Report on the 15th ASIF Council Meeting

Hotel Tequendama, Bogotá, Colombia

17 - 19 October 2024

ASIF is pleased to present this report on the 15th Council Meeting. Held every 2 years, this is the first ASIF Council Meeting to be held in any of the Americas. We are very happy to have been able to host so many members in Colombia and to develop new collaborations in the region. We had around 44 delegates from 25 countries across all continents. We had a further 5 delegates join via Zoom.

We are very grateful to Dieter Wiek who led lively exercise breaks to Latin American music throughout the event to keep us moving.

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Executive Summary

The 15th ASIF Council Meeting, held from October 17 - 19 2024, in Bogotá, Colombia, marked a significant milestone as the first ASIF meeting in the Americas. Delegates from 25 countries, along with virtual participants, gathered to share insights, strengthen collaborations, and celebrate the progress of the global axial spondyloarthritis (axSpA) community.

Growth and Strengthening ASIF

Zhivko Yankov, ASIF Chair, welcomed participants, emphasising the organisation's expansion, with 20 new members in eight years, bringing the total to 56. ASIF has also transitioned into an incorporated charity, enhancing governance and allowing for broader expertise on its Board.

ASIF Initiatives and Campaigns

ASIF showcased its main work:

- **IMAS (International Map of Axial Spondyloarthritis):** The global report was published in January and the team continue to disseminate findings; ASIF took ownership of IMAS in January 2024.
- **Delay to Diagnosis Campaign:** The signs and symptoms awareness campaign materials were translated into nine languages and used widely be ASIF members.
- **World AS Day 2024:** The annual campaign was a resounding success, reaching 9.8 million people online, with campaign animations viewed 93,000 times.

Scientific and Research Developments

Dr. Wilson Bautista-Molano provided an in-depth look at axSpA in Latin America, highlighting key research findings; the need for greater awareness of the disease; and the significant challenges faced in the region.

Jo Lowe shared updates on IMAS, outlined how research themes could shape future initiatives, and how ASIF members can play a significant role in research.

Workshops

Two workshops addressed research priorities and healthcare professional education. Key takeaways included:

- **Supporting patients through research:** Discussions highlighted various areas of research where evidence is still needed and explored ways to influence, and be more involved in, relevant research.
- **Psychosocial Support for Patients:** Delegates identified gaps in mental health support and brainstormed solutions, including peer support programs and greater collaboration with healthcare providers.

Improving axSpA knowledge with HCPs

A panel discussion highlighted the challenges faced in raising awareness of axSpA amongst non-specialist HCPs as well as educating rheumatologists about patients' concerns. Interesting initiatives from around the world were discussed and options for improvements were explored.

Regional Collaboration with ASOPAN

Following a dedicated Latin American meeting to explore mutual aims, an MoU was signed to underpin the new ASOPAN and ASIF collaboration. A new working group will focus on increasing axSpA awareness and supporting patients across Latin America.

Emerging Therapies and Digital Innovations

Professor Raj Sengupta presented advancements in axSpA, including:

- **Personalised treatment strategies** tailored to patient profiles.
- **Digital tools such as the SPADE diagnostic tool and Project Nightingale** for real-time symptom tracking.
- **Machine learning and AI** to enhance disease management and improve patient outcomes.

Showcasing Global Impact: ASIF Member Reports

Member organisations from around the world shared their achievements and challenges. From advocacy in Chile and India to digital awareness campaigns in Norway and Canada, the passion and drive of the community were evident. Thank you to all the ASIF members who presented their work.

Recognising Dedication

A special session honoured two long-time advocates, Dr. Muhammad Asim Khan and Michael Mallinson, for their tireless dedication to the axSpA community. Their insights underscored the progress made and the work still needed to ensure earlier diagnosis, better treatment, and improved quality of life for patients worldwide.

Closing Reflections

Zhivko Yankov closed the meeting with gratitude, reflecting on the importance of face-to-face connections and the invaluable role of ASIF's members in driving change. Delegates concluded the event with a sightseeing trip to Monserrate, celebrating the shared vision of a stronger, more connected axSpA community.

The 15th ASIF Council Meeting was a testament to the power of collaboration, innovation, and advocacy. With ongoing commitment and strengthened partnerships, ASIF continues its vital work of improving the lives of people with axSpA across the globe.

Thursday 17 October

Welcome

Zhivko Yankov, Chair of ASIF, welcomed the delegates to the first ASIF Council Meeting in the Americas. He thanked AbbVie, Novartis and UCB for their support of the meeting. Zhivko highlighted the growth in membership, with twenty new organisations joining us in the past eight years, bringing our total membership to 56 patient organisations. The expansion of ASIF's activities were highlighted and the creation of a new committee of expert advisors was announced. Zhivko impressed the importance of collaboration with organisations such as ASAS (Assessment of SpondyloArthritis International Society) and the new collaboration with ASOPAN – the network of RMD patient organisations in Latin America.

Since January 2024, ASIF has operated as an incorporated charity which mandates stronger governance processes which better suits our work. The Trustees have agreed that people from outside the axSpA world can now join the Board, to ensure we have all the relevant expertise required. They also increased the maximum number of trustees allowed on the Board from 8 to 12. Zhivko concluded by making a final call for trustee applications.

Julieth Buitrago from Fundación de Espondilitis Anquilosante en Colombia (Ankylosing Spondylitis Foundation of Colombia), welcomed delegates to Colombia. Julieth, John and Yanneth from the Foundation were invaluable support to the ASIF Team and delegates throughout the meeting. ASIF offers our sincere thanks to them.

Update on ASIF's work

Jo Lowe and Jo de Bry presented the main activities of ASIF since the last council meeting.

- **IMAS (International Map of Axial Spondyloarthritis):** Jo L highlighted the progress of the IMAS project, including the publication of the global report, ongoing dissemination, and ASIF's ownership of the project.
- **Delay to Diagnosis Campaign:** Jo L discussed the impact of the materials from the campaign, emphasising the need to help members connect with non-specialist healthcare professionals (HCPs).

- **World AS Day 2024 Campaign:** Jo dB mentioned that the orange character from the Delay to Diagnosis campaign developed into a key feature for the World AS Day 2024 campaign. The success of the £500 social media grants was acknowledged, noting that more than 9.8 million people engaged with social media content from World AS Day, with campaign animations viewed 93,000 times.
- **Website Refresh and Communication:** ASIF's website was updated to improve accessibility and content, including a new "about axSpA" page and improved member organisation search features. Jo dB also mentioned the use of newsletters and social media for ongoing communication.
- **Collaboration with ASAS:** ASIF has strengthened its collaboration with the Assessment of SpondyloArthritis International Society (ASAS) with a Memorandum of Understanding signed in 2022, and ASIF is now regularly invited to ASAS meetings.
- **EULAR Congress Participation:** ASIF had a booth at the EULAR congress in Vienna in 2024, with IMAS and Delay to Diagnosis abstracts accepted for presentation.
- **Regional Rheumatology Networks:** The potential for providing regional support for members was discussed.
- **Expert Advisory Committee:** ASIF is forming a new Expert Advisory Committee (EAC) to guide their workstreams and partnerships.
- **Psychosocial Support for Members:** ASIF is looking at how to provide skills and knowledge to their members to offer psychosocial support, with a workshop planned to gather input on this initiative.

