

ASIF Newsletter: December 2024

Message from the President

Dear friends,

What an incredible experience it was to see so many of our members in Bogotá, Colombia for our Council Meeting. Thank you to everyone who travelled to join us in person and to those who attended online. You can read more about the meeting below.



Following our recent call for new Trustees, we are delighted to announce the successful appointments. Prachee Bhosle, Julieth Buitrago and Nadia Malliou. The quality of applications was impressive, and we thank all who applied. The new Trustees will bring fresh ideas and expertise to the Board. I am sorry to report that Susan Davies resigned from her position as Treasurer.

The full Trustee Board is now as follows:


Zhivko Yankov, Chair
Lillann Wermskog, Vice Chair
Andri Phoka, Secretary
Prachee Bhosle
Julieth Buitrago
Tuncay Duruöz
Nadia Malliou
Cassie Shafer

In addition to welcoming our new Trustees, we have said goodbye to Raj Mahapatra and Maranda van Dam who have stepped down as Trustees. I have spoken more about them later in the newsletter.

Mike Mandelbaum has also left ASIF. During his time with us, Mike contributed significantly to our work, especially in advancing key initiatives and strengthening our partnerships. We are grateful for his efforts and the dedication he has shown to the organisation. We wish him every success in his future endeavours.

Together, with the Trustees and staff, I wish you a happy end to the year and a great start to 2025. Thank you for all you have done this year; we look forward to working with you to improve the lives of people living with axSpA next year.

Best wishes,


Zhivko Yankov, Chair of ASIF

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News from ASIF

Bringing our members together



Bringing together over 40 patient representatives from 25 countries resulted in a melting pot of conversations and ideas for the future.

Perhaps the most important outcomes from the meeting were sharing experiences and strengthening new and existing

relationships.

Running a patient organisation is incredibly rewarding but also hugely challenging. Knowing that the challenges faced are not unique and hearing how others have overcome them is incredibly powerful.

Delegates heard a presentation on emerging therapies and research in axSpA and participated in workshops exploring what research is needed to support the work of patient organisations. They participated in a panel discussion on improving axSpA knowledge among healthcare professionals and heard about how they can help strengthen relationships between patient organisations and professional rheumatology bodies.

One of the most popular sessions focused on psychosocial support – where the gaps are, how patient organisations can support their members and best practices to

overcome barriers. Throughout the meeting, delegates were invited to present a poster about their organisation, facilitating the sharing of experiences and an increased awareness about how different organisations work around the world.

“Learnings from the speakers, the moderators, the workshop leaders and the new information and knowledge acquired from other participants”, this was one of the responses to the question ‘what did you like best about the ASIF Council Meeting?’ in the feedback survey.

[View Posters.](#)

Much of what was discussed at the meeting will go on to inform ASIF’s work going forward. A full report on the ASIF Council Meeting, which was held in Colombia in October will be available early in the new year.

The Council Meeting educational programme was sponsored by Novartis, AbbVie and UCB



First Latin American Regional Meeting



Collaboration is a vital step in improving the lives of people living with axSpA. ASIF and The Pan American Network of Associations of Rheumatic Patients (ASOPAN) held a joint Latin American Regional meeting the day before the ASIF Council Meeting began in Bogotá. This meeting was the first of its kind and resulted in representatives

from Patient Organisations in Brazil, Chile, Panama, Mexico, and Colombia sharing experiences and discussing the needs of their members.

ASOPAN (The Pan American Network of Associations of Rheumatic Patients) is a network of patient organisations throughout Latin America supporting patients with RMDs. Of their members, few specialise in axSpA and many have limited knowledge of the disease. One objective of this meeting was to explore how ASOPAN and ASIF could

work together. After a stimulating day of discussions and learning, it was agreed that ASOPAN would create a working group on axSpA and ASIF would assist in the development of a workplan to educate patient organisations in the region on axSpA. This would both enable them to better support people living with axSpA and raise awareness of the disease across the continent.

