

**Report on the 14th ASIF Council Meeting**  
**Scandic Copenhagen Hotel, Copenhagen, Denmark, 29-31 May, 2022**  
**By Michael Mallinson**



ASIF is pleased to present this report on the 14<sup>th</sup> Council Meeting, held four years after the 13<sup>th</sup> Council Meeting because of the global SARS-CoV-2 (Covid 19) pandemic that started in late 2019. The opportunity to meet face-to-face after the pandemic was embraced by nearly 40 representatives from 23 member organisations. The wonders of technology allowed an additional five representatives from two other member organizations to participate in the meeting remotely. We also opened a few sessions to our corporate partners so they could understand more about ASIF, its members and what we do.

**Sunday, 29 May, 2022: Arrival of delegates**

Delegates, observers and guests arrived throughout the day in time for an evening reception at the Scandic Copenhagen Hotel. The reception was an opportunity for everyone to get together, greet old and make new friends and to meet, for the first time face-to-face, the staff of ASIF; Jo Lowe, Project Manager, Joanne de Bry, Communications Manager and Valeria Tassi, Administrative Assistant. Unfortunately, Jo Davies, Executive to the Board, was unable to be with us in Copenhagen due to a recent operation. The reception was followed by a dinner in the hotel.

## Day 1 - Monday, 30 May, 2022



The day started with an optional exercise programme lead by Iryna Bublik and breakfast. The Council Meeting was held in a conference room at the hotel, the walls of which were adorned with posters prepared by many members on the mission, vision, work or projects of their organization. You may view the posters [here](#).

The Council Meeting was officially opened at 9:00 am by Zhivko Yankov with the President's Welcome and introductions.

### **Presentation: The Current state of ASIF**

**By Zhivko Yankov, President of ASIF**

President of the Bulgarian Ankylosing Spondylitis Patient Society

Zhivko gave a report on the current status of ASIF and how it has grown and improved since 2016, noting that if you want to change the world you have to first change your behaviour and then watch the world change. Changing behaviour starts with small steps. Zhivko outlined those steps over the past few years, all taken to change and improve the world for people living with axial spondyloarthritis.

**Membership.** Membership has increased by 18 or 44% to 52 member organizations from all continents since 2016.

**Organization of ASIF.** A chart showed the organization of ASIF, including nine Trustees and Officers, four staff, two Scientific Advisers, one volunteer plus external support from ASIF's accountant, auditor, human resources specialist and lawyer. Also included on the chart were the four Sub-Committees and their leaders.

**ASIF Objectives.** ASIF's objectives are driven by the requirements of its members. They are:

1. Exchange of information and experiences throughout member societies.
2. Co-operation in international research projects.
3. Exchange of articles in publications of member societies.
4. Support for the development of newly formed societies.
5. To make contact with axSpA stakeholders where a domestic society does not exist.



Zhivko gave a report card on each objective over the years 2018 and 2020-2022 inclusive, recording that:

1. ASIF's website is much improved, is interactive with new sections and updated information.
2. IMAS (International Map of Axial Spondyloarthritis survey project) is the primary international project with over 4,300 participants to date.
3. There are regular ASIF newsletters with value-added content and more contributions from members.
4. ASIF has started webinars and projects to support members.
5. Discussions opened with ASAS (Assessment of Spondyloarthritis International Society) with a view to a closer relationship and co-operation on reaching stakeholders in the axSpA community.

**Trustees' Agenda.** The trustees' agenda and report card over the past six years are summarized below. Zhivko noted again that the Trustees' agenda is driven by the wishes and suggestions of members.

1. **Staff.** In 2016 ASIF was all-volunteer with no staff. In 2017, the Executive to the Board was hired. A Project Manager and Administrative Assistant were added in 2020 and a Communications Manager in 2021.
2. **Newsletter.** In 2016, there was no regular newsletter. Regular quarterly newsletters commenced in 2017 and today the newsletter has member-input, and is used, often translated, by member societies to inform their own members.

- 3. Constitution.** In 2016 a new constitution was drawn up. This was finalized in 2017, when ASIF was registered as a charity in the United Kingdom. The Constitution was amended in 2019 with ASIF's new name.



- 4. Scientific Adviser.** In January, 2018, Dr. Uta Kiltz accepted ASIF's invitation to become a Scientific Adviser, replacing Prof. Dr. Ernst Feldtkeller who retired in 2016.

- 5. Global awareness and World AS Day.** ASIF's efforts for World AS Day greatly improved in 2018 and

have continued to improve since. World AS Day now has many countries and participants creating increased awareness of axSpA.

- 6. Quality Management System.** During 2020 and 2021, new policies were drafted and approved, and are working well.

- 7. Collaboration and Development Tools.** A membership notice board was added to the website in 2018 but was not used. This is under discussion and review and has been included in the new Strategic Plan.

**Trustees' Agenda for the Future.** Zhivko presented the Trustees' Agenda for the years 2023-2028. It includes seven objectives, intended to change the world:

1. Grow, strengthen and empower the community.
2. Support member advocacy, communications and capacity building.
3. Increase ASIF's understanding of the global axSpA landscape.
4. Foster partnerships with medical societies, researchers, global patient organizations working in related disease areas, global policymakers, etc.
5. Raise global awareness.
6. Enhance ASIF's performance and increase capacity.
7. Increase ASIF's financial sustainability.

**Trustee Meetings.** There is a responsibility for Trustees to meet regularly to deal with decisions and give staff directions. Trustees have been meeting monthly online and have given support and guidance to staff in developing the Strategic Plan, incorporating the objectives above. In view of the progress made over the past few years, Trustees have been doing their job and decisions have been made in a timely fashion.

### **Trustee - Member Communications.**

- 1. Newsletters.** Zhivko noted that the content and value of the newsletter to members has improved significantly due to their engagement. He further noted that the content of the newsletter is not meant just for the ASIF representative or executives of member societies, and encouraged them to share content with their membership, translating the newsletter where necessary.
- 2. Sub-committees.** There are four sub-committees, reflecting four major projects. There had been six sub-committees, but as staff were hired, the sub-committees for Communications and the AGM and Council Meetings became redundant. Zhivko advised the Trustees highly recommend member societies nominating people from their organizations to sit on the sub-committees. He also advised the sub-committees are producing very positive output useful to Trustees and staff alike.

**Website.** Zhivko addressed the development of the website and stressed its importance as the face of ASIF to the world. Over the past three years new sections have been added to provide information on ASIF projects and content that members can use. The website is being up-dated regularly.



**Project Updates.** Zhivko gave a quick update (they are dealt with in more depth later) on ASIF's four major projects: World AS Day, IMAS, Delay to Diagnosis and Talk to be Heard.

**Trustee Succession Plan.** Zhivko gave an overview of ASIF's Trustee succession planning. There are three Trustees who will be stepping down at the end of their terms in 2023 and another two in 2024. The Trustees have laddered terms so that



there is not too much turnover every year. There is a recruitment plan in place for 2023. Zhivko encourages members to submit applications for Trustee positions, and more importantly, to nominate people to sit on sub-committees. Sub-committee experience will be useful in getting to know ASIF and in learning its workings for anyone hoping to be a Trustee.

In closing his review of the state of ASIF, Zhivko stressed the importance of clear communications, not only between Trustees and members, but also between Trustees, staff and stakeholders.

### **Presentation: Welcome to Denmark and Foreningen for Rygsøjlegigt og Morbus Bechterew**



Merian Brastrup Clasen, representing Foreningen for Rygsøjlegigt og Morbus Bechterew (The Danish Association for Spine Arthritis and Ankylosing Spondylitis), welcomed everyone to Denmark and gave a brief review of the Danish association. It has 1,000 members (out of a possible 50,000 people diagnosed), was founded in 1973 and is divided into nine regions.

The Association has a Facebook group with 1,857 members. Its main activities are producing a quarterly magazine for members, together with handbooks and flyers for new patients, hospitals and physiotherapists. The Association also runs booster camps (exercises and topics of interest), lectures and excursions for members.

The future focus of the Association is on attracting more members, particularly young people and the newly diagnosed; collaborating with doctors and the medical industry, and helping members by offering activities and new information.

## Presentations: ASIF Project Updates

### 1. **Delay to Diagnosis** presented by **Raj Mahapatra**

Trustee, ASIF and Chair of the National Axial Spondyloarthritis Society, U.K.,  
Chair of the ASIF Steering Committee on Delay to Diagnosis.



Raj provided a brief recap of what the Delay to Diagnosis project is about. It is to focus on the considerable and unacceptable delays in diagnosing axSpA patients globally. Its ambition is to support action that can help reduce delays through three steps:

- Understanding of the global impact of axSpA diagnostic delay.
- Mapping the key barriers to diagnostic delay.
- Identifying opportunities for addressing these barriers through a partnership of ASIF and its members.

The overall objective of the project is to help create a future where no-one living with axSpA has to wait several years for a diagnosis.

And what is the progress of the project to date? In the autumn of 2020, ASIF held two global forums bringing together patients, patient organizations and health care professionals, representing 24 countries on five continents, to explore different perspectives on delays to diagnosis. The insights from the forums helped inform the Delay to Diagnosis Report that was released in June, 2021. The Report drew on the latest academic and clinical research and featured contributions from 28 clinical and patient experts. The Report sets out a global call to action on the impact of diagnostic delays and the importance of addressing them.

Raj also set out a recap of the Report. It contains four key sections:

- What is axSpA and the impact of diagnostic delay?
- The identification of six barriers to timely diagnosis.
- Five recommendations for change.
- Showcases four case studies from different countries where best practices have shown practical success in reducing the delay to diagnosis.

It is worth setting out the six barriers to delay identified in the Report:

1. Limited awareness of axSpA amongst those with symptoms.
2. Lack of axSpA understanding amongst the general public.
3. Incorrect or misdiagnosis at the first point of healthcare system contact.
4. Pathway and referral challenges.
5. Challenges in accessing specialist care.
6. Challenges within rheumatology.



Following the launch of the Report, ASIF established a new Steering Committee to provide independent and expert advice to guide the next steps of the project and establish how the findings of the Report can be put into action. The Steering committee is comprised of 14 members, including six internationally renowned rheumatologists, patient advocates

and ASIF staff.

The first meeting of the Steering Committee was in March, 2022 and was in the form of a workshop with three aims:

- To reach agreement on the strategic focus for the Delay to Diagnosis work program, a key part being to explore how to prioritize the six barriers to timely diagnosis.
- Exploring at what level (global/national) advocacy work should take place.
- Identify priority activities that can be taken forward in 2022-23.

The overall objective of the workshop was to develop a Delay to Diagnosis strategy and 2022/23 work plan informed by the steering committee and ASIF members through the workshop scheduled for Day 2 of the Council Meeting.

The Steering Committee identified three Barriers which it thought ASIF could be most effective in helping reduce the diagnostic delay. The first of these were Barriers 1 & 2, put together because they both concern awareness and ASIF can address any proposed activities for both at the same time.



The second was Barrier 3 (incorrect/misdiagnosis at the first contact with the healthcare system) and the third Barrier 6 (challenges within rheumatology).

The Steering Committee reached a consensus on what level advocacy efforts should be focused. As a global organization, ASIF can play a key role in developing global resources that its members can adapt to suit their local health care system and circumstances. There was a consensus that resources and activities developed by ASIF will help offer a consistent global approach to advocacy, but such resources should be developed to allow enough flexibility so they can be adapted differently by member organizations. There was also a consensus that ASIF should develop as many tools as possible to help members.

Raj asked the question, what would help address the barriers? In the case of Barriers 1 & 2, ASIF could develop 'how to' tool kits for use by members in their awareness campaigns. The development of materials and case studies, videos and testimonials demonstrating how people living with axSpA can thrive will help support member organizations in raising awareness of axSpA as a condition and help change perceptions about it.

In the case of Barrier 3, the Steering Committee identified several activities to improve GP education by focusing on symptoms and the importance of early referral. Some of the proposed activities are information programs, assisting setting up workshops and engaging with relevant professional groups. In regard to training, activities should focus on a greater recognition and inclusion of axSpA in undergraduate and graduate programs. There is a powerful role for personal case studies here too. ASIF can play a role in the development of diagnostic guidelines and algorithms, particularly in the primary care setting.

For Barrier 6, the Steering Committee came up with three areas that ASIF could assist in; supporting education and awareness of axSpA amongst rheumatologists, particularly through articles in media specific to rheumatology; helping create a perception of rheumatology as an attractive speciality and promoting the specialty; focusing on diagnostics, particularly the ability to interpret imaging results in the context of axSpA and including clear advice in the interpreting of biomarkers, drawing on the latest accepted evidence.

In summary, Raj gave five activities for ASIF to focus on in its Delay to Diagnosis work program.

1. The development of materials, resources and guidance for member organizations to use in awareness raising campaigns in their countries.
2. Researching, and using existing research where available, a figure for the economic cost of delay to diagnosis.
3. Developing best practice examples and resources highlighting successful initiatives from across the world addressing the delay to diagnosis, and giving guidance on how they can be replicated.
4. Supporting engagement with health care professionals at a country level to raise awareness in key specialities.
5. Promoting rheumatology as a speciality to address capacity challenges.

Finally, Raj listed three questions to be considered for the ‘Reducing the Delay to Diagnosis’ workshop to be held on Day 2. These are found later in this report.

## 2. World AS Day 2022, presented by Jo de Bry, Communications Manager, ASIF.



Jo started by saying that the theme for this year’s World AS Day was axSpA Awareness in general. The campaign was created and developed by the World AS Day sub-committee and PlatformCan, a creative agency that has been engaged for previous World AS Day campaigns.

ASIF provided its member organizations with a campaign toolkit hosted on the ASIF website, consisting of key messages, creative assets, new logo, social media posts, blank templates, social media covers, website banners and a Healthcare Practitioners’ leaflet. It also held two well-attended webinars for members to explain the World AS Day campaign and to answer any questions.

Key aspects of the campaign included the popularity of symptom checkers provided by member organizations, the Leave Your Footprint message board,

Walk Your AS Off, the Spondylitis Association of America’s Global Spondyloarthritis Summit and the social media wall on the ASIF website.

Jo advised that to obtain reach on social media posts, it is necessary to pay to boost the posts. The outcome of paying to boost posts resulted in some impressive numbers.

<b>Platform</b>	<b>Posts</b>	<b>Reach</b>	<b>Engagement</b>
Facebook	36	4.5 million	1 million
Instagram	33	5.9 million	400,000
Twitter	28	1.8 million	41,000
Linked In	7	1,300	63 website link clicks
<b>Tik Tok</b>	<b>3 videos</b>	<b>1,670</b>	<b>30 reactions</b>

The Linked-In account had been opened just before the campaign started, to try to reach rheumatologists and healthcare professionals, as had the Tik Tok account, opened to try to reach a younger demographic.

During the campaign there were many social media posts in several languages using templates provided to members. Additionally, individuals and some organizations posted about World AS Day on their own channels and using their own graphics. Many of these posts were placed on the social media wall on ASIF’s website.

The Leave Your Footprint feature allowed anyone, during the month of May, to go to the webpage, select the colour of their footprint and post it, with a message of

support or encouragement. The footprints appeared on clouds that later took the form of the continents.

The Global Spondyloarthritis Summit attracted 3,124 registrants (2,000 of whom had axSpA) from 103 countries. ASIF is proud to have sponsored the translation of the presentations into 12 languages, while the Spondylitis Association of America produced the Summit in English and Spanish. ASIF is thankful to its members for assisting with some of the translations. The most popular sessions were 'Arthritis and Nutrition' and 'Exercise, Physical Activity and Staying Active with AxSpA'.

ASIF maintained a virtual booth at the Global Spondyloarthritis Summit. It received 120 visitors and there were 170 downloads of documents, the documents having been largely provided by members. There were also 230 views of the Talk to be Heard video.



335 participants in 45 teams from 41 countries participated in Walk Your AS Off this year. The number is reduced from 2021 but comparable with 2020. As of the date of the presentation, some 39.8 million steps had been recorded. The Walk ends on May 31 so still has a day to go. (Note: Because steps could be logged until June 4, the final number of steps logged exceeded 89.3 million!)

Jo highlighted a few World AS Day activities from around the world:

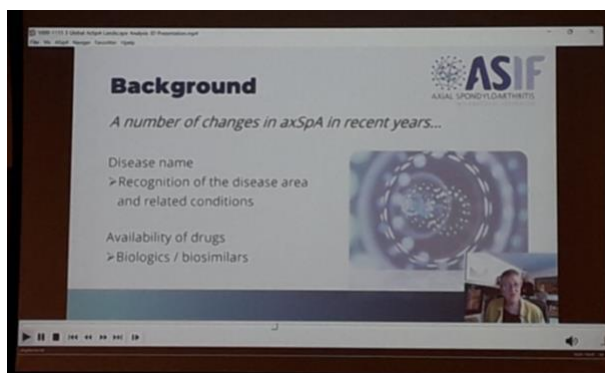
- In South Africa, Maranda was interviewed on the radio and the interview became a podcast.
- In Norway, Spafor Norge broadcast a video from Felix Baldaauf, a Greco-Roman wrestler who has represented Norway internationally.
- The Ankylosing Spondylitis Association of the Philippines held a medical mission offering free check-ups.

