitis increases with age but psoriasis and IBD did not show this increase. Both manifestations were quite stable after reaching a plateau beyond year 3 after diagnosis.



## Treatment

Various presentations on JAK Inhibitors: Filgotinib, Tofacitinib and Upadacitinib showed a good efficacy in patients with r-axSpA. Safety profile in r-axSpA studies was comparable to those reported for patients with rheumatoid arthritis. None are approved by FDA or EMA but approval is anticipated for 2021.

Various presentations on Bimekizumab, an IL-17 A inhibitor. BKZ, a monoclonal antibody that selectively inhibits interleukin (IL)-17A and IL-17F showed a good efficacy in patients with r-axSpA in a phase 2a study with long-term effects up to 96 weeks. Safety profile comparable to other IL-17 inhibitors. Another study showed BKZ showed clinical improvements in joint and skin outcomes and favourable safety profile in patients with active psoriatic arthritis (PSA)

[Bimekizumab Improves Patient-Reported Outcomes in Psoriatic Arthritis](#)  
[Bimekizumab Long-Term Efficacy and Safety over 96 weeks in Patients with AS](#)



We are delighted to welcome three new members to the ASIF Team....



**Lillann Wermskog** was elected as an ASIF Trustee in June 2020. Lillann has had ankylosing spondylitis since she was in her early twenties, but the symptoms started when she was 11 years old. She has been a Board member of Spafo Norge, one of two ASIF association members in Norway, since 2015 and is now the leader. She has also been writing articles for the member magazine Spondyltitten since 2008. Read more about Lillann [here](#).

**Jo Lowe** joined ASIF as Project Manager in September. She is working initially on IMAS and Delay to Diagnosis.

Jo was born in Manchester, UK - but now lives in Portugal. She has worked in a variety of healthcare research roles at The University of Manchester, including project managing clinical trials and studies involving healthcare workers in the NHS.



Jo has worked extensively with patient groups and is passionate about ensuring the patient voice is always heard. She brings to ASIF a wealth of experience, along with a desire to better understand the experiences of people living with AxSpA globally and a desire to help improve their quality of life.



**Thierry Vannier** was appointed as a Trustee of ASIF and as our Treasurer in November.

Thierry has been Secretary of Action contre les spondyloarthrities (ACS) for 10 years . Thierry is a very experienced in business and has been Treasurer of another organisation for four years.

Read more about Thierry [here](#).

You can see the full ASIF team on the [website](#)

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ASIF is grateful to its industry partners:

