ASIF
AXIAL SPONDYLOARTHRITIS
INTERNATIONAL FEDERATION

ASIF Newsletter: December 2023

Message from the President

Dear friends,

This has been an extraordinary year for ASIF. My highlights include the launch of the second phase of our Delay to Diagnosis project with powerful educational films and infographics; the creation of an invaluable Resource Library with information about axSpA, as well as material specifically for patient organisations; and raising awareness with more than 48 million people during our World AS Day campaign.

We gained six new members from Aruba, Brazil, Montenegro, Pakistan, Panama and a second organisation from The Netherlands. Some of them have introduced themselves over the following pages. We are committed to improving the lives of people living with axSpA around the world, and we hope our support of our new and existing members will enable more people to access the care they deserve.

We recently said goodbye to Valeria Tassi, who had been part of the ASIF team for more than 3 years as our Administration Assistant. We thank her for the great work she did, particularly with our members.

Lastly, I am very excited about the launch of the IMAS Global Report next month. It is an invaluable source of knowledge about the real life impact of axSpA.

Thank you to everyone who has supported our work this year. Wishing you very happy holidays and all the very best for 2024!

Zhivko

Zhivko Yankov, President of ASIF

A Message from Mike

As we approach the end of 2023, I hope you are reflecting on a successful 12 months. A highlight of my year was attending last month’s EULAR PARE meeting of RMD patient organisations (pictured below). It was inspiring to hear about the range of activities being run by different organisations across Europe. A handful of people from outside

Europe – including some ASIF members – attended under the umbrella of iPARE, the new initiative to connect and collaborate with patient organisations from other continents.

2024 will be a busy year at ASIF, beginning with the launch of the International Map of Axial Spondyloarthritis (IMAS) Global Report. IMAS is the largest ever survey of the impact axSpA has on people's lives. It provides the evidence base for much of the work we will develop over the coming years to help improve early access to treatment and ensure patients receive the care they need.

Finally, if you were at our AGM in June you will remember that ASIF's members approved a plan to improve our governance by changing how ASIF is registered as a charity. This will take effect in the new year when we will become a 'Charitable Incorporated Organisation'. I also mentioned that the Trustees may consider the need for new categories of ASIF membership, we will update you on this next year.

The ASIF team wishes you a happy, healthy and successful 2024. We hope to see you in Colombia in October for our Council Meeting - read more on this below!

With my very best wishes,

Mike

Mike Mandelbaum, Executive Director

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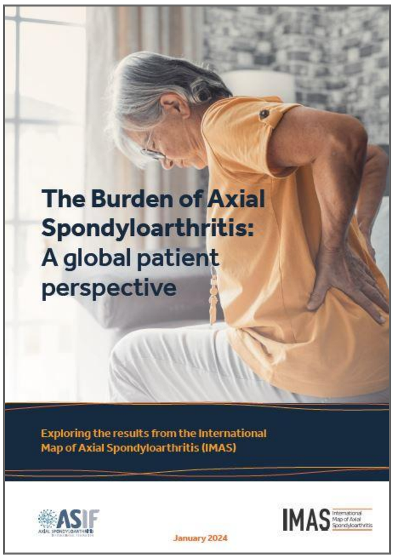
ASIF Projects

Global IMAS Report to be launched in January



Next month ASIF will launch its International Map of Axial Spondyloarthritis (IMAS) report, *The burden of axial spondyloarthritis: a global patient perspective*. The report demonstrates the challenges of living with axSpA - from getting a timely diagnosis to the health and socioeconomic impacts. A core aim of IMAS is to incorporate the patient perspective and experience into healthcare policy and into decisions about axSpA care. To support this, the report contains calls to action, aimed at healthcare professionals and policymakers. These include ensuring the needs of axSpA patients are fully understood, that a multidisciplinary approach is taken to care and that healthcare professionals are better equipped to recognise the signs and symptoms of axSpA.

The report will be an invaluable advocacy tool for our members and is an essential read for anyone interested in the impact of axSpA. Using IMAS results, we underline the real-life burden of axSpA on both an individual's life, and on healthcare utilisation.