Jo is interested in hearing from more members about what they did for World AS Day, what they tried, what worked and what didn't work. And also, importantly, Jo would like suggestions for the theme of World AS Day next year, which falls on May 6, 2023.

Jo ended her presentation by showing an animated wrap-up video on Leave your Footprint and by thanking ASIF's industry partners for their sponsorship and for participating in World AS Day by creating social media posts, running Facebook Live sessions with healthcare practitioners, entering teams in Walk Your AS Off and by raising awareness of axSpA amongst their staff and customers.

### 3. Introduction to the Global Landscape Analysis

Presented by Jo Davies, Executive to the Board, ASIF.



Jo spoke of a proposed new project, a global axSpA landscape analysis, to set the scene and allow everyone to gather thoughts about the proposed project for the workshop on it to be held on Day 2.

By way of background, there have been a lot of changes in our disease area over the last 10-20 years, not the least of

which is the recognition of non-radiographic axial spondyloarthritis (nr-axSpA) which has prompted some organizations like ASIF to change their names. But not all have done so. ASIF is not sure which member organizations support patients with nr-axSpA, or if they also support patients with psoriatic arthritis or other related spondyloarthritis conditions. ASIF doesn't know much about access to treatments and drugs around the world, particularly to biologics and biosimilars, or about access to rheumatologists or specialist rheumatologists, or where in the world healthcare systems and health insurers do not recognise nr-axSpA. There is no central record of these types of information.

The objective of the proposed project is to increase knowledge of axSpA globally. Such knowledge would help ASIF and others develop projects to identify potential areas of work and unmet needs and provide member organizations with information that might support causes in their own countries.

The possible areas of focus for the project could be:

- the recognition of nr-axSpA by patient organizations and healthcare systems.



- Who has access to treatments and drugs, particularly biologics/biosimilars?
- Who has access to rheumatologists and specialist rheumatologists?
- Are there other country-specific challenges?

For the workshop on Day 2, these are considerations to be discussed:

- What information is useful or of interest to be collected at a global level?
- How detailed should the information be? If it's too detailed it could be costly or difficult to gather and manage.
- Is information more useful if it is easily gathered and can provide a dynamic data set?
- Identify gaps in knowledge that it would be useful to include.

Further considerations for the workshop are:

- Would a global axSpA landscape analysis be useful to you?
- How do you see it being used in your country?
- What information would you like to see included?
- Is there anything specific to your country in axSpA recognition, prevalence or treatment?

#### **4. Presentation: IMAS Global Dataset By Prof. Marco Garrido Cumbreira**

Health and Territory Research, University of Seville Scientific Adviser, ASIF Trustee, CEADE - Coordinadora Española de Asociaciones de Espondiloartritis



Marco noted that the preliminary global data analysis from IMAS is still ongoing and is not to be publicly communicated as yet. The complete data set will be released in due course and properly communicated.

IMAS, the International Map of Axial Spondyloarthritis, came about because little was known about living with axSpA from the

patient's experience and perspective, plus there was limited awareness among key stakeholders of the impact on patients. Much is known about the scientific and clinical evidence of axSpA and the advances in diagnosis and treatment options, but not enough about the voice from patients. The patient community vision is to use IMAS data to ensure that the axSpA patient experience and perspective is integrated into healthcare policy and clinical decision-making. IMAS brings credibility to healthcare policy to improve the quality of life of axSpA patients by using its data to raise their unmet needs among policy makers, including the need to improve diagnosis, referral and access to care.



IMAS data is also to be used in disease management, to communicate data to physicians and patients, to advocate for multi-disciplinary care in axSpA and to re-focus the doctor-patient dialogue on the patient.

To date IMAS has generated 100 congress-level presentations and was named the overall winner of the EFPIA (European Federation of Pharmaceutical Industries and Associations) Connecting Healthcare award by an international jury.

IMAS so far has involved 23 patient organizations, 20 medical experts, 100 presentation abstracts, 13 scientific peer-reviewed articles in reputable rheumatology journals, six political meetings and over 2 million social media presentations.

There are now over 5,300 participants in the IMAS survey, the majority of whom are in Europe but patients in North, Central and South America, Africa and Asia are also represented.

Marco shared several slides of preliminary data from IMAS, the details of which will be released later when the Indian survey has closed and all data has been collated.

The key takeaways from the preliminary IMAS global data set are:

1. The delay to diagnosis is unacceptably long because of disease progression.
2. Active disease was observed, particularly in women.
3. Physiotherapists are strongly involved in axSpA care, especially in Europe and among women.
4. Most participants have at some point taken all therapy drug classes, while a similar portion had only taken NSAIDs.
5. Mental health is a global issue, yet differences exist in how people with axSpA access mental healthcare around the world.

Following Marco's presentation there was a question-and-answer session. Prior to a break, Iryna Bublik lead everyone in two minutes of stretching exercises.

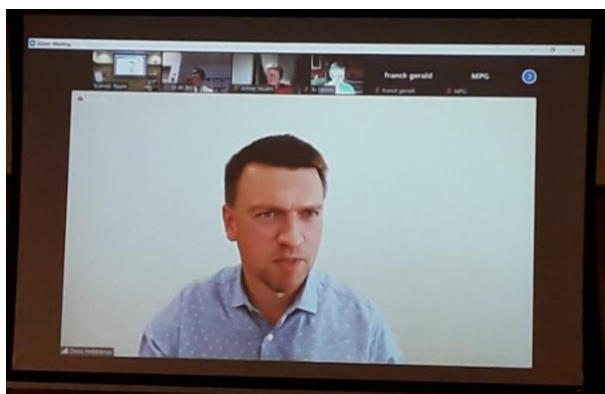
### **5. Presentation: What's new in Spondyloarthritis**

**By Prof. Dr. Denis Poddubnyy**

Charité University Hospital, Berlin, Germany

Executive Committee, Assessment of SpondyloArthritis International Society (ASAS)

Denis advised he had gathered several pieces of information related to diagnosis and treatment to make his presentation, but he started by looking at the continuum of axial spondyloarthritis, starting in 2012.

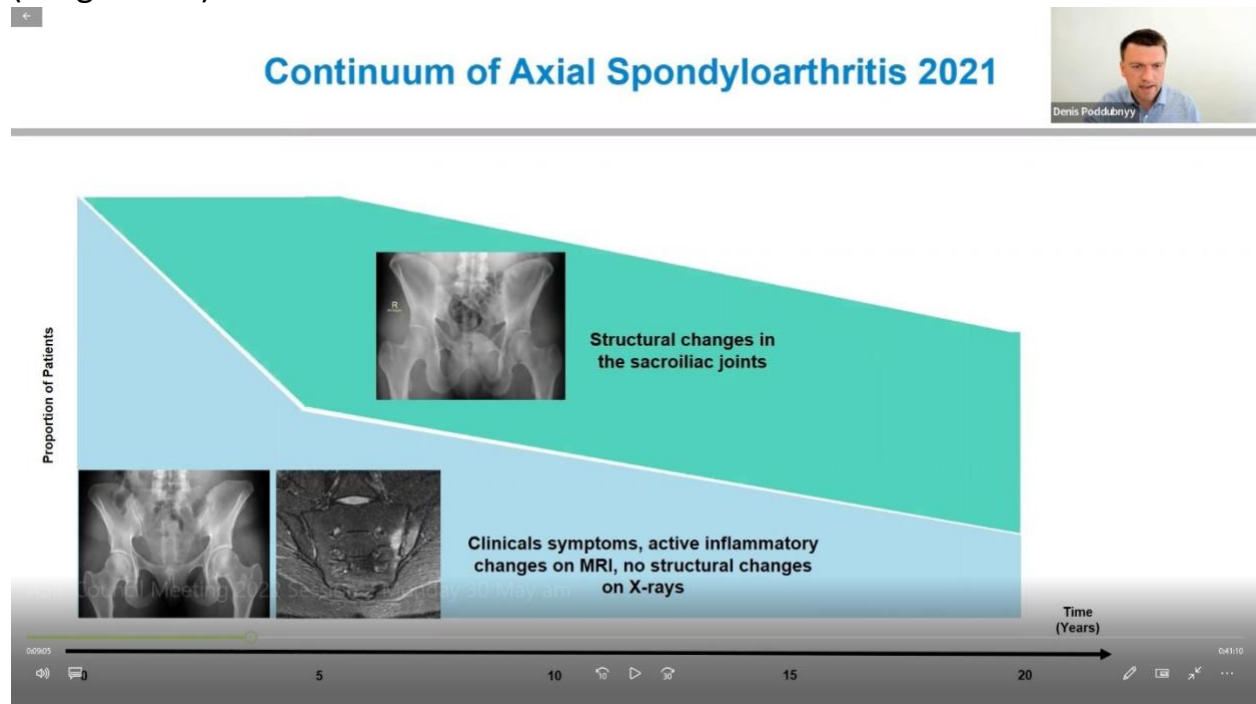


#### **The Continuum of AxSpA**

In 2012, there was an understanding that axial spondyloarthritis may be a continuum of a single disease, but there were debates as to whether it was a disease with two stages, non-radiographic and radiographic axSpA, or two diseases. This is still discussed but to Denis it makes no sense. Axial

Spondyloarthritis is single disease. But what we now know is that disease progression is not linear and may be more rapid in one patient than another. And

not all patients progress from nr-axSpA to r-axSpA as shown in the graph below (in light blue).