AxSpA in Colombia and Latin America

Dr Wilson Bautista Molano

Dr Bautista welcomed everyone to Colombia and to his city of Bogotá. He started by reminding delegates about the nomenclature of axial spondyloarthritis or axSpA and the recommended Spanish translation for that is now espondiloartritis axial or SpAax.

An abstract titled Prevalence, demographics, and clinical characteristics of Latin American patients with Spondyloarthritis, published in 2021 summarised the prevalence and features of SpA in Latin America, based on available small studies. The study estimated the prevalence of SpA at 0.28 to 0.9% which is similar to other studies from around the world. Further studies are needed to understand variabilities across the region and current treatment outcomes and socioeconomic impact within this large geographic region.

A study looking at the differences in disease manifestations (AS): EU vs LATAM (2012) concluded that the principal differences were the greater frequency of peripheral arthritis and enthesitis in the Latin America (LA) group, the higher percentage of HLA-B27 in EU group, and the form of treatment, with a greater use of NSAID, steroids, and DMARD in the LA group.

A 2018 study, ASAS-COMOSPA looked at the prevalence and risk of developing comorbidities in patients with SpA in 3 Latin American countries, and compared that prevalence with the general population. The conclusion was that patients with SpA in LA were at increased risk of hypertension and tuberculosis. The report concluded that a systematic evaluation of these comorbidities in all patients with SpA may help to monitor these conditions better.

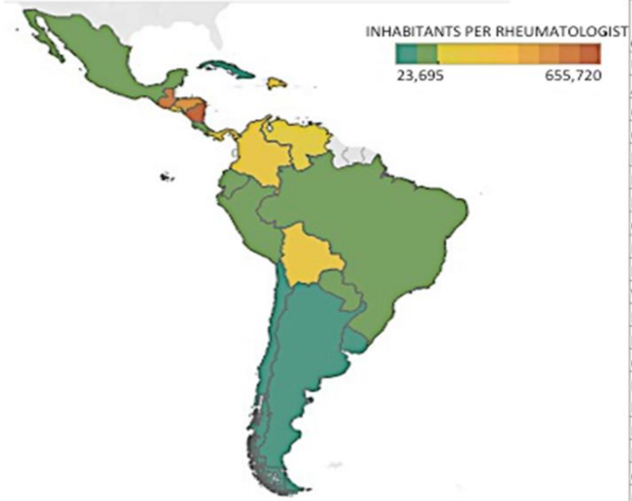
The results of the ASAS-PerSpA Study confirmed previous studies reporting a greater prevalence of peripheral arthritis and enthesitis in patients in Latin America compared with those in European and the Middle East. One plausible explanation for this finding could be, on the one hand, the lower prevalence of the HLA-B27 antigen in Latyin American populations (60% in Latin Americans vs 80% in Asian patients in the study), which has been classically associated with axial involvement, as well as by the higher prevalence of psoriasis in this geographic area. On the other hand, lifestyle and other factors such as microbiome may play a role in the higher prevalence of peripheral manifestations.

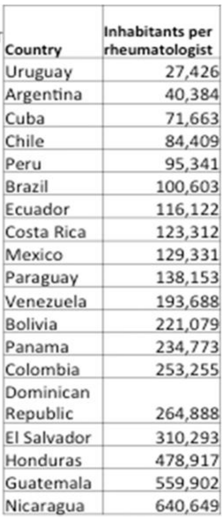
Dr Bautista also reminded delegates about the importance the gut microbiome and the results of a study into the differential gut microbiome in spondyloarthritis patients associated to Blastocystis colonization validated previous findings related to a significant decrease in gut microbiome richness and diversity in SpA patients versus control individuals. It also showed that Blastocystis colonization in control individuals increases gut microbiome richness and diversity, while in patients, it seems to have no impact. This is possibly driven by their chronic inflammation and altered immune system.

The availability of rheumatologists per person significantly affects delays:
Spain – one rheumatologist per 50,000 population
Canada – one rheumatologist per 75,000 population

UK – one rheumatologist per 85,000 population

Latin America – one rheumatologist per 106,838 population



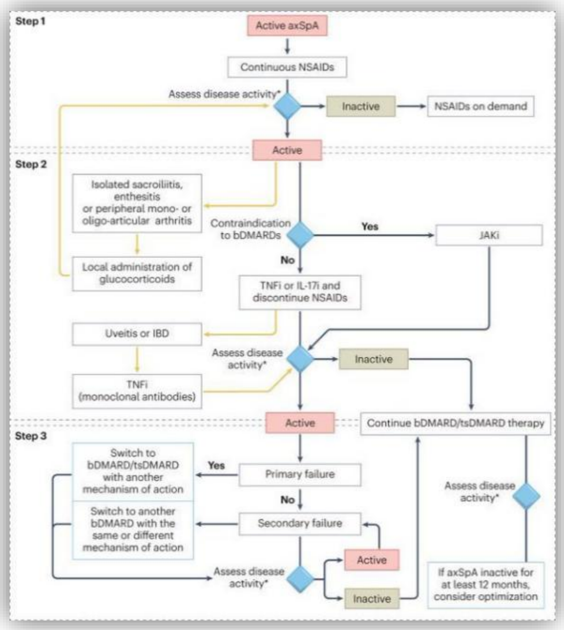


Country	Inhabitants per rheumatologist
Uruguay	27,426
Argentina	40,384
Cuba	71,663
Chile	84,409
Peru	95,341
Brazil	100,603
Ecuador	116,122
Costa Rica	123,312
Mexico	129,331
Paraguay	138,153
Venezuela	193,688
Bolivia	221,079
Panama	234,773
Colombia	253,255
Dominican Republic	264,888
El Salvador	310,293
Honduras	478,917
Guatemala	559,902
Nicaragua	640,649

The lack of awareness of axSpA among HCPs, the general population including those with symptoms remains a problem.

The main unmet needs in the field of SpA in Latin America:

- Diagnostic challenges
- Education and awareness
- Imaging interpretation
- Epidemiological data and disease burden
- Treatment recommendations



Dr Bautista serves as the Chair of the Study Group of Axial Spondyloarthritis and Psoriatic Arthritis of PANLAR leading continental initiatives in the field of Spondyloarthritis, leading webinars and presentations in axSpA. In 2023 Dr Bautista and PANLAR published recommendations for the management of axial spondyloarthritis.