In the lead up to the publication of the Report, ASIF continues to spread the word about the reality of living with the disease. Our abstract and presentation at this year's EULAR congress demonstrated how axSpA can affect almost every area of a person's life and highlighted numerous unmet needs of those living with the disease.

In November, we presented a poster on the IMAS findings and forthcoming global report at the Galapagos Patient Partnership Day and the EULAR PARE Best Practice Fair. Both events gave ASIF the opportunity to share the IMAS project with other patient organisations and to demonstrate how we can use the evidence gathered through IMAS to advocate for change.

We will continue to disseminate the important results from IMAS; we are busy working with the IMAS scientific committee to prepare five new IMAS abstracts for submission to EULAR 2024.

To coincide with the report publication, new webpages highlighting IMAS' key findings will be published on the ASIF website, providing a fascinating deep dive into the data. Additional materials, including an advocacy toolkit and infographic showing the key IMAS findings, have also been created to support our members' work. These resources will be available in January.

Exciting news about IMAS coming soon!

IMAS International Map of Axial Spondyloarthritis

ASIF Council Meeting 2024: Colombia, 16-19 October 2024

We are excited to announce that the 2024 ASIF Council Meeting will be in Bogotá, Colombia (pictured). We hope you will join us for what promises to be the biggest and best Council Meeting that we have ever held.

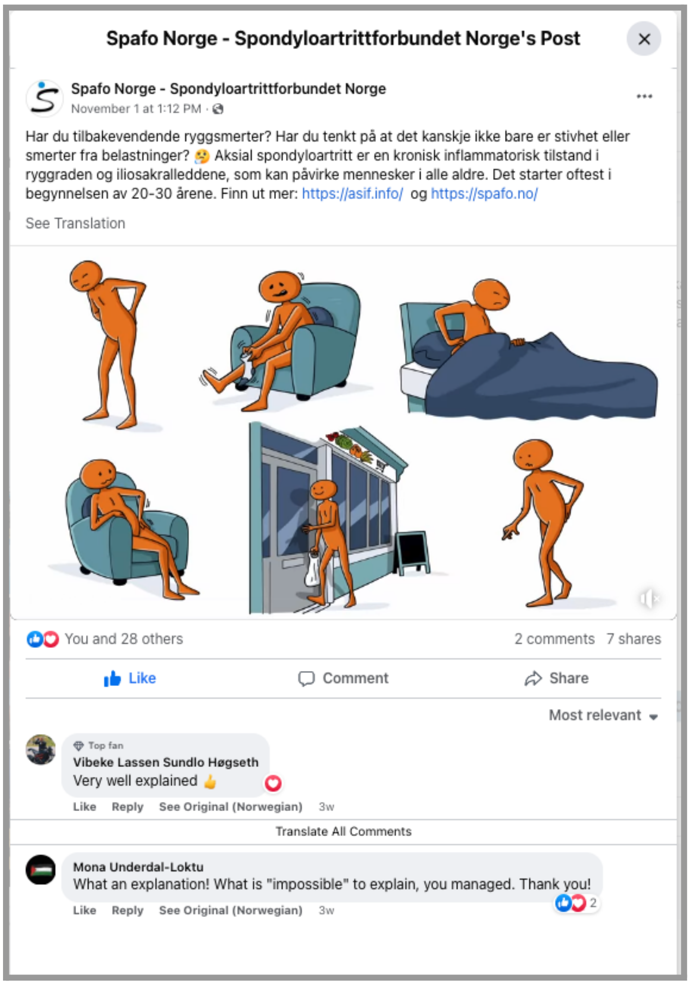
Since 1988 ASIF has held regular Council Meetings, with them now taking place every 2 years. The Council Meeting is a gathering of ASIF members from around the world. It is an opportunity to meet and to exchange ideas. There are educational talks from keynote speakers, including leaders in the global axSpA or RMD world. There will be workshops and a chance to discuss relevant issues about axSpA and about managing a patient organisation. There will of course be plenty of opportunities to network and to learn about each other's organisations and there is always a lot of fun to be had. You can find the report from our meeting in Copenhagen (pictured below) in 2022 here (asif.info/asif-council-meeting).