The graph also shows that high risk patients (in green and displaying radiographic structural changes) have rapid onset then the velocity declines. After 20 years there are still people without structural damage in the sacroiliac joint and spine. In fact, it is known today that it is not usual to have a lot of structural damage in the spine, which occurs in only about 20%-30% of patients.

**The natural course of the disease.**

A recent epidemiological study, PROOF, is examining the natural course of axSpA. It is an observational registry study conducted in clinical practices in 29 countries in five geographic regions over five years, with a focus on comparing demographics, peripherals and EMMs (Extra Musculoskeletal Manifestations) of axSpA across geographic regions. The regions are Europe, Canada, China, Arabia and Latin America. There are differences in clinical presentations in phenotypes in different countries. This means that clinical researchers may have to consider local characteristics regarding diagnosis and classification of axSpA.

For example, HLA-B27 positivity ranges from 80.3% of patients in Europe to 29.4% for patients in Arabia. Latin America has a much higher prevalence of peripheral

arthritis, 59.5%, compared with about 30%-31% for Europe and China. Latin America and Arabia have much more prevalence of heel enthesitis, 59.1% and 50% respectively, compared with the other regions, which range from 8.9% to 39%. Lastly, no IBD (Inflammatory Bowel Disease) was observed in axSpA patients in China, who also showed next to no psoriasis.

### **The role of imaging in diagnosis and classification.**

ASAS developed Classification Criteria for AxSpA fourteen years ago, for patients with three or more months of back pain and who were under age 45. There was criticism of the specificity of the imaging criteria. This was a problem because imaging has a really important role in diagnosis. It is virtually impossible to diagnose axSpA clinically (unlike rheumatoid arthritis, where inflammation in the joints can be felt by the clinician). The only method to test objectively that there is inflammation in the SI (sacroiliac) joint and spine is imaging.

Researches have learnt over time how unreliable x-ray of the SI joint is and today rely on MRI. They have also learnt that BME (bone marrow edema) of the SI joint can be detected by MRI, leading to a situation where, in one study looking at early spondyloarthritis, it was found that a high proportion of healthy young athletes showed sacroiliitis because of BME (caused by mechanical stress) in the SI joints. A further study demonstrated that healthy people, runners and women who had post-partum back pain also showed sacroiliitis because of BME. But what is known now is that you have to look at the precise location of the inflammation in the SI joint. Generally, BME from mechanical stress is found in the lower part of the joint. Taking this into account improves the specificity of the ASAS Classification Criteria.

### **Differential Diagnosis.**

There are many differential diagnosis options for axSpA, but the background of mechanical back pain is so high that clinicians still see as many referrals without axSpA as they do with it. It's necessary to differentiate between the common causes of back pain, such as degenerative disease and spondylosis for example, and the rarer causes, such as infection, fracture and cancer.

Denis and his colleagues put a lot of effort into educational activities to teach radiologists and rheumatologists about the different types of back pain. One of those activities is an ASAS [online case library](#) that started with 25 case studies,



each with discussion of the case, blood findings and detailed imaging. Another case study is added each month. The hope is that the library will help improve earlier and correct diagnosis.

### **“Improve axSpA”**

Improve axSpA is another educational project to help earlier diagnosis. It is a central consultation service, aimed at improving the interpretation of imaging. Any doctor can upload images for a second opinion. There is an ongoing assessment as to whether the service is useful and can be expanded. Denis noted there is a huge need for proper imaging and interpretation.

### **Artificial Intelligence.**

Denis and colleagues are also considering the use of artificial intelligence, AI, for imaging interpretation. The idea is that they take a collection of images that are reliably annotated, give them to a convolutional neural network that works like a brain and which is capable of extracting features that are relevant for concluding whether sacroiliitis is present or not. The results are compared with annotations of other cases. The system has been validated and shows a high degree of accuracy, meaning that, in principle, it should be possible to use AI as an additional tool in the diagnosis of axSpA.

### **MRI and Algorithms.**

Denis’ colleague, Dr. Keno Bressemer, will be presenting at EULAR the first successful attempt to develop an algorithm for the detection of active inflammation and structural lesions by MRI indicative of axSpA. The proof of concept shows that, in principle, it is possible to develop an algorithm that could help in imaging interpretation.



### **Treat-to-Target.**

The objective of Treat-to-Target (T2T) is to bring patients to a symptom and inflammation free state, or in other words, remission.

In 2017 there was an update of T2T recommendations for axial and peripheral spondylarthritis produced by an international task force. There are seven recommendations, which all speak to

achieving an absence of clinical and laboratory evidence of significant disease activity. For axSpA, the preferred measure of disease activity is ASDAS, while for peripheral SpA (specifically PsA) it is DAPSA or MDA.

A recent study, TICOSPA, of a one-year controlled trial compared T2T with a usual care approach. The end point was defined as a 30% improvement in ASAS-HI (ASAS Health Index). Those patients receiving T2T care were subject to a pre-defined strategy and were seen every 4 weeks. Treatment recommendations were provided by an electronic algorithm, with treatments being intensified until the target (ASDAS of less than 2.1) was met.

Patients receiving usual care were seen quarterly with treatments at the discretion of the rheumatologist. The results showed that 36% of patients under usual care and 47% of the T2T patients reached significant improvement as defined by ASAS-HI.

The results indicate that usual care works, but what are the costs of the more aggressive T2T care, which uses more drugs and showed more adverse side effects, to achieve an 11% improvement?

Nevertheless, T2T is important because rheumatologists should always try to bring patients to a symptom and inflammation-free state, but by not meeting the target ASDAS it doesn't mean treatment needs to be switched. The reason needs to be checked. Is it inflammation or could it be mechanical issues in the spine or chronic pain syndrome? This is a hot topic and we will be hearing more about it in the future.

### **ASAS-EULAR Recommendations for the management of SpA.**

Denis advised new recommendations will be released at EULAR in two days. The up-dated recommendation will include JAK Inhibitors (a targeted synthetic DMARD) for use after biologics have failed. This is the only substantial change to the recommendations.

### **TNF $\alpha$ Blockers (TNFi) and newer drugs.**

Denis reviewed the ASAS 40 response on ankylosing spondylitis (AS) patients treated with TNFi over 24 weeks. The drugs in question were infliximab, etanercept, adalimumab, golimumab and certolizumab. They all achieved a

similar 40%-50% improvement in ASAS 40 over 24 weeks. This is an important benchmark for all new drugs coming to market.

Similar ASAS 40 responses have been demonstrated for secukinumab and ixekizumab, both IL17A Inhibitors.

Upadacitinib, a JAK Inhibitor available in pill form, showed a similar response in Phase 2/3 trials, which allowed for it to be approved for AS.

Likewise, tofacitinib is a JAK Inhibitor that demonstrated a similar ASAS 40 response in Phase III trials, allowing it to be approved for AS.

There are plenty of treatment options for AS/axSpA that are more or less as effective as each other. The decision as to which to take may come down to the preferred way of administration; infusion, injection or pill. Another consideration is the safety and efficacy of the drug against any EMMs like uveitis or IBD.

### **The effect of drugs on structural damage.**

Doctors would like to prevent structural damage, the process of new bone formation known as syndesmophytes. If inflammation can be inhibited, it seems reasonable to believe that repair of the damage, new bone formation from inflammation, can be stopped too.