Dr Bautista talked also about the importance including the perspective of individuals affected by axSpA, seeking integration between an informed patient and a highly qualified multidisciplinary care team in the comprehensive management of patients with axSpA. The improvement in health outcomes and the reduction in the cost of chronic inflammatory diseases, such as SpA, are the main advantages of implementing a care model in specialised centre integrating a multidisciplinary team. (https://www.sciencedirect.com/science/article/abs/pii/S2444440524001298)

IMAS and the axSpA research agenda

Jo Lowe

Jo Lowe began the presentation by providing updates on the IMAS and discussing ASIF's approach to moving the project forward. She also shared some new research opportunities that ASIF had been approached about.

Jo discussed the data themes collected in IMAS and highlighted the future direction of the project, emphasising that ASIF members and the Expert Advisory Committee (EAC) would guide this process.

She then outlined some of the opportunities ASAS had presented to ASIF and mentioned other research approaches from private companies and academic/clinical researchers. Jo shared information about a new study ASIF will collaborate on in the upcoming year, which involves working with ASIF members in 17 countries to recruit patients for a survey on the delivery of ASAS quality standards.

Workshop – Research to support the work of patient organisations: what is needed?

Jo L explained how research can benefit patients and Maranda van Dam led the workshop; delegates split into groups and discussed the following questions.

What research evidence is needed and what is missing?

Patient journey and experience

- The full patient journey from onset of symptoms and beyond diagnosis (longitudinal study)
- How people are living with the disease
- Psychological impact
- Other unseen impacts like fatigue, brain fog – particularly when pain levels are under control
- Effects at different stages of life (ageing for example)
- Impact on sexual life

Economic impact of the disease

Aim for a comprehensive assessment of the economic situation:

- On society
- On individuals & carers; aim for a broad look at the socioeconomic impact
- Workplace research; what accommodations are needed / should be available?
- Benefits of being in employment for society and the individual

Clinical research

- Gut health research needed
- Understanding other environmental and lifestyle factors; the total human being
- What does remission mean (patient and doctor perspective)?
- Develop better PROMs that measure broader functionality / life impact
- Causes of axSpA / cure / better diagnostic tests

Can we influence research / ensure patient perspective is integrated

Develop the patient role in research

- Promote the PRP role to axSpA patients and encourage them to get involved
- Train patients in research participation – help to educate patients about research to provide good quality PRP input; this also eases the process for researchers
- Create a global pool of axSpA PRPs and advertise this to researchers

Collaboration is key

- Join forces with other POs from different disease areas in a particular country
- Connect with organisations like EULAR or EUPATI to promote the patient need for different types of research / create a united global voice
- Gather useful data that demonstrates needs of groups of people, for example all RMDs or people in a particular region
- Connect with universities and research centres; tell them what areas patients need research in and offer to support with input on lived experience

Awareness

- Ask patients what they need / what they want to see researched and convey that to researchers
- Highlight that young people have axSpA to demonstrate why economic analysis is needed
- Patient input into research is dependent on area of the world; in many parts of the world, patient participation is not done and often patients don't know what research is taking place
- Patient organisations have an important role in building relationships with relevant stakeholders and conveying what patient need

Improving axSpA knowledge among healthcare professionals

Chair: Raj Mahapatra,

Panellists: Dr Wilson Bautista Molano, Andri Phoka and Yoshihiko Shiono

The panel discussed global differences in rheumatology practices, highlighting the lack of consistency in healthcare professionals' (HCPs) approach to patients. Some rheumatologists do not conduct thorough examinations or value patients' knowledge, creating a significant knowledge gap. There was agreement that many HCPs do not take the time to listen to patients' experiences, with some exceptions. In Japan, patients without the HLA-B27 gene are often dismissed, and many HCPs are economically motivated to prescribe biologics. Andri pointed out that time pressures on HCPs lead to a focus on clinical aspects, rather than addressing patients' concerns.

The discussion also touched on patient empowerment. Maranda van Dam from South Africa noted that patients often feel intimidated by doctors and suggested that patient education and confidence are crucial for advocating for better care. Several participants, including Nadia Malliou from Greece and Prachee Bhosle from India, highlighted the importance of HCPs being open to shifting power dynamics in the doctor-patient relationship.

Dr. Bautista Molano remarked that rheumatologists should be prepared to engage with well-informed patients who bring research into clinical trials and other information. There was consensus that doctors should allow patients to guide conversations about their treatment goals. Michael Mallinson noted that younger doctors are often more open to listening to patients, while Yoshi Shiono spoke of a campaign funded by Pfizer in Japan that educated GPs about axSpA and addressed the patient perspective.

In Cyprus, Andri Phoka has been involved in training patient experts who combine personal experience with anatomical knowledge, and CYLPER has run training sessions for medical professionals on the importance of communication. The discussion concluded with the need for increased education for HCPs worldwide, especially in developing countries where axSpA is a low priority. Maranda van Dam shared that ASASA has successfully engaged HCPs through Continuing Professional Development (CPD) programmes, presenting patient stories to rheumatologists and other specialists. The importance of educating GPs early in their training was also emphasised by Moataz Daoud.

The question raised was what role ASIF should play in improving these efforts and advocating for better education and listening practices among HCPs.

ASIF Members' Reports Session 1 (of 3)

Julieth Buitrago, Espondilitis Anquilosante en Colombia

The foundation has been a member of ASIF since 2022. It focuses on improving the lives of patients with rheumatic diseases. She believes that educating patients about their illnesses enhances the quality of life for both patients and their families. The foundation has participated in numerous activities and events supporting patients, but they also acknowledge ongoing challenges and opportunities for growth.

Lillian Wermskog, Spafo Norge, Norway

Spafo Norge has created a report on axSpa, arthritis, and IBD, which aims is to shorten the referral process to rheumatologists and provide better treatment by educating GPs. Lillann discussed the importance of providing information directly to GPs. Thanks to funding from pharmaceutical supporters, over 5,000 GPs received a printed report. The feedback on the value of the report for both doctors and patients was positive.

Martina Neubauer, Österreichische Vereinigung Morbus Bechterew, Austria

Martina proudly shared that the Austrian Axial Spondyloarthritis patient organisation had celebrated its 40th anniversary. She spoke about the movement therapy groups offered by the organisation and the regional meetings which they hold for their 1600 members. She also described the Gastein Healing Gallery, which offers radon therapy in a unique mountain setting. Martina finished her presentation by talking about a new digital therapeutic app, which is designed to help support people living with axSpa, focusing on exercise, relaxation, and patient education.

Prachee Bhosle, Ankylosing Spondylitis Welfare Society, India

ASWS focuses on transforming the lives of patients in India, where there are many barriers to accessing healthcare. Delayed diagnosis, economic barriers, and social stigma, especially in rural areas, are often the main barriers. ASWS run educational webinars, undertake advocacy for policy changes, crowdfunding for medical expenses, and creating regional support groups where patients can share experiences in their local languages. In such a large country, where many patients live in remote areas, Prachee emphasised the importance of online platforms, like WhatsApp, for patient connection.