This will be the first ASIF Council Meeting in the Americas. We are excited by the growth in our membership in Latin America and we are delighted to bring other members to the continent for this meeting. These meetings are a wonderful celebration of our incredible community.

ASIF subsidises this event and, whilst we do have to charge a registration fee, we will keep it as low as we can. While you only need to fund your travel, there will be an opportunity for some of you to apply for subsidised travel. We will provide more information in the next couple of weeks.

Location: Hotel Tequendama Bogotá, Avenida Carrera 10 No. 26-21, 110010 Bogotá, Colombia (https://en.tequendamahotel.com)

Delay to Diagnosis in Action



Spafo Norge - Spondyloartrittforbundet Norge
November 1 at 1:12 PM

Har du tilbakevendende ryggsmerter? Har du tenkt på at det kanskje ikke bare er stivhet eller smerter fra belastninger? 🤔 Aksial spondyloartritt er en kronisk inflammatorisk tilstand i ryggraden og iliosakralleddene, som kan påvirke mennesker i alle aldre. Det starter oftest i begynnelsen av 20-30 årene. Finn ut mer: https://asif.info/ og https://spafo.no/

Vibeke Lassen Sundlo Høgseth
Very well explained 👍

Mona Underdal-Loktu
What an explanation! What is "impossible" to explain, you managed. Thank you!

“What is impossible to explain, you managed. Thank you!” were just some of the encouraging words that were posted in response to Spafo, Norway sharing the Delay to Diagnosis sketch animation on social media.

We have videos, infographics and social media content available in nine languages to support you in raising awareness about axSpA.

The sketch animation video clearly communicates what axSpA is alongside the main signs and symptoms. We also have a video, presented by Dr Raj Sengupta, that helps healthcare professionals better understand the clinical presentation of axSpA.

Lise Mette, Spafo’s Communications Manager, says: “We are delighted that the feedback about the film is…good and easy to understand for everyone”.

You can see the films in the different languages on our Delay to Diagnosis awareness pages. If you would like access to the toolkit, or share your feedback on the campaign, please contact Jo Lowe (projectmanager@asif.info).

World AS Day Social Media Grants available for Members

We are delighted to launch our new Grants Programme, exclusively available to our Members to support their World AS Day activities.

Members can apply to use one of six £500 grants to boost their social media posts and raise more awareness with their target audiences, drive more people to their website, and encourage more conversations on their channels!

Find out more about our social media grants and how to apply on our website: https://asif.info/wasd-2024-grants

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World AS Day

On World AS Day, 4 May, the international axSpA community will join together to raise awareness online and at local events.

The ASIF '*World AS Day Sub Committee*' is currently working with Platform (creative agency) to develop the campaign. On 6 February we will hold 2 webinars (different time zones) to inform our members and industry partners about the campaign. We will share a Toolkit containing editable assets and key messages which will ensure a cohesive global campaign.

The theme of World AS Day 2024 is 'Signs and Symptoms'.

Webinar: 6 February 2024

Save the date for the World AS Day Webinar on 6 February 2024. The Webinar will be your chance to find out about the campaign, explore the Toolkit and see the assets that have been created. It will also be an opportunity to discuss how World AS Day can be used to engage Heathcare Practitioners. The final part of the Webinar will be an interactive demonstration on using paid advertising on social media.

There will be two sessions to cover different time zones:
Session 1: 08:00 GMT Session 2: 17:00 GMT

Please register for the Webinar by emailing Jo de Bry at communicationsmanager@asif.info. Please indicate which session you will attend.