But a study, GESPIC, conducted over two years was disappointing. It showed no inhibition of radiographic progression with TNFi therapy compared with a control group. The reason for this was found to be that two years is not long enough. Looking at four years data showed a clear difference. TNFi users experienced a retardation of new bone formation. If inflammation is suppressed early and maintained at low levels, over time there will be no new bone formation.

### **Summary.**

Denis covered a lot of ground and was good enough to summarize it here:

- There are substantial differences in clinical presentation of SpA in different regions.
- Diagnostic work-up including the proper use and interpretation of imaging is key to the diagnosis of axSpA. AI and expert-based central reading approaches for imaging may be helpful in diagnosis of axSpA in addition to educational programs for rheumatologists.

- Remission/low disease activity is the primary treatment target in SpA.
- T2T is a management framework that does not imply automatic treatment escalation if a pre-defined treatment target has not been reached.
- TNFi, IL-17i and JAKi are effective anti-inflammatory treatments in axSpA patients not responding to NSAIDs.
- Early, effective and continuous inhibition of inflammation is able to inhibit structural damage progression in axSpA.

Following Denis’s presentation there was a short questions-and-answers session and then a break for lunch.

## **6. Presentation: ASAS’ Work and Collaboration Opportunities**

**By Dr. Victoria Navarro Compán**

University Hospital La Paz and IdiPaz in Madrid, Spain  
Executive Committee & Executive Secretary, ASAS

### **What is ASAS?**

ASAS, the Assessment of Spondyloarthritis International Society is a scientific society with 209 members in 47 countries in Europe, Asia, the Americas, Africa



and Oceania. Its mission is to support and promote the study of axSpA and Peripheral SpA, which it does by increasing awareness and promoting early diagnosis of the disease, developing and validating assessment tools (its main focus) and evaluating treatment modalities, all with the objective of promoting clinical research to improve outcomes for patients.

ASAS is run by a nine-person Executive Committee that includes two advisory members and two representatives of Young ASAS. There is also a six-person Advisory Committee, usually comprised of past Executive Committee members. Xenofon Baraliakos is the current President. ASAS has partnerships with corporate partners (for funding), ASIF, and other scientific societies such as EULAR and ACR.

## What does ASAS do?

ASAS has three areas of activity; research; consensus and recommendations, and Education/awareness. ASAS has had many projects in the past, but Victoria concentrated on the main projects today. The projects are grouped under four headings.



### 1. Understanding AxSpA.:

- ASAS COMOSPA is a study assessing co-morbidities in patients with SpA.
- ASAS perSpA aims to define the prevalence of peripheral manifestations in patients with SpA. There are over 5,000 patients in the study and there will be many abstracts on it at EULAR.

### 2. Diagnosis and Classification.

- CLASSIC is a project that aims to update classification criteria to overcome the shortcomings of the ASAS Classification Criteria of 2009.
- AXIS is a project in co-operation with GRAPPA to look at axial manifestations in Psoriatic Arthritis and to build a consensus definition of what they are. There are some differences compared to axSpA.
- Imaging Reporting, a project established a year ago to define how a rheumatologist orders imaging from a radiologist and what a radiologist should report back to the rheumatologist. There will be a presentation on this project at EULAR.

### 3. Assessment tools and outcomes.

- ASDAS, a disease activity score for axSpA patients.
- ASAS-HI, the ASAS Health Index ten years in the making, to assess the overall functioning and quality of life of SpA patients. ASAS-HI is being used widely in research studies and clinical practices.
- ASAS Physical Performance Index, evaluates how physical exercise can be achieved.
- ASAS-OMERACT (Outcome Measures in Rheumatology) Core Outcome Set. This project is to up-date mandatory measures that need to be assessed in every clinical trial. The original core set was developed about 20 years ago for AS. There have been



many advances since then. The core set was up-dated five years ago, but now the last part of the updates will be presented at EULAR.

#### 4. Consensus and Recommendations.

- ASAS-EULAR Recommendations for the Management of AxSpA. These were last updated in 2016. A new update will be presented at EULAR (as also mentioned by Denis Poddubnyy).
- ASAS SPEAR addresses the question of what is early axSpA? The term is used frequently but there is no standard definition. The project is a to find a consensus definition of what is early axSpA for research purposes.

There are many publications of ASAS research, which can be found on the [ASAS website](#), many of which have been translated into several languages. ASAS has also developed an [ASAS app](#) that includes a calculator for ASDAS and BASDAI and the classification criteria. The app is very easy to use. Victoria advised that in her clinical practice, she asks patients to complete the measurement tools on their mobile devices and not on paper.

The above covers research and consensus and recommendations. What about education and awareness? Victoria advised they are a work in progress. They can be found on the ASAS website and comprise the following:

- Core Course. Run annually, done virtually during the pandemic but the next one will be an in-person course in Belgium.
- Slide Library. Over 500 slides on all aspects of SpA, in many languages, that can be used to teach or present.
- Case Library. To teach clinicians how to diagnose and monitor SpA, with a special focus on imaging in clinical practice.
- Handbook. The ‘bible’ of SpA, published in 2009 and which now needs to be updated.

ASIF is also trying to disseminate information through social media and has accounts with [Twitter](#), [Facebook](#) and [Linked In](#).

Getting together is an important part of being an ASAS member. Before the pandemic, members used to meet three times a year, once for an annual meeting for two days and again at EULAR and ACR. Virtual meetings have been held in the

past two years but the next in-person annual meeting is scheduled for January, 2023 in Athens. ASAS established a newsletter during the pandemic. This was found to be an effective way of keeping in touch and will be kept up.

### **The ASIF-ASAS Relationship.**

ASIF is looking for a closer relationship with and ways of collaborating with ASAS. Victoria listed some things that illustrate a relationship. ASIF has participated in Delphi survey rounds on ASAS projects and in qualitative interviews for the ASAS-HI. There have been and are patient representatives in ASAS research projects and on the task force for recommendations. Additionally, the ASAS Executive Committee has agreed to having two ASIF representatives at its annual meeting.

In terms of ASIF projects, there are several ASAS members who participate in Delay to Diagnosis, IMAS and Talk to be Heard.

Following Victoria's presentation there was a questions-and-answers session. This prompted one member, NASS, to make a plea to enrich the ASAS Quality Standards by giving a patient as well as a clinical perspective on what quality actually means. Victoria had overlooked this aspirational project, which is lead by Dr. Uta Kiltz. Details of the Quality Standards may be found [here](#).

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After the presentation there were stretching exercises followed by a coffee break.

The rest of the afternoon was taken up with member presentations. ASIF was very pleased to have new member organizations that had never attended a Council Meeting before from Columbia, Greece, Philippines, South Africa and Ukraine included in these presentations.

## 7. Member Presentations

1. **Columbia.** Presented by **Julieth Samantha Buitrago**, Founder and Director of Fundación de Espondilitis Anquilosante en Colombia.



In Columbia, axSpA is not well known even in the medical community. The Foundation's aim is to create awareness of the disease to advance early detection and to help improve the quality of life of those already diagnosed. Funding is an issue because there is no financial support from the state. The Foundation is a non-profit

organization which relies on donations. However, in 2019 funding was obtained from industry partners to enable the Foundation to run an early detection campaign in three cities where there are no permanent rheumatology services. This resulted in 59 people receiving a diagnosis.

In 2021, the Foundation worked with the Colombian Association of Rheumatology on the preparation and publication of clinical practice guidelines for SpA.

The Foundation has a presence on social media with 2,000 followers on Facebook.

2. **Cyprus.** Presented by **Stalo Papamichael** of the Cyprus League of People with Rheumatism (CYLPER).

CYLPER's vision is to an equal, quality and productive life for all patients in all aspects of their lives. It has 500 registered patients with axSpA, and intends to grow this number. The pandemic has hindered efforts to support patients but technology has helped by providing various platforms to support patients psychologically, and with exercises and lectures. Stalo thanked ASIF for sharing materials that helped support its efforts.



CYPLER is very proud that it has completed its own premises where members can use a gym with special equipment and attend physiotherapy clinics with experienced physiotherapists.

CYPLER believes it is important to assist patients with axSpA to get out of their comfort zones and face their disease with psychological strength. Stalo's motto is "Life is too short and beautiful. Let's fight for a better life!"

3. **Germany.** Presented by **Martina Irrgang**, Vice-President, Lower Saxony, Deutsche Vereinigung Morbus Bechterew, DVMB (German Association for Ankylosing Spondylitis)



DVMB's aim is to raise awareness through public relations, something it has been doing since 1980. It produces a quarterly journal that is quite scientific, plus booklets and flyers. It is active on Facebook and, through local branches, offers support on how to live an active life. Members of more than one year can get free legal advice.

