

## EULAR 2024 In Review

Attending EULAR is one of the highlights of ASIF's year. It is an opportunity to share our work with the international rheumatology and healthcare community, connect with our members and meet with our supporters.

The axSpA patient community played an important role at EULAR, representing the international patient voice in one of the biggest rheumatology meetings in the world. We are proud to share reports on some of the work that ASIF members, trustees and staff presented at EULAR and their experiences of the meeting.

### Page

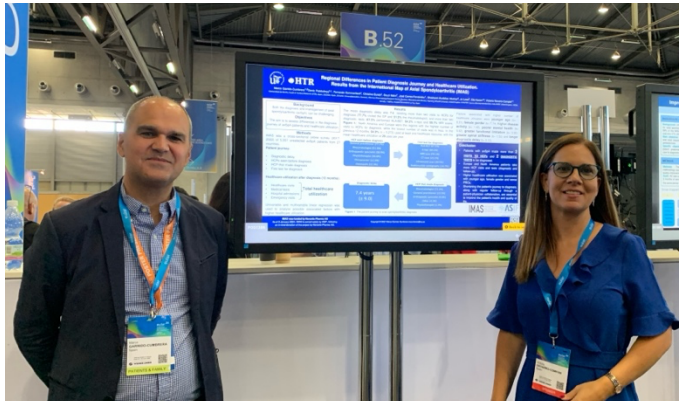
1	<b>ASIF, IMAS Abstracts</b>
2	<b>ASIF, Delay to Diagnosis</b>
3	<b>AGORA, Southern Europe</b>
3	<b>ASWS, India</b>
5	<b>ASASA, South Africa</b>
6	<b>ELEANA, Greece</b>
8	<b>NASS, UK</b>
9	<b>Spafo Norge, Norway</b>

### **ASIF, IMAS Abstracts**

Professor Marco Garrido-Cumbrera on behalf of ASIF, the University of Seville and the International Map of Axial Spondyloarthritis (IMAS) Scientific Committee, presented three abstracts from the IMAS study. The following three topics were presented as posters at the Spondyloarthritis Session on July 12 and 15; and a fourth abstract was accepted for publication.

- Factors Associated with Poor Mental Health in Patients with Axial Spondyloarthritis. Results from the International Map of Axial Spondyloarthritis (IMAS). Reference: POS0507
- What Factors Are Associated with Pain Intensity in Axial Spondyloarthritis? Results from the International Map of Axial Spondyloarthritis (IMAS). Reference: POS0508
- Regional Differences in Patient Diagnosis Journey and Healthcare Utilization. Results from the International Map of Axial Spondyloarthritis (IMAS). Reference: POS1386

The presentation of the IMAS abstracts generated discussions with rheumatologists from the ASAS group. They debated with the authors about factors associated with poor mental health, pain intensity and regional differences in the use of services across the countries included in IMAS. These discussions provided an international, interdisciplinary view based on the patient perspectives captured in the IMAS study.



Marco pictured with Dr Victoria Navarro Compán, President Elect of ASAS

The fourth abstract was accepted for publication in the issue of the Annals of the Rheumatic Diseases (ARD) dedicated to the EULAR 2024 Congress:

- The Impact of Axial Spondyloarthritis on Patients' Sexual Life. Results from the International Map of Axial Spondyloarthritis (IMAS). Reference: AB0945

For more information, these four IMAS-derived abstracts were published in the Abstract Book of the ARD and are available at: [https://congress.eular.org/abstract\\_archive.cfm](https://congress.eular.org/abstract_archive.cfm)

## ASIF, Delay to Diagnosis

### Recognising the signs and symptoms of axial spondyloarthritis: a global awareness campaign to support reducing the diagnostic delay

Authors: Lowe J; Escarda P; van Dam M; Wermisog L; de Bry J

**Background**

- \* Axial spondyloarthritis (axSpA) is a painful, chronic inflammatory disease<sup>1</sup>
- \* One of the main problems is the time it takes to get a diagnosis; average time globally 7.4 years<sup>2</sup>
- \* Condition can significantly deteriorate and irreversible structural damage can be caused<sup>3</sup>
- \* Huge impact on physical and psychological health whilst waiting for correct treatment
- \* Barrier to timely diagnosis is lack of public and HCP awareness of signs and symptoms

**Toolkit of materials available**

- 3 main films: animation; patient experience; clinical presentation of axSpA\*
- Social media short film versions\*
- Social media suggested content
- Social media quote cards and infographics
- Stand-alone infographic on axSpA; stand-alone infographic on impact of the delay
- Guide to advertising and boosting on social media

**Objective**

Design a campaign that could be used by ASIF and patient organisations around the world to increase awareness of the signs and symptoms of axSpA, including with healthcare professionals who are likely to see people with symptoms.