Research Spotlight

- Written by Muhammad A. Khan, MD, FRCP, MACP, Professor Emeritus of Medicine, Case Western Reserve School of Medicine, USA

This year marks the 50th anniversary of the groundbreaking discovery linking HLA-B27 to ankylosing spondylitis (AS)[1,2]. Beyond HLA-B27, over 116 additional recognised genetic risk factors have been identified, while exploration of environmental factors in this context remains limited [1,2]. Notably, HLA-B27(+) AS patients exhibit a distinct clone of potentially autoreactive (self-reactive) CD8+ T cells with TRBV9-containing T cell receptors (TCR) in their bloodstream and within inflamed tissues [2-4].

Figure 1 elucidates the persistence of autoreactive CD8+ T cells that manage to evade elimination in the thymus during early life. This phenomenon is observed in individuals born with the disease-predisposing HLA-B27 subtype (HLA-B27:05) but not in those born with the non-disease-predisposing subtype (HLA-B27:09) [3]. The proposed mechanism involves clonal expansion of these T cells upon exposure to microbial-derived peptides, followed by cross-reactivity with self-derived peptides. This cascade triggers an autoimmune inflammatory process, ultimately in AS in individuals with the disease-predisposing subtypes of HLA-B27 [3].

A recent outstanding study from a year ago has effectively unravelled the 50-year-old puzzle surrounding HLA-B27's role in AS [5]. This breakthrough has notably expedited the potential for targeting and eliminating disease-causing T cells, offering promising prospects for curing those affected [5].

A subsequent groundbreaking paper, published a month ago, highlights the success of targeted elimination of the disease-causing TRBV9^{+} T cells in an HLA-B27(+) patient with AS [6]. After successful testing in nonhuman primate models, the authors observed a dramatic efficacy in elimination of these T cells in AS. The patient achieved remission within 3 months, discontinuing anti-TNF therapy used for 5 years. Complete remission has now persisted for 4 years, with three annual doses of anti-TRBV9 treatment [6].

The authors aptly concluded that the selective depletion of a TRBV9-defined group of T cells presents a promising avenue for safe and effective therapies in AS. This innovative approach may extend to other HLA-B27-associated forms of spondyloarthritis [6]. Targeted elimination of the disease's root cause, without resorting to systemic immunosuppression, holds the potential for a new era of safe and efficient autoimmune therapies.

These pivotal advancements not only signify a paradigm shift but also enhance the prospect of preventing the disease in individuals with high-genetic risk factors [5,6]. Furthermore, the discovery of enhanced biomarkers, coupled with the evolving technology of electric field molecular fingerprinting, holds promise for significantly improving early diagnosis and facilitating the initiation of curative treatments [2].

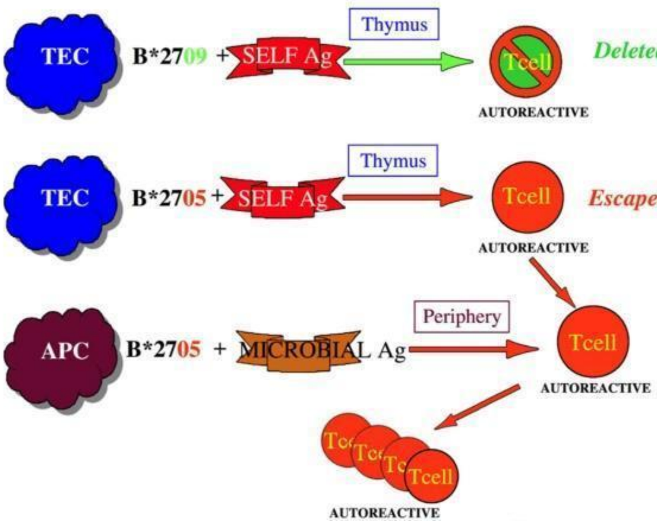

Figure 1: Title: Auto Reactive CD8+ T Cell Generation and Their Implication in Disease.
Legend: This figure illustrates the persistence of potentially self-reactive CD8+ T cells, which evade elimination during early thymic development in individuals with a disease-predisposing subtype of HLA-B27.
TEC = Thymus Endothelial Cells
APC = Antigen Presenting Cells
SELF Ag = Self Antigen
MICROBIAL Ag = Microbial Antigen
(From: Khan MA, Mathieu A, Sorrentino R, Akkoc N. The pathogenetic role of HLA-B27 and its subtypes. Autoimmun Rev. 2007;6(3):183-9. doi: 10.1016/j.autrev.2006.11.003).