ASIF and ASOPAN signed a Memorandum of Understanding (MOU) which will underscore our future work together. Both foundations, along with the patient organisations are committed to using this partnership to improve the lives of people living with axSpA across Latin America.

A report on this meeting will be available soon.

Introducing our new Trustees



Prachee Bhosle, India

Prachee is the President of the Ankylosing Spondylitis Welfare Society (ASWS), a patient-led charity in India dedicated to raising awareness and advocating for axSpA patients and caregivers.

Prachee holds a Master's degree in Social Psychology and a Postgraduate Diploma in Counselling Psychology. While raising her children and taking care of several pets, she remained committed to social work and advocacy. Prachee has represented ASWS at international platforms such as the GAfPA Roundtable in Brussels, the EULAR Conference in Vienna, the ASIF meeting in Bogota, and the PARE Conference in Brussels. She was also a member of the Novartis Health Advocacy Council. Prachee continues to balance her family life and advocacy work, striving to create positive change for the axSpA community.



Julieth Buitrago, Colombia

Julieth was born in Colombia and raised in Bogotá. She earned her degree as a lawyer and business administrator. She specialised in labour law, social security and business management and has an MBA in Business and Administration.

She was diagnosed with axSpA in 2010 and since then has worked to lead and support the axSpA community and those with other conditions.

In 2014, Julieth became a founding member of the Ankylosing Spondylitis Foundation in Colombia, an organisation created to spread knowledge of the disease through a network of multipliers, to advance early detection and support patients by improving their quality of life.



Nadia Malliou, Greece

Nadia is a licensed cognitive and experimental psychologist experienced in various professional settings both in mental health services, primary care services and administration. She's an axSpA patient herself and focuses on RMDs and chronic pain working as a volunteer with EULAR PARE, the Pain Alliance Europe-PAE, the European Pain Federation EFIC, ASIF, the Hellenic League Against Rheumatism ELEANA and the Federation for Rare Diseases.

Nadia recently started her PhD. Meanwhile, she's a volunteer supporting patients in the Pain Unit of Thessaloniki General Hospital AHEPA. She has participated in several research projects either as a researcher or a patient research partner and has been an invited speaker in numerous conferences. Working with HCPs but most importantly with other patients has been a meaningful experience that contributed to her empowerment and self-improvement as a patient and a professional. Nadia's inspirational quote is: everyone you meet is fighting a battle you know nothing about. Be kind. Always.

Thank you

A message from Zhivko Yankov, President of ASIF



"I would like to acknowledge two individuals who have played an essential role in ASIF's journey: Raj Mahapatra and Maranda van Dam. Both have served ASIF with remarkable dedication and passion over the years, and their work has had a profound and lasting impact on the organisation.

"Raj, your wisdom and strategic insights have been invaluable. From guiding critical decisions to helping shape the future of ASIF, your leadership has steered us through both challenging and prosperous times. Your thoughtful contributions have left an indelible mark on this organization, and ASIF is stronger because of your efforts.



Maranda, your tireless work and commitment to ASIF's mission have been nothing short of inspiring. You have been a driving force behind many of our key initiatives, and your passion for supporting people living with Axial Spondyloarthritis has brought us closer to our goals. Your dedication has made a tangible difference in the lives of those we serve.

"ASIF is what it is today because of the hard work, dedication, and vision that both of you brought to the table. We will forever be grateful for the time and energy you've invested in helping us grow and thrive.

"On behalf of everyone at ASIF, thank you both for your service. While we will miss your presence on the board, we know that your contributions will continue to echo throughout the organisation for years to come. We wish you both all the best in your future endeavours and hope that our paths will cross again soon."

Spotlight on our Members

A message from CEADE...

It is with great enthusiasm that we inform you that, after the CEADE General Assembly held in Cordoba on 29 June 2024, it was agreed that a new Board of Directors would assume the responsibility of the organisation.