**1**

What is axial spondyloarthritis (axSpA)?

**2**

What are the main signs & symptoms?

**3**

What is the impact of the delay?

↓

**Consistent messages about signs & symptoms**

- Lower back pain
- Gradual onset before the age of 40
- Worse with rest, better with movement
- Fatigue
- Other conditions that are often present with axSpA

Dr Raj Sengupta  
Consultant Rheumatologist

\* Films available in: Bulgarian, English, French, German, Greek, Hebrew, Hindi, Norwegian, Spanish, Tagalog

References:

1. Sieper J, Poddubnyy D. Axial spondyloarthritis. 2017. *Lancet*; 390(10089):73-84.
2. Poddubnyy D, Garrido-Cumbrera M, Sommerfleck F, et al. POS0689. Diagnostic delay in patients included in the International Map of Axial Spondyloarthritis: associations with geographic, socio-demographic and disease-related factors. *Annals of the Rheumatic Diseases*. 2023;82:628-629.
3. The unacceptable delay in axSpA diagnosis: a global call to action; Axial Spondyloarthritis International Federation; June 2021

www.asif.info

Jo Lowe presented an ASIF poster, *Recognising the signs and symptoms of axial spondyloarthritis: a global awareness campaign to support reducing the diagnostic delay*. The poster summarises our Delay to Diagnosis awareness campaign. The project developed three films and a range of other resources to highlight the signs and symptoms of axial Spondyloarthritis (axSpA) aimed at a range of audiences, including healthcare

professionals. Whilst presenting, Jo spoke to rheumatologists and physiotherapists about the campaign and the importance of an early diagnosis.



## **AGORA, Southern Europe**

AGORA (Federation of Associations for Patients with RMDs of Southern Europe) made a significant impact at the EULAR Congress through its active and engaging participation. The federation's booth served as a focal point, featuring informative leaflets, announcements about its forthcoming annual conference, and a compelling corporate TV spot displayed on a large monitor.

AGORA Federation's board members played pivotal roles within the congress sessions, contributing as moderators, presenters, and interviewees. Their participation not

only highlighted AGORA Federation's leadership in advocating for RMD patients but also emphasised its commitment to advancing knowledge and support within the rheumatological community.

Throughout the event, AGORA Federation forged meaningful connections with key stakeholders in the pharmaceutical industry, holding numerous productive meetings. These engagements aimed to foster collaborations aimed at enhancing research, treatment options, and advocacy efforts for individuals living with RMDs. AGORA Federation's proactive involvement and collaborative approach underscored its dedication to empowering patients, advancing healthcare standards, and driving positive change within the field of rheumatology.

## **ASWS, India**

*A personal account from Prachee Bhosle, President of the Ankylosing Spondylitis Welfare Society (ASWS) in India.*

Attending the EULAR conference was an incredibly enriching experience, especially since it was my first time at such a large event. One of the major highlights was presenting our

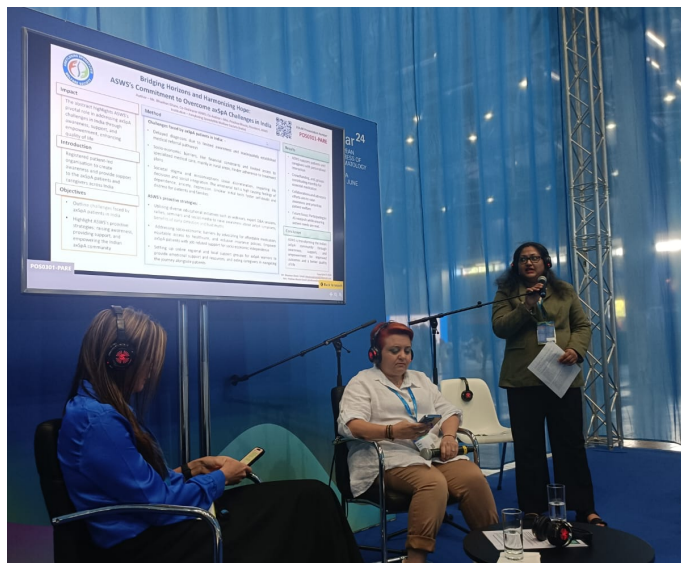
abstract on the challenges faced by axSpA patients in India and how our organisation addresses and overcomes these challenges. The presentation, held at the PARE (People with Arthritis/Rheumatism in Europe) Poster Auditorium, was overwhelming yet rewarding, providing a fantastic platform to share our work and receive valuable feedback.