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New Members

Gruparj Petrópolis Institute, Brazil

- Written by Wanda Heloisa Ferreira

"Gruparj Petrópolis Institute completes 22 years of fulfilling its mission: to educate and mobilise society towards the importance of prevention, diagnosis, treatment and early rehabilitation of rheumatic diseases, through health education."

The Arthritic Patients Group of Rio de Janeiro in Petrópolis – Instituto Gruparj Petrópolis was founded in 2001 with the support of the Rheumatology Society of Rio de Janeiro. In 1998 the society held the first Forum for Laymen on Rheumatism in Rio de Janeiro. At the time, rheumatologists observed the population's lack of knowledge about rheumatic diseases. Since then, Gruparj has worked to meet the needs and interests of people with rheumatic diseases, especially Rheumatoid Arthritis and Spondyloarthritis.

The purpose of the institution is to promote social assistance through information, education and support for people with rheumatic and related diseases; enable and rehabilitate people with functional limitations for the job market; promote patient integration into society; and offer multidisciplinary care to people with rheumatic diseases.

Achievements in Numbers

These numbers are not just statistics; they are tangible testimonies of our positive impact and ongoing commitment to a future with a higher quality of life for people with rheumatic diseases.

- 2,100 members: A solid community that continues to grow, strengthening connections and collaborations.
- 10 thousand services per year: Commitment to support, resources and opportunities for our community.
- 30 thousand people reached: Extending our influence beyond borders, serving not only members, but the community in general.
- 53 Health Education Courses on Rheumatic Diseases carried out: providing knowledge about treatment, specificities of rheumatic diseases and quality of life for people with rheumatic pathologies across the country.

Comprehensive and Interdisciplinary Service

What makes Instituto Gruparj Petrópolis truly special are its comprehensive activities and services, designed to optimise the physical, emotional and social rehabilitation of people with rheumatic diseases. Our main activities are: lectures, congresses, occupational rehabilitation workshops including through painting and crafts, medical and psychological care and rehabilitation. To achieve this, we count on the effective collaboration of doctors, physiotherapists, occupational and body therapists, psychologists, nutritionists, art therapists, who develop interdisciplinary work, taking into account programming that optimises the physical, emotional and social rehabilitation of people with rheumatic diseases.

Comprehensive and Innovative Support

- Multidisciplinary service

Instituto Gruparj offers medical, psychological, physiotherapeutic, nutritional care, among others, aiming to optimise the physical, emotional and social rehabilitation of patients.

Therapeutic Support
Weekly consultations with a rheumatologist and nutritionist.

Physiotherapy Support
Highlight is the stretching services, offering not only targeted exercises, but also a recreational moment for patients.

Psychological Support
A fundamental pillar, with group and individual services.

Rehabilitation through Art – Art and Life Project
The project uses art as a means of physical, emotional and social rehabilitation, with weekly workshops.

- Educational Events and Awareness Campaigns

The Institute promotes educational events such as lectures, congresses and occupational rehabilitation workshops through art, such as painting and crafts.

A highlight is the Social Medical Meeting on Rheumatic Diseases, bringing together approximately 450 participants annually. In addition, 53 Health Education courses have already been held in Brazil and Portugal.

- Awareness campaigns

The social responsibility of Instituto Gruparj Petrópolis is evident in its annual awareness campaigns, open to the community. Annually, the Institute promotes campaigns open to the community on Hepatitis, Osteoporosis, Rheumatoid Arthritis, Lupus, Psoriatic Arthritis and Ankylosing Spondylitis, among others.

- Financial Strategy

The institution remains resilient through financial strategies, mobilising resources and seeking support from foundations, companies, the public sector, individual donors, donation campaigns and events, as well as participation in public notices.