Maranda van Dam, Axial Spondyloarthritis Association of South Africa

Maranda shared a candid account of the challenges faced by ASASA, particularly regarding the lack of recognition of their disease by the government and their limited team of volunteers. Despite starting with only three volunteers and nearly shutting down due to burnout and overwhelming growth (from 50 to 1,700 patients), they survived and are now even stronger. After taking a six-month break, they regrouped, signed up new volunteers, and received critical support and resources from other organisations, which helped them rebuild.

Maranda shared how proud she is of their achievements, including recognition for their work in South Africa, and is optimistic about the future. They are preparing to launch more patient support initiatives across the country. She stressed the importance of changing a long-held assumption of who axSpA affects, as an increasing number of Black Africans are being diagnosed. Maranda concluded by offering advice to young organisations, emphasising the importance of building a strong volunteer team and connecting with external support for times of need.

Dr Tu Luidan, Association of Chinese AS Patients, China

Dr Tu Luidan from China introduced a set of guidelines developed by a team of experts, aimed at improving understanding and addressing key concerns for patients with ankylosing spondylitis (AS). The guidelines were created by a multidisciplinary group, including rheumatologists, surgeons, ethicists, imaging specialists, evidence-based medicine experts, and patient society members. The team conducted literature reviews, original studies, and interviews with both experts and patients. The guidelines provide answers to the 15 most frequently asked questions about AS, such as the role of the HLA-B27 gene in diagnosis, the importance of monitoring inflammation, drug selection, and the impact of medications on various health aspects.

The guidelines were published in Chinese and have been well-received by patients and their families. Dr Luidan also introduced a survey to gather feedback from patients on how they prioritise various aspects of AS care.

Friday 18 October

Introducing the Latin American Collaboration between ASIF and ASOPAN

Jo Davies, Priscilla Torres and Gonzalo Tobar

The first ever Latin America Regional Meeting had been held on Wednesday 16 October. The meeting aimed to give an understanding of the situation across Latin America. ASIF has long struggled to gain a wider foothold in the region. We now have 5 members; 2 dedicated axSpA members in Colombia and Chile and 3 x general RMD members in Brazil, Panama and the Caribbean. We believe there are many more potential members out there and we also believe that it is possible that axSpA may be being underdiagnosed in some countries. We think with a good collaboration we might be able to help to improve the lives of axSpA patients in the region.

Mike and Jo Davies had attended the PARE Conference in 2023, where they connected with ASOPAN, a network of patient organisations across Central and South America that had been set up by PANLAR. Following a meeting with ASOPAN at PANLAR, the idea of a collaboration was developed. It was agreed that although there are many differences across the region, there could be strength in working together.

Gonzalo gave an overview of the Regional Meeting (a separate report on this meeting is available). The meeting agree the next steps would be:

- It was agreed to create an ASOPAN axSpA working group
- ASOPAN and ASIF to work together to develop a workplan to introduce axSpA to patient organisations in the region
- Focus on: Communication / Awareness (WASD) and Advocacy

ASIF and ASOPAN were delighted to sign an MOU, signifying our commitment to working with each other to improve the lives of people living with axSpA in the region.

Gonzalo acknowledged the support of Dr Wilson Bautista and Marco Garrido Cumbrera

Emerging therapies and research in axSpA

Prof. Raj Sengupta, Royal National Hospital for Rheumatic Diseases, Bath, UK

This presentation delved into recent advancements in axial spondyloarthritis (axSpA) research, focusing on emerging therapies, digital health innovations, and machine learning applications. It highlighted new diagnostic and monitoring tools, personalised treatment strategies, and insights into disease management.

Personalised Medicine and the Patient Pathway aims to improve patient outcomes by tailoring treatments based on individual disease characteristics. The patient pathway includes early detection, timely referrals, and continuous disease monitoring.

Professor Sengupta outlined some digital innovations in axSpA diagnosis and management

SPADE Tool (Spondyloarthritis Diagnosis Evaluation Tool)
A machine-learning-based tool designed to assist healthcare professionals (HCPs) in diagnosing and managing axSpA.

- Developed for use in primary care, helping general practitioners (GPs) identify patients who may require further rheumatology evaluation.
- The tool includes an **audit component**, which retrospectively analyses patient data, and a **pop-up alert system**, which provides decision support during consultations.
- The tool is accessible via **www.spadetool.co.uk**.

GP Pop-up Tool for Early Detection
Developed by the PRIMIS team at the University of Nottingham.

- Designed to identify patients with suspected axSpA by analysing clinical system searches.
- Provides real-time prompts for GPs to consider axSpA when patients present with symptoms like chronic back pain.

Project Nightingale: Digital Patient Monitoring
A digital initiative aimed at enabling **remote patient monitoring** and **self-reporting** of symptoms.

Digital PROMs (Patient-Reported Outcome Measures)
Captures real-time patient data related to:

- Pain severity
- Mood fluctuations

- Fatigue levels
- Physical activity
- Sleep quality
- Morning stiffness
- Pain interference with daily activities

Allows for better tracking of disease progression and treatment effectiveness.

Flare Tracking and Patient Self-Reported Symptoms

Patients report flares and symptom severity using a digital platform.

- Data analysis shows key flare characteristics, including:
    - Increased pain and fatigue
    - Mood disturbances
    - Stress levels
    - Sleep disruption
    - Increased physical activity in **non-radiographic axSpA (nr-axSpA)** patients during flares
    - Greater reliance on NSAIDs in **radiographic axSpA (r-axSpA)** patients during flares

- Study findings suggest two distinct flare subgroups:
    1. **Shorter duration, severe symptoms**
    2. **Longer duration, milder symptoms**
- These insights enable a **patient-centric approach** in managing flares.

Understanding Pain Mechanisms in axSpA

Types of Pain in AxSpA:

1. **Inflammatory (nociceptive) pain** – Driven by joint inflammation.
2. **Neuropathic pain** – Caused by peripheral nerve damage.
3. **Central sensitization (nociplastic pain)** – Resulting from an overactive nervous system.

- **Pain DETECT and WPI/SSS Scores** are used to assess neuropathic and nociplastic pain components.
- Studies highlight the association between persistent pain symptoms and **incomplete treatment response** to biological therapies.

Future Directions: Digital Revolution in Rheumatology

- **Spinal Mobility Monitoring via ViMove & OpenCap**
  - Technologies like ViMove and OpenCap enable remote tracking of spinal range of motion.
  - Machine learning and image recognition are used for assessing movement patterns.

- **Patient Education & Self-Management**
  - Resources for axSpA management, including exercise programs, are available at **www.ruh.nhs.uk**.
  - Improved education leads to better disease self-management and treatment adherence.

Key Takeaways & Conclusion

- **Earlier diagnosis of axSpA is crucial** for better long-term outcomes.
- **Digital tools** like SPADE, GP pop-ups, and Project Nightingale enable more efficient disease monitoring.
- **Personalized treatment approaches** and emerging therapies are transforming axSpA management.
- **Validation in real-world settings** is essential before widespread adoption of new digital solutions.
- The field is undergoing a **digital revolution**, offering new possibilities for patient care and research.