DVMB has representation in politics, media and society. It has 13,500 members and 350 local branches, run by Boards for 14 regions. It has five full-time employees and three part-time. Its website, re-launched three years ago, has powerful images showing how you can lead an active life.

A current project is to produce an AS app which will work with a combination of animations (videos) and a point reward system. The app is expected to be available in 2023.

Under the motto “Movement, Encounter and Counselling” DVMB offers information, support, social activities and weekly group exercises.

**4. Greece.** Presented by **Nadia Malliou**, General Secretary of the Hellenic League Against Rheumatism, ELEANA/HELAR.



ELEANA has been supporting patients with Rheumatic musculoskeletal diseases (RMDs) since 1978, when it was founded as an initiative of the Greek Rheumatology Association. After a few years ELEANA was handed over to patients. It has a Scientific Committee comprised of 11 rheumatologists, clinical pharmacologists and immunologists. It’s 9,000 members are made up of patients, caregivers, rheumatologists and other health care providers interested in rheumatology.

ELEANA has nine branches spread around the mainland and islands. It strategically co-operates with other patient organization dedicated to arthritis, autoimmune, psoriatic and rare diseases. Its main services are:

- Help line for psychological support and information.
- Awareness events and campaigns. In 2022, for the first time ELEANA had an axSpA specific campaign due to its collaboration with ASIF.
- Publishes a “Clinical Assessment of the Musculoskeletal System” handbook that is distributed for free to rheumatologists, general physicians and medical students.
- Self-management education program meetings.
- Co-operation with the authorities.



ELEANA has several initiatives underway, including Health School events, sexual life and RMDs, work and RMDs, patients’ rights, a Stigma app for chronic pain, and patient pharmacovigilance. Its Lupus initiative was very successful. It included tv commercials featuring famous Greek actors. There have been no initiatives on axSpA as yet, but Nadia promises one for the future.

**5. Norway.** Presented by **Lillann Wermskog**, Leader, Spondyloartrittforbubdet Norge (Spafo) and Trustee, ASIF and **Lise Mette Eidet**, Organization Advisor, Spafo.



Lillann and Lise Mette highlighted one initiative from Spafo Norge, the making of four diagnostic movies with a goal to reach out to doctors, patients and society at large about the symptoms of SpA. The movies were shown as commercials on tv as well as featuring on social media, where there were 31,000 views.

Lillann and Lise showed [the movies](#)

which were about:

- Inge, who took 20 years to be diagnosed with AS.
- Elin, who has PsA and was diagnosed in her 30s.
- Ida, who developed Crohn’s Disease when she was 17.
- A mother, with AS, of an active son who developed juvenile arthritis but who took two years to be diagnosed.

Each of the movies promoted the support, information and community provided by Spafo Norge.

**6. Philippines.** Presented by **Clark Ferrer**, President, Axial Spondyloarthritis Association of the Philippines (ASAPH), **Jose Francisco Juan Rivas** and **Percival Escarda**, Trustees of ASAPH.

Jose opened the presentation by saying it had taken the delegates 18 hours to get to Copenhagen, but it was worth it to meet new friends and be part of a larger axSpA family. Jose shared the expression *Mabuhay!* meaning welcome or cheers!

Percival noted that through membership of ASIF the Philippines had been given a larger voice for Filipino axSpA patients. He also noted that the three presenters were wearing traditional Philippines wear for men, barongs (embroidered long-sleeved formal shirts). They did look dapper!



Percival introduced the founder and President of ASAPH, and someone living with axSpA, Clark. Clark's presentation concentrated on IMAS in the Philippines, PMAS, with an emphasis on how axSpA affects every aspect of a patient's life. PMAS showed that disease onset, at 25 on average, is early in a patient's career-building life and limits their choices of profession. The delay in diagnosis adds

to the burden of the disease and is compounded by the fact that there are only 200 rheumatologists, with 95% of them concentrated in Manila, in a country of more than 7,100 islands and with a population of over 110 million! The health care system is very poor.

PMAS illustrated that axSpA affects patients' abilities to participate in sports, and to perform daily activities. Clark noted that commuting on trains in cramped conditions when you have to stand is an ordeal for patients.

Clark addressed the limitations in careers and the ability to work and be productive. Clark himself had open-heart surgery at 21. He noted how difficult it is for patients to explain pain, stiffness and loss of mobility at work. Patients have to continually raise awareness of axSpA in order to be treated as functional members of society.

Constant pain brings on anxiety and depression. These psychological issues affect how patients deal with friends, families and colleagues. Because axSpA is poorly understood, it causes patients to worry about their futures. In Clark's case he didn't want to have children because he didn't want to extend the misery of axSpA to anyone else. But, as it turned out, he had a son who is now his inspiration to live his life beyond his condition.

Generally, awareness of axSpA has increased due to the efforts of ASAPH, the Philippines Rheumatology Association, Novartis and ASIF. Patients having the right information will provide opportunities for them to discuss their condition and treatment options with their doctors and be empowered to participate in their disease management.

PMAS will be useful in helping to raise the voice of axSpA patients, and to raise awareness among family, friends, colleagues and the general public. Hopefully, PMAS will provide information for health policies so that patients can get better access to care, reduced times to diagnosis and a better future.

7. **South Africa.** Presented by **Maranda van Dam**, Founder and Chair of Axial Spondyloarthritis Association of South Africa (ASASA).

Maranda, wrapped in a South African flag, said that she had to fight back tears



because it was such a privilege to be included in this room of ASIF members. She has axSpA and it took eight years until diagnosis. Maranda tried to find some support in South Africa, but there were no resources available. In doing an internet search, Maranda stumbled across ASIF and started a year-long email correspondence with Michael Mallinson, who asked her why not start an association in South Africa? At first Maranda thought “No way I can do that” but a year later decided to go for it.

The poster that Maranda prepared for the Council Meeting contains what she called the ‘boring stuff’. Accordingly, Maranda presented on the interesting stuff. South Africa has nine Provinces, six of which have no rheumatologist. In fact, with a population of 60 million, South Africa has only 85 rheumatologists. The health care system is terrible, compounded by the vast distances in the country and the fact that the surrounding countries and Lesotho have no rheumatologists, so patients come to South Africa for care. Creating awareness in a country with 11

official languages, where it's hard to translate 'axial spondyloarthritis', and there are only 2.9 MRIs per 1 million population, means it is little wonder that the average delay to diagnosis is 10.8 years.

The realities of a third world country are that the infrastructure is on its knees; the roads are bad, load shedding means power cuts, 71% of the population are underfunded in health care, 26 rheumatologists in the public sector serve 4.2 million people, infectious disease are rife, particularly HIV, the symptoms of which mimic those of axSpA. Medical Aid does not fund axSpA; there is no state medical aid and the most basic private insurance is a minimum of 120 Euros per month, equivalent to one third of the basic income. In summary, biologics are unaffordable.

Maranda addressed the challenges for the ASASA, not the least of which is building credibility for the organization when it is not robust and has no history. Starting from nothing was hard work, especially when axSpA awareness is so low and the government doesn't even list axSpA on its website. Also, Medical Aids (health insurers) dominate decision making in PMB (a set of defined benefits to ensure that all medical scheme members have access to certain minimum health services).

In finishing, Maranda gave a summary of where the ASASA is today. It has 272 members, up from 29 in 2020, and 900 members in its very active Facebook group. It has alliances with several rheumatologists. It did not receive any funding until 2021. It has been campaigning to train GPs and Physiotherapists in axSpA. A session training 10 GPs resulted in 16 axSpA patients being diagnosed! The challenge is to train healthcare providers nearer to patients. In South Africa in the rural areas, patients don't even get to see a GP. They go to local clinics and see a nurse.

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After each of the Member Presentations there was a questions-and-answer period. When all the Member Presentations were over, Julieth Buitrago kindly gave everyone a present, a poncho from her Fundación de Espondilitis Anquilosante en Colombia. A photo was taken of everyone wearing their poncho.

The rest of the day was free time, giving everyone an opportunity to rest, network or explore Copenhagen. At 7:00 pm everyone convened for a dinner together at the hotel.

## Day 2 - Tuesday, 31 May, 2022

The day commenced with an optional exercise programme lead by Iryna Bublik, and breakfast.