In its 22-year journey, the Gruparj Petrópolis Institute has fulfilled its mission, and exceeded expectations, becoming an institution that promotes hope and support for those facing rheumatic diseases. Its trajectory is an inspiration to everyone, highlighting that, with commitment and innovation, we can truly transform lives and communities.

Find out more at: https://gruparjpetropolis.com.br

Arthritis Care Foundation, Pakistan

- Written by Asad Ali

Arthritis Care Foundation (ACF) became a registered trust in 2010 for the welfare of patients with rheumatic diseases in Pakistan. It is the only non-for-profit organisation in Pakistan, striving to provide free and subsidised treatment to less privileged patients from all walks of life. In 2010, three founding members started volunteer services. As of today, eight volunteer rheumatologists and twelve doctors on ACF's payroll provide services at ACF Centre and five collaborative projects.

آرتھرائٹس کیئر فاؤنڈیشن
Patient Care
Research
Education
Arthritis Care Foundation

Patients' Care: ACF provides medications (including biologics), diagnostic support and joint replacements for indigent arthritis patients. Apart from patient care, supporting rheumatology fellowship training programmes and arranging awareness seminars are our main objectives. Since inception, PKR 382 million (USD 2.3 million) has been spent on providing free and subsidised treatment to thousands of arthritis patients.

Each year ACF spends approximately PKR 17,500,000 (USD 61,000) and PKR 20,000,000 (USD 72,500) on provision of biologics and JAK-inhibitor drugs respectively; a significant portion of which is being used for treatment of SpA patients and SLE patients.

In a less developed country like Pakistan, the cost of treating rheumatic diseases is very high, there is little support from the public sector and no health insurance facilities. The Sehat Sahulat Card scheme, recently launched by the government, covers outpatient treatment but does not support full treatment, which leads to many patients suffering poor outcomes and delayed diagnostics.

(Pictured: Prof. Nighat Mir examining a patient who lives with rheumatoid arthritis.)

Teaching and Training: Despite international standards recommending at least 2500 rheumatologists for a population of more than 240 million, Pakistan only has 125 qualified registered rheumatologists. To meet the dire need of specialists, ACF started scholarship support for teaching and training programmes in collaboration with various teaching institutions.

So far 31 rheumatologists have been trained by the ACF Faculty, covering more than 50% of total practising rheumatologists in Punjab province of 120 million. Out of these, 21 specialists have fully or partially been trained through the ACF scholarship programme. ACF funded rheumatologists are not only working in the public and private sector of Pakistan but they are also serving abroad (UK and Middle East). So far around PKR 42 million (USD 2.39 million) has been spent on a scholarship programme for fellows undergoing training.

Education and Research Activities: ACF is consolidating its research endeavours in collaboration with renowned national and international teaching and research institutions. Partnering with the Fatima Jinnah Medical University (FJMU) and National Institute of Health (NIH) USA, ACF is conducting research involving the genetics of lupus in patients and their families. ACF faculty recently conducted research on prevalence of musculoskeletal disorders through a grant by WHO. The ACF team also organised a nine months educational programme for family physicians, covering rigorous modules, with the help of ILAR funding. ACF has set up a support group for ankylosing spondylitis and lupus patients (pictured). Expert rheumatologists and psychologists provided their expert opinions to all registered patients and families in the support group.

Advocacy programmes: ACF team has been actively involved in raising awareness among the general public, physicians and medical students through educational seminars, walks, interviews and public relationship activities. This is part of the ACF commitment towards public awareness about these diseases.

Find out more at https://arthritiscarefoundation.org

International Conferences

Galapagos Patient Partnership Day

On 15 November, Mike Mandelbaum and Jo Davies from ASIF attended Galapagos' first ever Patient Partnership Day at their Head Office in Mechelen, Belgium. The one-day event was attended by representatives from around 30 patient organisations mostly representing RMDs, and many Galapagos employees from around the world.

The aim of the day was to share ideas about what good patient engagement (PE) is.