Marco Garrido, who already served on the Executive Board as liaison with ASIF, has been elected as the new President, accompanied by an experienced team of patient representatives.



Marco Garrido has extensive experience in axSpA research, being responsible for the REUMAVID study, the Atlas of Axial Spondyloarthritis in Spain, the European Map of Axial Spondyloarthritis (EMAS) and the International Map of Axial Spondyloarthritis (IMAS), collaborating with rheumatologists from ASAS, several scientific societies in Rheumatology and patient representative members of ASIF, and rheumatologists and entities from more than 25 countries.

We thank Pedro Plazuelo Ramos for his great dedication and hard work during the last 12 years as President of CEADE. His legacy has been fundamental for the positioning and credibility of the organisation.

ASIF would like to congratulate Marco and thank Pedro for his commitment to improving the lives of people living with axSpA.

Ankylosing Spondylitis Foundation in Colombia

Since its creation, the Ankylosing Spondylitis Foundation in Colombia has contributed to helping those patients recently diagnosed, guiding, and promoting care to achieve a better quality of life and effectiveness in treatments or medical recommendations.

The work carried out by the Foundation is achieved through social networks such as Facebook, Instagram, YouTube, LinkedIn and WhatsApp through which patients, caregivers, family members and others seek information and advice on Spondyloarthritis.

Patients are fundamental in the development of our mission, since we have sought to create a network of patients who multiply knowledge, who through education achieve empowerment for decision-making by encouraging them to participate in the responsibility of their care and in what can affect their health status. Likewise, we teach patients to have the ability to prepare for their medical consultations in order to improve the doctor-patient relationship and ensure that health care is effective.



It is important that the Foundation seeks to raise awareness in society about Spondyloarthritis, which is an invisible disease in some cases and for which there is a lack of knowledge both in citizens and in the primary health care medical community; thus, through information campaigns in health care centers or public places, we deliver brochures that can raise awareness about a medical condition.

We have the support of stakeholders such as the academic and medical community who value the patient as important in their research, trials, studies and seek to work hand in hand to innovate in pharmacological and non-pharmacological treatments and to have a better understanding of the condition in the patient by analysing the impact that a chronic disease brings with it.

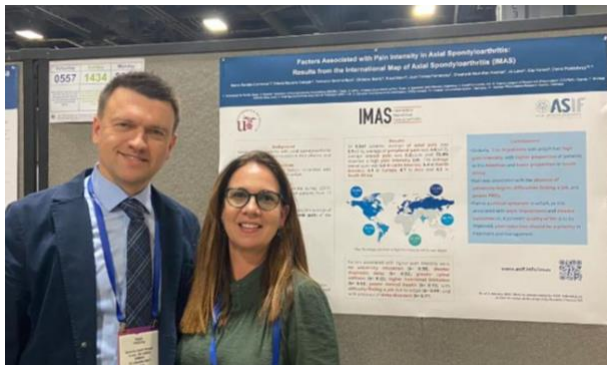


We hold face-to-face meetings for patients, caregivers and family members that have the purpose of sharing and exchanging experiences, learning relevant aspects through the direct interaction of patients and health professionals.

Patient representation with health authorities is essential, since policies are changing and it is necessary to have their opinion on those reforms that may affect medical care and treatments. To this end, the Foundation interacts with other patient organisations to defend and voice their needs. Additionally, the Foundation has legal advice in situations of inconveniences in the provision of services as well as in the recognition of economic benefits such as disability pensions.

Every day the Foundation is strengthened by the work carried out, generating positive impacts in the community and promoting solidarity among patients. We are grateful to all the volunteers who participate in the development of our work.

International Meetings



American College of Rheumatology

Annual American College of Rheumatology annual meeting (ACR Convergence) 2024 took place November 14–19 in Washington, D.C.