This presentation underscored the rapid advancements in axSpA research, emphasizing the integration of **AI-driven diagnostics, remote monitoring, and novel therapies** to improve patient outcomes.

Patient-focused research: Value of Achieving Remission in Inflammatory Rheumatic Diseases

Lillann Wermskog

In November 2023, in Brussels, the Global Alliance for Patient Access (GAfPA) hosted a roundtable discussion on the necessity of improving RA and axSpA patients' rates of remission, or at least achieving the tightest possible disease control. Lillann joined others, including 14 patient and expert representatives from different disease areas and countries.

The conversation highlighted the great benefits of remission for individuals' quality of life; identified barriers to achieving remission and produced tactical recommendations for how to overcome those barriers

She concluded by stating that one of the most important things PO's can do is to share reliable knowledge about the disease, giving people the opportunity to have a better quality of life.

Lillann encouraged the use of the report with policy makers, HCPs and key decision makers.

The Report is available here. And the glossary, translated into a few languages can be found here.

Rheumacensus

Andri Phoka

Andri explained that the Rheumacenus project is funded by UCB and is led by a Consensus Council of 22 HCP, patient representatives and payors. This group reached consensus on the unmet needs and potential improvements for axSpA and PsA care. Rheumacensus seeks to confront the difficulties in the existing care pathways for PsA and axSpA and achieve a mutual agreement on possible enhancements.

The Concensus Council meeting provided a forum for multistakeholder collaboration. The group participated in a Delphi e-consultation process, resulting in focusing on four key areas of unmet need: Patient empowerment, patient knowledge, patient-HCP consultation and optimal initial treatment. Calls to action were then developed to support these four areas. The findings were published in Rheumatology and Therapy in April 2024 and can also be found here.

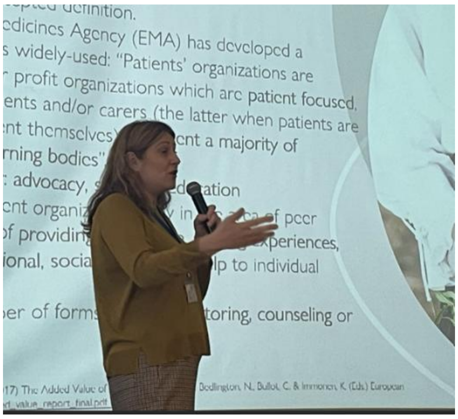
Together with UCB, the group is developing materials to elevate the standard of care. These include axSpA and PsA patient consultation guides, nurse shared decision-making toolkit and an axSpA e-module for patients.

Scan the code to find out more:

You can also find out more on the ASIF website.

How can patient organisations provide psychosocial support for their members

Nadia Malliou



Psychosocial support (PSS) is the dynamic relationship between the psychological and social dimension of a person, where the dimensions influence each other. To perform PSS, you must undergo training and supervision. It should be offered to people in need. Nadia continued, early and adequate psychosocial support can prevent distress and suffering.

For axSpA patients the psychological and physical sides are interlinked. The more physical challenges we have the more stress, fatigue, loss of sleep etc we experience, which leads to greater psychological difficulties.

The IMAS data demonstrates the link between sub-optimal disease and greater psychological burden. The reduction of stress is key to achieving better health outcomes. Nadia recommended exploring the IMAS data on the ASIF website to understand more about the impact of axSpA on patients.

Nadia described the forms of psychological support that patient organisations can offer patients, either directly or referring them to professional services:

1. Peer Support Programmes
2. Psychological Support Services
3. Workshops and Educations

It is important to consider the stigma of living with chronic pain. This flows across many relationships – with HCPs, family and work. Promoting awareness and acceptance of the disease is crucial. We are not the disease. We live with the disease. There is a difference and psychosocial support can help to build resilience and empower patients.

Workshop – Mapping the gaps in psychosocial support within patient organisations

The workshop asked delegates to discuss gaps, barriers to providing support and possible solutions.

The gaps and barriers identified could be split into 2 main categories; financial/structural and cultural.

Financial/structural

- Mental health is typically under-funded;
- Shortage of psychologists/MHHCPs;
- Funding in POs, only limited funds available if any for psychological support; lack of volunteers and difficulty training them;
- Medication, when needed can be difficult to afford/not covered by insurance/not available in public system
- Mental health services do not look at the root cause, such as the disease and only treat symptoms of depression, anxiety etc
- Lack of awareness of the disease and what it means to live with axSpA, other diseases have priority

Cultural

- Stigma: in some regions (Mexico, Colombia, India) all poor mental health is stigmatised and it can be particularly difficult for men to feel that they can talk about their psychological issues; generally people don't want to need to ask for help or accept it; family stigma;
- Hard to reach younger newly diagnosed people; hard to reach and work with families of people living with axSpA
- Undiagnosed people struggling with pain, fear and not getting help.

Delegates then explored possible solutions:

Collaborate with others to raise awareness

- We need to create awareness of the disease and the psychological needs of people living with axSpA
- Is there an opportunity to have joined up global social media campaigning around world mental health day?
- Collaboration with HCP societies and be involved in seminars from specialist MH teams
- Draw on the experiences and ideas of HCPs who live with axSpA; can they help to raise awareness of mental health needs?

Provision of psychosocial care by patient organisations

- Provide virtual peer support between patients / axSpA community
- Train volunteers to provide support and if possible, train some family members of patients
- Host monthly support sessions (could be online)
- Create social media platforms specifically for people to talk about psychological challenges
- Provide information and materials; including information about exercise benefits and techniques to alleviate stress / anxiety

- Host podcasts with mental health HCPs – would need to be geographically and culturally relevant

Special focus on newly diagnosed patients

- Recognise that, often, newly diagnosed patients need extra psychological support
- Focus on trying to reach people at the point of diagnosis in the HC system
- Try to connect with rheumatology services, asking that they provide information about PO at point of diagnosis

Battling the stigma

- Share patient stories with other patients so they do not feel alone / different
- Create an online support network, including asynchronous messaging
- Enable people to seek support anonymously

Funding

- Seek funding or sponsorship specifically to develop PSS services
- Prioritise things that will have the biggest impact
- Diversify funding sources; is money available from MH or chronic disease foundations?
- Can crowd-funding work?

Strengthening relations with the LARS

Dieter Wiek, Gonzalo Tobar and Dr Dzifa Dey

The presentation discussed the collaboration between patient organizations and professional rheumatology networks.

Dieter Wiek talked about EULAR PARE (People with Arthritis/Rheumatism in Europe), one of the 3 pillars or communities of EULAR (European Alliance of Associations for Rheumatology). PARE is a network of national organisations united to ensure the voice of people with rheumatic and musculoskeletal diseases (RMDs) is heard and has influence among decision makers within Europe.

EULAR provides professional and patient education materials and courses available globally. They have a School of Rheumatology which also includes some free of charge webinars.