### 8. Annual General Meeting.

The Agenda for the day started with the Annual General Meeting, including the election of a Trustee. The AGM is Minuted elsewhere, but we record that Maranda van Dam of South Africa was elected Trustee and Aleksei Sitalo of Russia, stepped down as a Trustee. The AGM was followed by Member Presentations.



## 9. Member Presentations

### 8. Switzerland. Presented by René Bräm, CEO, Schweizerische Vereinigung Morbus Bechterew, SVMB.

René opened his presentation by giving a few facts about SVMB. It was started by volunteers in 1978 and now has 4,500 members, 15 employees, 100 physiotherapists and 100 volunteers.



René then showed a photo of the first ASIF Council Meeting, in Loèche-les-Bains, Switzerland, in 1989. René was there as a newly diagnosed patient. He said he felt the spirit of ASIF then, as he does today at this Council Meeting. He congratulated ASIF on what it has achieved over the last several years.

The main part of René's presentation focused on the results of a large survey of 1,560 patients participating in therapy groups, of whom 1,000 were members of SVMB. The results on delay to diagnosis were similar to IMAS results, showing an average time from first symptoms to diagnosis for women of 10.8 years and men 7.9 years. Patients spent an average of 92.4 minutes per year consulting with their rheumatologist. René noted that in Switzerland, with a population of about 8 million, they are fortunate to have 500 rheumatologists.

Members of SVMB were asked 'How do you see your future in relation to AS?'- 52% replied that they were optimistic, confident or neither confident or worried. This compared with only 27% of non-members, 73% of whom were worried.

To the question 'How well informed about AS and treatment options do you feel?', 82% of members responded positively, compared with only 44% of non-members.

In showing a chart of the increase in members versus the increase in participation in group therapy sessions, René noted that membership continues to climb (350



new members were added last year), while the number of therapy participants was fairly stagnant, perhaps because of the pandemic.



Another question was: ‘How do you rate the quality of AS group therapy sessions?’ These were highly rated across all age groups. Nevertheless, René felt the survey showed that SVMB has a lot to do to increase group therapy participants, as well as to improve the sessions and collect data about how well people are doing.

René then introduced a new project of SVMB, “Be Fit”.

Be Fit has four components:

1. Group therapy sessions run by trained physiotherapists.
2. An assessment. People are measured for endurance, strength, co-ordination, mobility and balance as well as filling out a questionnaire on illness, physical activity and quality of life. The measurements are taken by physiotherapists from the University of Applied Science, who receive course credits for it. The data is put into a registry.
- 3 Coaching of patients by physiotherapists.
4. Individualized training, by using [Rheumafit.ch](https://www.rheumafit.ch).

A mid-term project is to take the data from Be Fit and merge it with data from the SCQM register. SCQM stands for Swiss Clinical Quality Management in Rheumatic Diseases, a body that together with the Swiss Rheumatology Association maintains anonymized data from medical records on such things as blood tests, x-rays, BASDAI, BASFI and ASAS-HI. The combined data can be used as a quality management tool for treatment and as a basis for discussions with patients.

9. **Ukraine.** Presented by **Iryna Bublik**, Founder and Head of the Board, Анкилозу.нет (Ankylosing No! All-Ukrainian Public Organization of People with Bechterew’s Disease)

Iryna, wrapped in the flag of Ukraine, received a very warm applause. Iryna has had axSpA for 15 years, but was lucky in that she was diagnosed quickly. She has



spent all her adult life teaching fitness and after her diagnosis, started studying spondyloarthritis, got herself in shape and went into remission. People with axSpA started coming to see her, so she developed her own effective and practical rehabilitation method for the disease. When this small group of people with axSpA started to grow, Iryna started the organization four years ago. Since then, it has held 16 events. These include educational sessions in Kyiv,

Odesa and Lviv where the presenters were the best rheumatologists in Ukraine, rehabilitation specialists, psychologists and physiotherapists.

Another event was in Kyiv on World AS Day to walk, picnic, exercise and share experiences together.

Six months ago, a group of lawyers with axSpA joined the organization, which allowed it to start communications with the Ministry of Health and pharmaceutical companies. In terms of awareness, articles about the organization have been published in the media, and Iryna had a debate with a representative from the Ministry of Health that was aired on tv. In other activities, the organization has made exercise videos, available on its [You Tube channel](#).

On February 24, 2022 war came to Ukraine and disrupted not only the planned activities of the organization, but every aspect of life. Millions of refugees were created. Iryna and the organization's biggest concern is in getting medications to patients who need them, which is being accomplished with the help of pharmaceutical companies and humanitarian organizations.

There were lively question and answer sessions following each presentation. After Iryna's presentation, she took everyone through stretching exercises before a coffee break.

## 10. Member Initiatives on Awareness and Diagnostic Delay Reduction.

### 1. Diagnosis of Axial SpA: Time for a Gold Standard Approach

Presented by Dr. Dale Webb

CEO, National Axial Spondylarthritis Society (NASS), U.K.



Dale acknowledged NASS's partners and sponsors, particularly UCB, and the NASS team for making the Gold Standard Approach a reality. The idea behind the Gold Standard Approach is simple. It's a belief that every person with axSpA can be diagnosed within 12 months of symptom onset. A national consultation process found this could be done. Clinicians said it was ambitious but feasible.

Dale's presentation starts 12 months into the story, after consultations were completed and a route map, which is the strategy to achieve the Gold Standard, had been published. Everyone in the room was given a copy of the report and virtual attendees had received a digital copy. The report is titled 'Act on Axial SpA; A Gold Standard Time to Diagnosis' Much of Dale's presentation is taken from the report, which the reader is encouraged to view [here](#).

Pages 10 and 11 of the report set out the route map, a Driver Diagram, to achieve a gold standard of 12 months to diagnosis. The driver diagram consists of four columns. The first gives the objective: to improve time from symptom onset to diagnosis to a maximum of 12 months.

The second column lists the four barriers to timely delay that NASS identified. Dale noted that ASIF, in its Delay to Diagnosis Report, identified six barriers. A NASS literature review had revealed some reasons for delayed diagnosis but had not identified interventions to reduce the delay to diagnosis. This is because the literature doesn't follow the patient journey. The Gold Standard Approach does. The four barriers are:

- Help the person with inflammatory back pain to recognize that it might be axSpA.
- Ensure swift identification of axSpA and referral in primary care.
- Ensure direct referral from secondary care for people with extra-musculoskeletal manifestations of axSpA to a rheumatologist. (At present in the U.K., secondary care doctors such as ophthalmologists, if they suspect axSpA, have to refer the patient back to their primary care physician.)
- Ensure timely assessment and appropriate imaging within rheumatology.

The third column states what is required to address each of the barriers And the fourth, the actions to support the requirements. Dale's presentation addressed the solutions, of which there are four:

- Public Awareness campaign
- Addressing Primary Care
- Addressing Secondary Care
- Addressing Rheumatology

### **Public Awareness Campaign**

In June, 2021, NASS launched Phase 1 of the Awareness Campaign, using the vivid imagery of a sand timer to illustrate how critically important time is. Other aspects of the campaign are an on-line validated symptoms checker for anyone with back pain and the use of a SPINE acronym:

- S** Symptoms start slowly
- P** Pain in the lower back
- I** Improves with movement
- N** Night time waking
- E** Early onset (under 40)

NASS also launched the largest resource in the world on axSpA diagnosis, a dedicated website [actonaxialspa.com](http://actonaxialspa.com) which has sections both for patients and health care professionals.

The reader is encouraged to visit the website, where they can see that completion of the eight questions [symptoms checker](#) results in a printout that the patient can take to their doctor. The printout has instructions regarding diagnosis, and points the doctor to an online [Spondyloarthritis Diagnosis Evaluation Tool](#).



The Act On Axial SpA website, which has been viewed by 45,000 users, has many resources, including videos on how to prepare for GP appointments if axSpA is suspected, and how to prepare for the first visit to a rheumatologist. The awareness campaign has been run on social media, with content reaching 1.35 million people, the campaign videos have been watched 750,000 times, the symptoms checker has been completed 4,000 times, and national press coverage with a reach of 121 million has been achieved.

The awareness videos (which can be viewed [here](#)) use comedy to put their message across and show how it is possible to live the life you want after diagnosis.

Phase II of the awareness campaign will be launched in about a month. It will feature new collateral and focus more on the core symptoms of axSpA.

Phase III will be launched in early 2023 and will use travel infrastructure for advertising, things such as billboards and metro signs plus radio partnerships.