Patient engagement is maturing. Patients are rightly becoming more important in research and with policy makers and pharmaceutical companies.

There were sessions covering best practice, the importance of shared decision-making in clinical trial settings. There was also an opportunity to take part in workshops in patient engagement and communications and health literacy. The day ended with a poster session and dinner. ASIF members were also present: Antonella Celano from APMARR (pictured above, on the right with Jo) and Andri Phoka from Cyplar, EULAR PARE, Agora and an ASIF Trustee.

EULAR PARE 2023 Conference

Mike Mandelbaum and Jo Davies from ASIF attended the EULAR PARE 2023 Conference in Brussels on 16 and 17 November. This year's conference was mostly about implementing the EULAR Manifesto Campaign, an advocacy campaign outlining RMD-related policy asks. The manifesto focuses on influencing three policy areas:

Quality of care: improving RMD prevention, early diagnosis, treatment, and rehabilitation interventions.

Social Policy: mitigating the burden of RMDs on health-related quality of life, education, and employment.

Research and innovation: developing better RMD prevention and treatment strategies.

You can find out more about the EULAR Mainfesto at www.eular.org/eular-manifesto.

The campaign is largely focussed right now on influencing European Parliament. However, the manifesto will have resonance with all of us and it is a document that could be adapted to suit other countries.

Everyone who attended EULAR PARE also took part in the Best Practice Fair. Forty posters were presented; Mike presented an ASIF poster on IMAS (pictured above). It was wonderful to see the work that other organisations are doing. There were a number of ASIF members at the event.

Sandoz

Jo Davies attended a Biosimilars roundtable event ‘towards best practice in patient support’ run by Sandoz. This was a small group that met in London to talk about challenges in patient care and support and to look at how biosimilars are received by the patient community. This event was very UK based but provided some good ideas about the role of patient organisations and how they have a crucial role supporting healthcare systems.

AGORA Conference

- Written by Andri Phoka, President of Agora and Trustee of ASIF

AGORA is an umbrella platform representing patient organisations of people with Rheumatic and Musculoskeletal Diseases (RMDs) in Southern Europe. Each year our annual conference takes place in a different country hosted by one of our member associations. This year, the Association for Patients with Rheumatic Diseases Montenegro (NVO RAM) hosted the conference. The theme was Empowerment to manage our own *health and our own care*.

Throughout the two days, we had the honour of hosting expert speakers from our partner organisations around Europe and the USA. They shared knowledge on mental health, strategic planning, empowerment and raising awareness. Mr Raj Mahapatra, President of National Axial Spondyloarthritis Society (NASS) in the UK, spoke about how patient organisations can be successful and expanded on strategic planning. I presented a project together with ASIF on how other countries work and how we can raise awareness for patient associations.

Funding from our industry supporters enabled us to create a professional and high-level conference, which will impact the advocacy work of patient associations. The feedback from delegates was overwhelmingly positive.

The AGORA Annual Conference will be hosted by ARAM in Malta in 2024.

Member Survey

ASIF Website: Member Survey

We are looking to improve the ASIF website, and input from our members is invaluable. Please complete this short (2 minute) survey to help us understand what is important to you.

Go to Survey (Deadline 20 December)

Dates for your Diary

December 2023
7-11 25th Asia-Pacific League of Association for Rheumatology Congress 2023 (APLAR), Thailand

February 2024
15 International Conference on Rheumatology (ICR), UK
28-2 Mar Canadian Rheumatology Association (CRA) and Arthritis Health Professions Association (AHPA) Annual Scientific Meeting, Canada

March
1-4 Emirates Society for Rheumatology Annual Meeting in conjunction with 3rd Gulf Cooperation Council Rheumatology Conference, Dubai

April
10-13 PANLAR, Columbia
24-26 British Society for Rheumatology, UK

June
12-15 EULAR, Austria
27-29 World Psoriasis & Psoriatic Arthritis (IFPA) Conference, Sweden

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

ASIF is grateful to its industry partners

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