EULAR PARE's key annual event is the PARE conference. There is also a network of patient research partners that support and contribute to scientific research and projects. PARE also runs webinars, podcasts and a regular newsletter. Anyone can register, see here. A number of ASIF's members are represented on IPARE, which is the International PARE Working Group. This was convened to connect and exchange with POs from continents other than EUROPE to create a globally active network and initiate collaborative projects in the field of education, research, quality of care, congress and advocacy.

Dieter reminded delegates they can submit abstracts to the congress and there are some funds available each year towards travel available for successful presenters.

Gozalo Tobar was welcomed to the stage to talk about ASOPAN and PANLAR. There are 35 countries in Latin America and 650 million inhabitants. According to ECLAC, LatAm is the most inequal region in the world and on average, there is only one rheumatologist per 106,838 inhabitants, but the variation between countries differs dramatically.

There are also problems of large countries. In Chile for example, the 3 regions in the North of the country have only 2 rheumatologists for more than 1,200,000 inhabitants. And patients may have to travel over 2,000km to get to see a rheumatologist and even then it is a private rheumatologist for maybe more than €70

Gonzalo talked about ASOPAN, the Pan-American Network of Rheumatic Disease Patient Associations. Created at PANLAR in 2018. The association has more than 60 associations in 17 countries. They have created a manifesto, detailing the care needs for RMD patients in the region.

The network aims to improve the quality of life for patients, focusing on access to healthcare and early diagnosis. Gonzalo emphasised the need for unity and shared practice across countries

One rheumatologist per x population:

Uruguay: 27,426
Argentina: 40,384
Cuba: 71,663
Chile: 84,409
Perú: 95,341
Brazil: 100,603
Panamá: 234,773
Colombia: 253,255
Honduras: 478,917
Guatemala: 559,902
Nicaragua: 640,649

Gonzalo concludes by emphasising the benefits of taking part in IPARE and doing the EULAR PRP course. He encouraged delegates present to participate in conferences, submit abstracts, and contribute to global advocacy efforts.

Dr Dzifa Dey joined the conference via Zoom. She spoke from multiple perspectives: as a rheumatologist in Ghana, an advocate for patients with rheumatic diseases, and as the president of the African League of Associations for Rheumatology (AFLAR). She emphasised the importance of patient engagement in improving rheumatological care in Africa. She believes that patient involvement in healthcare leads to better outcomes, better disease management, and improved adherence to treatment.

In Africa, however, there are challenges such as lack of awareness, education, resources, and cultural barriers. There is also a shortage of rheumatologists, with only three in Ghana serving a population of 30 million people. Stigma around rheumatic diseases, especially when people associate them with spiritual causes, further hinders care.

To address these issues, Dr Dey and a group of volunteers established the Rheumatology Initiative (tRi), focusing on education, advocacy, and research. They use social media and other platforms to increase awareness, advocate for better policies, and gather data to challenge misconceptions about the diseases. The initiative also provides ancillary services, such as physiotherapy and dental screenings, and works to reduce the financial burden on patients by teaching them life skills for income generation.

Dr Dey highlighted the importance of engaging healthcare professionals, especially general practitioners, in diagnosing and treating rheumatic diseases. In Ghana, they successfully advocated for the inclusion of rheumatology medications on the national health insurance scheme and encouraged pharmaceutical companies to reduce medication costs.

Dr Dey also mentioned the lack of patient organisations across Africa, noting that only 16 countries have active support groups for rheumatic disease patients. She advocates for building structured networks and partnerships across Africa, adapting educational materials to local contexts, and ensuring patient voices are heard in health policy discussions.

In conclusion, she stressed that collaboration between healthcare professionals and patient organisations is crucial for improving awareness, outcomes, and access to care in Africa. She believes that through collective effort, real change is possible.

Dr Dey said social media and mobile technology can help with the African population, at least the younger ones.

It would be great to increase the number of patient organisations. However, there is a need to ensure that doctors and HCPs understand the impact of patient engagement and at the same time to think about how to get patients themselves to see the benefit of this. The question is how to find and support, or support the establishment of, patient groups.

ASIF Members' Reports Session 2 (of 3)

Anita Sofie Hauknes, Bekhterev Norge, Norway

Anita talked about being in the room with other patients. It feels good because everyone understands the pain, the fatigue, the joy of life. Creating communities for axSpA patients is the main objective of Bekhtereve Norge and its 6 local associations. They also support local associations in planning and carrying out activities for the local members. The main activity is hydrotherapy exercise sessions. Altogether there are around 20 groups meeting each week.   Additionally, patients benefit from meeting other patients and being in a community. Since the 1980s, patients in Norway have been able to apply for treatment abroad in warmer countries.   In 2024 1,717 patients will spend 4 weeks with active and passive treatments giving them a new lease of life. There is pressure now on this treatment and Bekhtereve Norge fights to retain it on behalf of its members.

Massiel Oro, FUNARP, Panama

FUNARP is the arthritis association of Panama, and a member of ASOPAN. Their main objective is to support and empower people with disease to live a fulfilling life via programmes and to provide tools and resources to navigate their daily life. FUNARP plans to advocate. FUNARP can help members with legal advice, especially for work. Every month they have educational Instagram Life programmes where they talk about areas of arthritis and recently had their first on axSpA. They had 1,200 people watch the Instagram video. AxSpA is not well known in Panama. FUNARP uses social media a lot to raise awareness.

As in many countries, people in Panama think that arthritis is only an old person's disease. FUNARP are working with young people to raise awareness that it can also affect younger people. They are trying to provide emotional support with community/art groups.

There are some biologics available in Panama but there are not enough rheumatologists in Panama. FUNARP is trying to make it easier for both doctors and patients.

Jimit Thakkar, StandforAS, India

StandforAS was formed in 2016 and registered in 2019. The main objective is to reduce the delay in diagnosis. They believe that there are 3 key things that will help to do that. First is to raise awareness, second is to raise awareness and third is to raise awareness.

They believe that social media is the way to go. There will be 900million active internet users in India by 2025. This will help to overcome geographical boundaries and maximise their reach. StandforAS has received an award for their facebook posts.

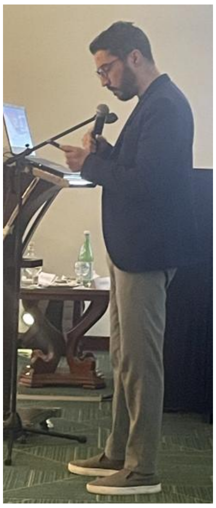
For World Arthritis Day 2016 they formed the largest human image of a human bone to get into the Guinness Book of World Records. They took part in the ASIF Talk to be Heard campaign and reached 35k views. For WAS Day 2019 they reached out to 60k professionals about back pain and the difference of inflammatory and mechanical back pain. StandforAS are a trusted source of information for many subscribers and followers (called axSpa warriors) and have more than 5.8million views on YouTube.

The next task is to create a website and they are forming an alliance for rheumatic diseases in India (ASWS is also part of that). They want to organise 20 in person seminars in 2025.