Meeting members of ASIF felt like reuniting with old friends. Our conversations were warm and full of mutual understanding. We instantly bonded over shared experiences and goals, and it felt like we were building lasting friendships.

During my interactions, I had the opportunity to share in-depth discussions and connect with Dieter Wiek, EULAR PARE International Collaboration Liaison Officer, and Dr Jürgen Clausen, Scientific Advisor for Deutsche Rheuma-Liga. Being part of the PARE family was another highlight. I got to know that EULAR is dedicated to supporting patients and patient advocates, including newer initiatives like iPARE (international PARE). Learning about the bursary for the Patient Research Partners course highlighted EULAR's commitment to empowering patient leaders and broadening their knowledge, which was inspiring.

The Family Dinner provided a relaxed setting to interact with many colleagues, which helped strengthen bonds and build new connections within the network.

Meeting the iPARE family was also memorable. I bonded well with patient organisation leaders including: Maranda van Dam from South Africa, Gonsalo Tobar Carrizo from Chile, Franklin Hiagbe from Ghana, Luris Higuera from Panama and others. It was a wonderful feeling to connect with such passionate individuals and strengthen our bonds within the community.



*Prachee presenting with panel members, Maranda van Dam and Andri Phoka*

Presenting the challenges faced by axSpA patients in India on a global platform was a rewarding experience. Learning from others about the challenges they face and gaining insights into fundraising and increasing viewership was invaluable.

The sessions I attended were very insightful, broadening my understanding of various aspects of rheumatology. Networking with other organisations was also fruitful. I was approached by representatives seeking help to form patient



organisations in Nepal and Bangladesh, affirming that our efforts to help are not limited by national borders.

Furthermore, participating in discussions and workshops allowed me to contribute to ongoing global efforts in patient advocacy and healthcare improvement. It was inspiring to witness the collective dedication and innovative approaches shared by diverse healthcare professionals and advocates from around the world.

Overall, the EULAR conference was a remarkable experience, filled with opportunities for knowledge sharing, networking, and collaboration. Presenting our abstract and engaging with the global rheumatology community has left a lasting impact on my professional and personal growth.

### **ASASA, South Africa**

The Axial Spondyloarthritis Association of South Africa (ASASA) presented the inaugural abstract: *The road to inclusion for axial spondyloarthritis in South Africa*. This milestone was a significant achievement for the organisation, marking their increasing contribution to the rheumatological community. Maranda van Dam, Chair of ASASA, chaired a session at the PARE Booth, facilitating discussions and sharing insights with attendees.

Additionally, ASASA participated in the iPARE meeting (pictured), where they had the opportunity to engage with representatives from various countries. This gathering fostered a sense of international collaboration, allowing ASASA to exchange valuable information and perspectives with other stakeholders in the industry.



*The iPARE group (Back L to R): Prachee Bhosle, Gonsalo Tobar Carrizo, Franklin Hiagbe, Brenda Delodder, Dieter Wiek, Boryana Boteva, Mike Mandelbaum, Birte Gluesing (Front L to R): Loreto Carmona, Luris Higuera, Jo Davies, Maranda van Dam*

ASASA's active involvement in the congress highlighted their dedication to advancing the understanding and management of axSpA. By presenting their research, leading discussions, and participating in the iPARE meeting, they demonstrated their commitment to improving patient care and fostering collaboration within the field. Their presence at the PARE Booth and the iPARE meeting allowed them to engage with a wide audience, enhancing their connections and collaborative efforts.

Overall, ASASA's participation in the EULAR Congress underscored their growing influence and leadership in advocating for patients with axSpA. Their efforts not only contributed to

the success of the event but also reinforced their mission to enhance awareness, research, and treatment for this condition.

## **CyPLeR, Cyprus**

Chryso Kyriakou Yiasoumi presented her abstract on Cyprus League for People with Rheumatism's (CyLPeR) Support Centre. CyLPeR has more than 5,500 members and runs a variety of programs and services.

The support program, under the psychosocial support center for RMDs, is one of CyPLeR's most important programmes and is run under the guidance of a psychologist and social worker.

The psychosocial programme aims to:

- help members/patients accept their disease
- support them and their families
- exchange experiences with others with the same condition
- provide an opportunity to socialise
- implement and improve their life with new activities such as painting, exercise, dancing, computer use etc.
- support them financially
- inform them and assist them with government allowances.

The programme uses both individual and group support programmes. The individual programme includes face-to-face, phone or zoom sessions, home visits and use of a help line. The group support programme uses the power of group environments, including colour and music therapies, support groups, self-management programs, reading club and special groups of different diseases (Lupus group, Fibromyalgia group, children and parent group).