ASIF continued dissemination of the International Map of Axial Spondyloarthritis (IMAS) findings at the congress. Drs Victoria Navarro-Compán and Denis Poddubnyy (pictured) from the IMAS Scientific Committee presented the poster on 'Factors Associated with Pain Intensity in axSpA'.

The data analysis seeks to identify which factors, such as sociodemographic factors, lifestyle or comorbidities are most often reported alongside higher pain intensity. The poster identifies several factors, including difficulties in finding a job; poorer mental health; greater spinal stiffness and increased functional limitation; as well as a lower level of education (lack of university degree). The poster concludes that pain is a critical

element and that to improve overall quality of life, pain reduction should be a priority of treatment.

Thank you to Drs Navarro-Compán and Poddubnyy for their continued support of IMAS.

EULAR PARE Conference

The EULAR PARE Conference is an annual educational and networking event featuring a different topic each year and offering a high-quality programme for the RMD community with keynote speakers, debates and workshops spanning three days.

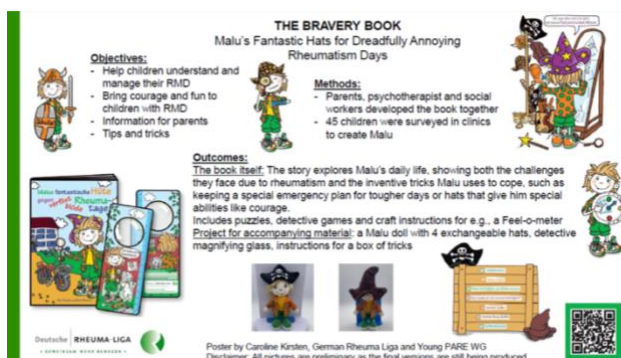
Running from 28-30 November in Brussels, this year's meeting focussed on the role of patients and patient representatives in rheumatology research.



Jo Lowe, ASIF's Project Manager, represented ASIF at the conference and took part in several workshops exploring how to involve patients in research, including how to make collaborative research the standard approach and how to work with research consortia. The workshops provided a fantastic opportunity to better understand

barriers and to collectively develop solutions. The conference also provided valuable information on the EULAR manifesto campaign and advice on submitting abstracts to the annual EULAR congress.

During the conference, several sessions were dedicated to Best Practice and Inspiration from the RMD community. These sessions give the opportunity to learn about PARE activities and projects presented by the community. Patient and patient representatives from around the world presented almost 50 posters showcasing their work. Jo presented the ASIF poster about developing awareness materials on the 'signs and symptoms of axSpA'.



The winning poster was about a book developed especially for children with RMDs. The poster titled 'THE BRAVERY BOOK: Malu's Fantastic Hats for Dreadfully Annoying Rheumatism Days' was presented by Caroline Kirsten from the German Rheuma Liga and a member of the Young PARE working group. You can [read more about the book here](#) (website in German).

International Collaborations



Rheumacensus

Navigating healthcare appointments with confidence

The challenges that come with axial spondyloarthritis (axSpA) can be varied, which calls for a personalised approach to care. Shared decision-making encapsulates this idea by bringing together the expertise of healthcare professionals (HCPs) and the lived experience of those with axSpA to create a strong alliance in the management of healthcare decisions. RHEUMACENSUS, an initiative led by HCPs, payors and patient representatives, is dedicated to elevating the standard of care for patients with axSpA. With the support of UCB, the initiative has launched a step-by-

step guide to help patients prepare for their healthcare appointments. A similar guide has also been developed to support those with psoriatic arthritis.

How do these guides work?

Patients often feel rushed during their appointments, highlighting the need to create a tool that empowers them. By providing a step-by-step approach to follow and prepare for healthcare appointments, these guides encourage patients to consider:

1. Their current condition, goals for treatment and what they want to discuss in their appointment
2. Their role in making decisions about their management plan
3. How to communicate effectively with their healthcare team in both in-clinic and virtual appointments

Complete with prompts and examples of key questions that patients can ask, these consultation guides help to ensure that patient concerns are fully addressed. This is important to enable patients to gain a deeper understanding of their disease and management options.