Ruta Grigiene, Judesys, Lithuania
Judesys means movement. Every year they have 2 events to support and educate those affected by axSpA. The first is a one-day event giving up to date information and practical advice on managing your condition. The second is a 1-2 night retreat for patients and their families. The retreat emphasises the importance of patient interaction and family integration, helping to build a supportive community and provide a space for sharing experiences and strategies for coping with the disease. These activities are supported by the Ministry of Social Security in Lithuania.

They are currently undertaking an important project to update the association's name and remove the term Bechterew's disease from their official documents and communications. This is to better align with worldwide standards.

Bilel Belkham, FEAS, Algeria
FEAS was established in 2020 to address the needs of individuals suffering from Spondyloarthritis and Rheumatoid Arthritis in Algeria. The main mission is to provide information about these diseases; facilitate dialogue between patients and HCPs; advocate for patient rights; and support medical research to develop new treatments.



The association also organises events for example for WAS Day to raise awareness. In Algeria, a large number of people are affected by RA. Since its creation FEAS has supported thousands of patients with psychological and practical support. Together we break the silence, remove the pain and move forward hand in hand against spondyloarthritis.

Raj Mahapatra, NASS, UK

The poster was about a campaign that NASS ran in Belfast, Northern Ireland. They were trying to work out the best way to engage a younger audience to get them to fill in a symptom checker and then to access healthcare as part of that process. They engaged with local radio stations and other media outlets, but also worked with primary and secondary healthcare doctors and providers. They ran a 6-week campaign targeting 18-40 year olds who had persistent lower back pain. It was shaped around 'broken dreams'.

They used poster and billboard advertising, a radio campaign, running 30 second adverts 100 times. There were also two magazine articles and a paid-for social media campaign targeting people in Belfast. In just 6 weeks the social media advertising reached 831,000 people. The advertising engaged 88,000 people reaching 81% of the targeted people in the audience. As a result of that, the online symptom checker was completed 389 times of which 73% met the threshold for a referral to rheumatology. NASS are now tracking that data to see where those referrals end up.

Wanda Heloisa, Instituto Gruparj Petropolis, Brazil
The institution was founded in July 2001. They offer education, assistance and advocacy. They offer health education throughout Brazil. They run 58 health education courses and they have seen a huge increase in health literacy and in knowledge of rheumatic diseases, including spondyloarthritis. They have presented 3 papers at the EULAR congress. They have trained 183 primary care HCPs. They run an event where they bring together patients, families and HCPs to learn about the most recent treatments and public policy. In the last 20 years, they have received various honours and awards.

Dieter Wiek, EULAR PARE, (Germany)
Having talked earlier about EULAR PARE, Dieter talked about expanding IPARE. He hoped that more from Asia and Africa might join, but funding is a bit tight as it currently comes from PARE. He is seeking extra funding. There is some for participation at the EULAR congress. He recommends that delegates submit an abstract.

Marco Garrido Cumbrera, Ceade, SPAIN

Marco presented the ‘tie your shoelace’ campaign. One problem people with axSpA can have because of stiffness is being able to tie shoelaces. The idea is to use fluorescent orange shoelaces in order to raise awareness. They will ask people to take part and try to get famous people to also take part. The idea is to record yourself tying your shoelaces. According to IMAS data, tying your shoelaces is the third functional limitation in a very long list. It is a way to start conversation. When people upload the video or ask the question, they will be led to the website where they will find out about axSpA. The campaign will last a long time – it will not be limited. Marco also had an orange backpack. He asked Gonzalo, who is not an axSpA patient, to put the backpack on and to try to tie his shoelaces – to feel the functional limitation. This is to indicate the everyday burden of living with the disease.

Marco was happy for ASIF and ASIF members to take part in the campaign.

Saturday 19 October

ASIF Members' Reports Session 3 (of 3)

Moataz, CSA, Canada

The CSA ran an awareness campaign for axSpA featuring the story of an orthopaedic resident who struggled to get diagnosed. The campaign included social media marketing, an inflammatory back pain quiz, and resources to help patients advocate for themselves with their doctors. The campaign was very successful, reaching over 1.2 million impressions and resulting in over 3,300 downloads of the patient guides. The CSA has now built the capabilities to run these types of campaigns in-house rather than relying on external vendors.

Yoshi, Japan AS Club

In Japan, the number of registered AS patients has increased 5-fold from 2015 to 2022, but the proportion of younger patients (20s and 30s) has decreased from 33% to 20%. To address this, they are building a network between AS experts and family doctors to improve diagnosis and treatment, using an e-consulting platform. They are also providing support and education for both newly diagnosed and experienced AS patients, including annual meetings and a patient magazine.

Nadia Malliou, Hellenic League against Rheumatism (ELEANA), Greece

ELEANA did not previously have any AS-specific activities, but after joining ASIF, they were motivated to start focused initiatives. They ran a successful awareness campaign using the "It's all connected" videos after securing local funding. They also held a well-attended webinar featuring patient testimonials about living with AS. Going forward, ELEANA are working on a programme with rheumatologists and GPs in Greece to improve diagnosis and awareness.

Natalia Torres, Chilean Spondyloarthritis Foundation

The Chilean Spondyloarthritis Foundation has shifted its focus to advocating for access to treatment, as there are significant barriers in Chile. They worked with a Chilean rheumatologist to characterise the Chilean AS patient population through a survey. The 2022 survey of 313 patients found significant gender disparities, with women reporting lower quality of life, higher disease activity and impact, and less access to biologic treatments.

Geraldine Bonites, ASAPH, Philippines

The Ankylosing Spondylitis Association of the Philippines (ASAP) is part of the Philippine Alliance of Patient Organizations (PAPO)

- ASAP organized a mental health seminar for AS patients, recognizing the significant impact on mental wellbeing
- Future plans include registering ASAP as a non-profit to better assist members, conducting regular medical missions, and partnering with pharmaceutical companies on clinical trials

Marco Garrido Cumbrera, CEADE, Spain

Marco shared that CEADE (Spanish Association for Spondyloarthritis), represents 18 patient organisations across Spain. They engage in research projects such as IMAS and, its original project, Atlas. CEADE collaborates with the Spanish Society for Rheumatology and other experts in the field.

CEADE has a scientific committee that includes both clinical and scientific members. They participate in awareness campaigns, including a nationwide race where participants, including patients, relatives, and healthcare professionals, wear custom-designed t-shirts to show support.

They also award an annual scientific prize to outstanding rheumatologists in Spain, which is organised with the University of Cordoba. CEADE has held seven meetings in Spanish Parliament to raise awareness and push for new legislation regarding axSpA.