### **Addressing Primary Care**

NASS has launched a Primary Care Clinical Champions Program to ensure that axSpA is higher within the clinical reasoning of primary care professionals. The first Clinical Champions have just been appointed. They will do a two-year program in leadership development, quality improvement and local improvement

projects. Other actions will be taken to embed, and promote the use of, the eight-question symptoms checker and SPADE tool in primary care, to flag patients with suspected axSpA in primary care information systems, and to promote the widespread adoption of the Best MSK Health Collaborative axSpA referral pathway.

### **Addressing Secondary Care**

NASS is reviewing the current understanding of axSpA in secondary care (ophthalmology, dermatology, orthopaedics and gastroenterology) with a view to rolling out a national training program to raise awareness of axSpA symptoms. It is also undertaking a review of referral pathways to ensure that direct referrals from secondary care to rheumatologists can occur.

### **Addressing Rheumatology**

Dale gave the Gold Standard vision for care in rheumatology: that every hospital seeing axSpA patients has an inflammatory spinal MRI protocol in place and that every rheumatologist in the U.K. is able to access an axSpA-expert MSK radiologist, and that all radiologists and rheumatologists are aware of and use the [BritSpA MRI recommendations](#).

NASS is reviewing axSpA radiologist training in the U.K. It will launch on-line resources and e-learning to promote the use of BritSpA's imaging guidelines.

### **Aspiring to Excellence.**

Dale then turned to a related but different program '[Aspiring to Excellence](#)'. This program uses well-known quality improvement techniques to drive improvements in axSpA care. 20 hospitals are involved in working with NASS on this initiative. The first report from the program, [Driving Improvements in Axial SpA Services](#), was issued in October, 2021

### **'Rheum For Improvement'**

Dale advised this is a podcast, downloadable from your steaming platform, that is dedicated to improvement in axSpA care.



### **Policy and Campaigning Work.**

This work is being done to attract the support of Parliament and policy makers for the Gold Standard, and to get NHS organizations to both endorse the Gold Standard program and support its calls to action.

### **All Party Parliamentary Group for AxSpA.**

NASS has commissioned research on what is the total cost of diagnostic delay, through which it hoped to show that reducing the delay to diagnosis is cheaper than treating patients. Dale showed some preliminary figures for the costs, which are substantial but are subject to change as the research progresses.

### **Building a Social Movement for Early Diagnosis.**

Dale spoke about the idea of building a social movement for early diagnosis. NASS, in mapping the Aspire to Excellence departments and the Champions in Primary Care in the UK, will grow the networks over time and create a social movement that is serious about reducing diagnostic delays. He noted that social movements include and require collective action to create social change, an ideology, an organizational framework, techniques and results. The work that NASS has done so far on the Gold Standard approach to early diagnosis has all these elements, as demonstrated in the driver diagram in the Gold Standard report.

Dale finished his presentation by saying that NASS, together with health care professionals, will drive down diagnostic times and catalyse improvements in care.

## **2. Trusted Partner Program**

Presented by Moataz Daoud, Vice-Chair,  
Canadian Spondylitis Association (CSA)

Moataz gave a brief review of the Canadian Spondylitis Association. It has one full-time-employee and a very diverse and motivated Board. Its Vision and Mission are similar to those of other axSpA patient organization and its Strategic Pillars are Education/Information; Advocacy; Awareness and Support.

The CSA's awareness campaign is to address the fact that 45% of people living with axSpA are undiagnosed, and those people are not receiving the treatment

they need. The CSA recognises a need for a two-pronged approach to awareness. First, to reach the general public and second, to reach physicians and other health care providers (HCPs).



To reach the general public, the goal is to create an earned-centric (meaning getting earned media and social media attention, at little cost) campaign that helps put axSpA on the map and drives Canadians to learn more and take action. To earn the media attention where there are not the resources to

engage a large agency and pay for media, the CSA has opted to ask agencies to pitch proposals ‘at risk’. This means that the agencies are aware that the CSA requires full funding of any campaign before it can be implemented.

The campaign will include social media elements and a tv spot, and that the CSA is looking to launch it on the back of World AS Day 2023. The main theme will be “Take Back Your Years”.

To reach physicians and HCPs, the CSA has implemented a project called the Trusted Partners Program, which aims to educate and inform all types of HCPs during their training. In Canada, physicians receive only 45 minutes of training on axSpA. The training is didactic and easily forgotten. To overcome a lack of awareness of axSpA, the intention is to target HCP’s during medical training, and the method to bridge the gap in knowledge has been determined. The Trusted Partners Program is where patients tell their stories. The CSA identified five patients and trained them how to speak to HCPs of all disciplines, general physicians, physiotherapists, pharmacists, nurses, etc. So far, the five patients have been to three universities to speak, share their stories and be engaged in lectures.

An expansion of the program will take place by using members of the CSA’s Medical Advisory Committee, which includes some of Canada’s most experienced and respected rheumatologists, all of whom are university affiliated and are teachers and lecturers at those universities. The patients in the Trusted Partner Program and their stories will be integrated into lectures to medical students.

There were lively question and answer sessions after each of Dale’s and Moataz’s presentations. After this everyone, including on-line attendees, was broken into groups for the workshop sessions.

## 11. Workshops.



**Workshop 1.** Reducing the Delay to Diagnosis. Participants were asked to consider three questions:

- Of the activities mentioned\*, which 3 would you prioritise?
  - Is there any other support you would you find most helpful to help reduce diagnostic delay in your country?
- What is the one key change (in improving axSpA diagnosis) that you think is achievable in your country in the next 1-2 years?

\* The development of materials, resources and guidance for member organizations to use in awareness raising campaigns in their countries.

\*Researching and using existing research where available, a figure for the economic cost of delay to diagnosis.

\*Developing best practice examples and resources highlighting successful initiatives from across the world addressing the delay to diagnosis, and giving guidance on how they can be replicated.

\*Supporting engagement with health care professionals at a country level to raise awareness in key specialities.

\*Promoting rheumatology as a speciality to address capacity challenges.



**Workshop 2:** Global landscape analysis. Participants were asked to consider four questions.

- Would a global axSpA landscape analysis be useful to you?
- How do you see it being used in your country?
- What would you want to see included?
- Is there anything specific to your country in axSpA recognition, prevalence or treatment?

The workshops were followed by lunch in the hotel.

### **Workshop feedback and Summing Up.**

The workshops produced lively discussions and a lot of ideas. The workshop discussions are being evaluated by ASIF and the outcomes will be communicated in due course.

### **Summary of the Council Meeting, by ASIF President Zhivko Yankov.**



Zhivko asked attendees to read the ASIF Business Plan, derived from the Strategic Plan, that reflects what ASIF members have asked ASIF to do for them, and provide any comments they may have. It is expected that the Business Plan, with its actions and timelines for each strategic objective necessary to grow ASIF and complete its projects, will be adopted at the end of June.

At each future AGM, ASIF will report on the Business Plan and its progress will be measured. He noted the 2023-2028 Strategic Plan is a living document that will be re-visited frequently.

Zhivko considers that the Global Landscape Analysis, if done properly, will provide powerful data that will help to make changes.

Zhivko discussed the format of the Council Meetings. A main benefit of the Council Meetings is the opportunity to network and exchange information. There isn't much time for this in a two-day meeting, so it makes sense to have a three-day event next time, especially in view of the distances some delegates have to travel.

Zhivko briefly ran over the agenda of what we saw and heard during the Council Meeting and commented on how wonderful it was to see new members in attendance and all the presentations from members.



To end the Council Meeting, Zhivko asked if any member organization would like to host the next meeting in 2024 to let ASIF staff know. He also advised that presentations and information from this Council Meeting will be made available to everyone.

Lastly, there were thanks to the staff of ASIF for all their work in organizing and

running a successful Council Meeting.

A group photograph and a photograph of the Trustees concluded the Council Meeting at about 2:30 pm.

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### **Sightseeing and Dinner**

At 3:15 pm, a coach had been arranged to take everyone on a sightseeing visit to the Louisiana Museum of Modern Art located on the shore of the Øresund Sound in Humlebæk, 35 km north of Copenhagen. In a beautiful setting with outdoor sculptures, the art museum features post-1945 modern art in a gallery that is mostly underground. Everyone enjoyed strolling around the grounds and seeing the permanent collections and temporary exhibitions in the gallery.

At 7:00 pm the buses took everyone except for a few who walked, a very short distance to Gl. Humlebæk Kro, a restaurant that has been in existence since 1740 and which originally served as a coaching inn along the road from Copenhagen to Helsingør. Everyone enjoyed having dinner together with some fine Scandinavian food before returning to the Scandic Hotel by coach.