This tool is also available for HCPs to offer and share with their patients, and ultimately aims to help patients achieve improved health outcomes.

View your copy of the axSpA consultation guide [here](#).

ASIF is proud to have been involved in the development of the Guide. Andri Phoka, ASIF Trustee, provided input and guidance as a member of the Rheumacensus Consensus Council Members and was the lead on the axSpA patient representatives committee

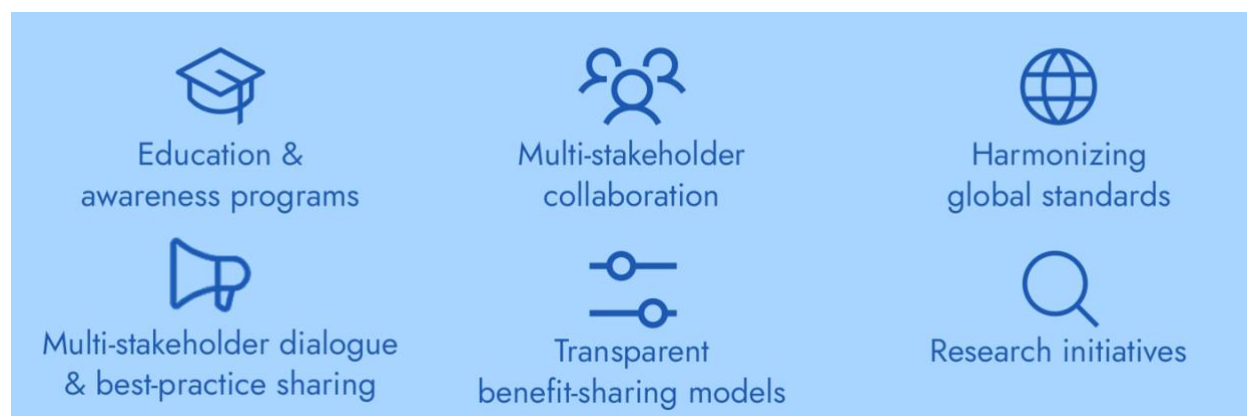
Making Access Happen

As we know, timely access to affordable and appropriate medications can significantly improve health outcomes and enhance quality of life. By expanding treatment options and promoting competition, generic and biosimilar medicines can improve access, sustainability of healthcare systems, and alleviate the societal burden of untreated illnesses.

Patient organisations provide a powerful voice for patients and can help policymakers understand the perspectives of the patient community as they work to implement better health policies. Many of our members play a vital role in enhancing access to medicines, educating their communities and empowering patients to make informed decisions.

Recently, ASIF participated alongside 30 patient advocacy leaders from 18 countries, in the Making Access Happen: Sandoz Global Access Forum.

One of the key highlights of the Forum was the Making Access Happen Consensus Statement, co-created with patient advocates worldwide, that addresses key strategies to make healthcare more accessible through generic and biosimilar medicines. The contributors outline 6 key actions:



Together, the patient advocates agreed that collaboration between patient organisations, healthcare providers, policymakers, pharmaceutical companies, and other stakeholders is essential for driving initiatives that improve access to medicines.

[Download Consensus Statement](#)

Our members can join the conversation on social media using #MakingAccessHappen. We will be sharing social posts about the campaign and encourage our members to share our posts or contact us for access to the content.

What's in a name?

Find out more about the nomenclature change to axial spondyloarthritis in this article published by Healio.

[Read article](#)

Dates for your Diary 2025

March 2025

6-8 Controversies in Rheumatology and Autoimmunity (CORA), Italy

April 2025

23-26 PANLAR, Mexico

28-30 British Society for Rheumatology Annual Conference (BSR), UK

June

11-14 EULAR, Spain

For more dates, visit our [events page](https://asif.info/events) (<https://asif.info/events>)

ASIF is grateful to its industry partners



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