Andri Phoka, CYLPER, Cyprus

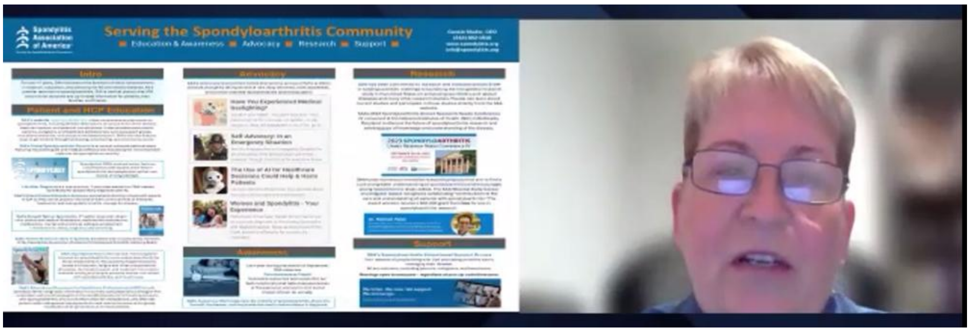
The Cyprus League for Rheumatic Diseases is celebrating its 40th anniversary. It covers all RMD's, including axSpA. Andri shared some of the organisation's key achievements, including last year's successful World Arthritis Day campaign. CYLPER collaborated with local organisations to achieve media coverage, as well as running promotional activities in major shopping malls.

CYLPER hosted a Self-Management Conference on managing rheumatic diseases. Distinguished speakers including government officials and renowned rheumatologists spoke at the event, which also included a mindfulness workshop.

As part of their awareness efforts, CYLPER ran an annual campaign with companies, celebrities, and the public who purchased and wore branded items (like t-shirts and bandanas) to show support and raise awareness. They sold 3,000 bandanas and had 250 participants in a walk along a coastline in Larnaca. The campaign has increased recognition of the organisation, resulting in collaborations with large companies and further partnerships for other initiatives. The campaign's focus is to raise awareness of the challenges of living with RMDs and foster empathy.

Finally, Andri stressed the importance of innovative marketing approaches to keep the organisation visible and engaging, suggesting the potential for collaborative campaigns in the future.

Cassie Shafer, SAA, USA (joined by Zoom)
The Spondylitis Association of America (SAA) celebrated its 40th anniversary in 2023 and runs numerous initiatives to support patients with spondyloarthritis (SpA). Some of their key accomplishments include launching a comprehensive website (spondylitis.org), hosting an annual Global Spondylitis Summit, and releasing a weekly podcast, "Spondy Cast," which has gained significant popularity. The SAA also offers a video series, "Life After Diagnosis," for newly diagnosed individuals, along with virtual webinars and patient brochures, now available in Spanish.



In addition to patient-focused resources, the SAA has created Continuing Medical Education (CME) courses for healthcare professionals, with over 15,000 physicians completing the training. They have also been active in advocacy, with over 2,500 registered advocates and ongoing efforts for Capitol Hill Day in 2026. The organisation runs awareness campaigns for Spondylitis Awareness Month, Pain Awareness, and Disability Awareness Month, and has invested over US$10 million in research since 2003. Their research conferences and early career investigator awards continue to promote scientific advancements in the field.

The SAA also offers virtual and hybrid support groups, which have allowed them to reach patients globally. Their broad range of activities and efforts to engage patients, healthcare providers, and policymakers make them a highly influential organisation in the spondyloarthritis community.

Zhivko Yankov, Bulgaria

The association is 15 years old this year. To advance its mission and improve the quality of life for people with axSpA, the organisation conducts a survey every three years, in collaboration with the Bulgarian Academy of Science. The survey, which is validated and accredited, collects data on physical health, medical support, rehabilitation, information access, and overall trends. The most recent survey revealed that over 60% of patients experience physical pain, while 80% have visible changes in their bodies, indicating late diagnoses.

The survey also highlighted significant challenges: over 50% of patients lack expert medical help, and 75% do not participate in physical activity due to pain and depression. Additionally, 30% of patients still lack access to information, which is concerning given the information age. While patients have access to medications and free rehabilitation twice a year, the organisation is advocating for more psychological support and improved access to consultations. The organisation also provides consultations for young people, with a focus on dermatology for those under 18. Their annual national events aim to raise awareness, with ongoing efforts to address these challenges.

Celebrating the dedication of two statesmen

Maranda van Dam spoke to Dr Muhammad Asim Khan and Michael Mallinson about their journeys in the world of axSpA. They explored how living with the condition inspired them to spend their lives working to improve the lives of others affected by the disease.

Michael shared his journey as a volunteer and advocate, from joining the Ontario Spondylitis Association to founding the Canadian Spondylitis Association (CSA). His motivation was to prevent others from enduring the 10-year diagnostic delay he experienced.

Dr. Khan reflected on his life as both a patient and clinician. As a child, he was misdiagnosed and treated with intravenous honey before finally receiving his diagnosis in medical school.

Michael highlighted how advocacy has evolved with technology, empowering patients and shifting the doctor-patient dynamic to shared decision-making. Dr. Khan discussed the progress in treatment, from NSAIDs to biologics and JAK inhibitors, though accessibility remains a challenge. He also emphasised the growing interest in rheumatology but noted there was still a shortage of trained specialists.

On motivation, Michael finds volunteering therapeutic, helping to educate and build a supportive community. It is known that a well-informed patient will have a better outcome. He's troubled by misinformation in online groups. Dr. Khan sees recognition from peers as a proud achievement and referenced his 2000 article, *Patient/Doctor*. He also published a key reference book on axial spondyloarthritis, endorsed by ASIF.

For emerging advocates, Michael advised learning about the disease, so that your voice is an informed one; value your voice – it is as important as anyone else's. He recommended joining an organisation rather than working alone and pacing yourself. Dr. Khan stressed the importance of ethics and empathy in rheumatology, noting that truly listening to patients is vital for diagnosis.

A question from the audience addressed volunteer burnout. The advice: seek support, find funding for help, and take breaks when needed. Maranda closed by thanking Michael and Dr. Khan for their lifelong dedication to the axSpA community.

Rene Bräm (on Zoom) said, *Michael and Dr Khan, you have improved the quality of life of many patients all over the world, thank you for your commitment over the decades and the great collaboration. What an honour to know you, wonderful session, thank you so much.*

On behalf off the delegates and the wider axSpA community, Maranda thanked both Dr Khan and Michael for their unwavering dedication to the international axSpA community.

Closing remarks

The delegates presented the three Jo's with thank you bouquets for all their hard work.

Zhivko addressed the delegates with his closing remarks. As we bring this remarkable event to a close, he wanted to take a moment to reflect on everything we had achieved together. We shared ideas, built meaningful connections and reaffirmed our commitment to the mission that unites us. He said it had been truly inspiring to witness the dedication and passion that each of the delegates brings to this work. One of the things Zhivko valued most about this gathering is that, whilst online meetings and technology have their place, nothing can replace the power of face-to-face meetings. Zhivko thanked our wonderful hosts. Their warmth and hospitality made everyone feel at home. Their organisation ensured the success of the event and their support made it all the more unforgettable. Julieth, John and Yanneth were presented with thank you gifts.

The Council Meeting closed with a sightseeing trip up Monserrate, with its magnificent views and a dinner of Colombian specialities.

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