Over the last ten years the psychosocial support program has and continues to help and improve the lives of hundreds of patients with RMDs, both in Cyprus and globally as they share their experiences with others.

## **Diagnosed with an RMD - what do I need to know?**

Persefoni Markidou, CyPLeR's Psychosocial Support Officer, presented a model of five stages of grief that may be experienced when diagnosed with a chronic condition like Rheumatic and Musculoskeletal Diseases (RMDs). She explained why it is important to understand the impact that this condition has on their daily life, their family, and their social environment. Persefoni suggested steps the person can take to help them face the

realities of an RMD diagnosis, and furthermore, accept the “loss of having a good health”. Persefoni stressed the importance of having a good team of healthcare professionals (GP, rheumatologist/psychologist/dietitian/physiotherapist), friends, family and colleagues, as well as people from patient associations, who can all interact with each other for the benefit of the patient. She concluded the presentation talking about adjusting to loss, redefining and re-evaluate life, making new memories, starting new things and getting back to ‘normal’ in a new, improved way!

### **Fashion Show with a Cause!**

Simone Makri presented CyPLer’s Fashion Show with a Cause. Every year CyPLer seeks to organise a big event to inform and educate its members and the public about its activities. In 2022 and 2023 we organised two fashion shows. The 2022 event aimed to raise awareness of JIA and funds and was organised with the help of many volunteers along with NEW CODE modelling. In 2023, CyPLer was invited to attend and support a bigger Fashion Show event. This helped avoid the expense of hosting an independent event. The Fashion Show included famous Cypriot models and fashion designers. The success of both events, helped to emphasise the fact that RMDs can anyone regardless of age. All the profits from the fashion shows were used to support CyLPers programmes which help people with RMDs.

### **ELEANA, Greece**

Hellenic League Against Rheumatism ELEANA’s board member, Machi Spanou Salamaliki presented a poster on: *Looking at Life with Courage: A fashion show with models-patients with RMDs and other types of disabilities and chronic diseases*. The poster aimed to showcase how a community of people with chronic diseases and disabilities can come together and work



towards common goals: raising awareness on RMDs and several others chronic diseases, empowering the local community of Patras and patients living there and fundraising. The fashion show was promoted through press releases and social media campaigns. The campaign will be used as an example of best practice for future fundraising events in collaboration with local stakeholders and contributing to empowering patients living with RMDs.

ELEANA’s Secretary, Katy Antonopoulou (pictured speaking), presented a poster on:

Hellenic League's Against Rheumatism *Helpline: A very important, effective and interactive way to help the people with RMDs and their caregivers.* The helpline provides support to people living with RMDs and their caregivers, to people that want to understand RMDs, and aims at improving the quality of life and reducing the burden of the disease.

The helpline has operated since 2007 and has supported thousands of patients and loved ones, calling to either receive info on RMDs and/or to get psychosocial support.

Psychologists, trained volunteers, and peer supporters have worked to maintain the helpline offering support to everyone who reaches out. We endeavour to be open and inclusive for all patients living with RMDs.

ELEANA's Vice President, Nadia Malliou, spoke at the session *Multidisciplinary Care in Rheumatology, on Health Center for RMDs Patients: an example from the Hellenic League Against Rheumatism.* She presented how the multidisciplinary approach is the optimum method to treat and manage RMDs and how this has been implemented in Greece after the primary healthcare reform in 2017. She presented the gaps and barriers in primary healthcare and the multidisciplinary health center of Kavala. This is a team of volunteers offering multidisciplinary care to people living with RMDs. We did a survey on patients' satisfaction to explore what is missing, and what is working well. Patients were very satisfied with services in general, happy with their physician, and the whole team, commenting especially on the politeness of staff. The main comment on what's missing was the accessibility of the building and the need for more available appointment times, particularly in the evenings.



Nadia Malliou and Dr Maarten De Wit co-chaired the session: *In Dialogue with the Expert: Health Technology Assessment (HTA).* HTA in Rheumatology, the patient perspective of HTA, joint HTA, patient experts and patient education in joint HTA were discussed. The discussion highlighted the need for more Patient Research Partnerships, for patient empowerment and education. The partnerships will facilitate patient participation in the HTA process and will enable more patients to be involved and trained so HTA committees have a pool of patients that they can work with.

Lastly, Nadia Malliou co-chaired a poster presentation session with Slađana Rumlj Tunjić in which several posters were presented. These included interesting nationwide patient surveys on the interaction between RA and the menopause which found a strong association between the menopause and deterioration of arthritis symptoms. Patients desire more discussion about the menopause.



A poster on *Patients' and Healthcare Professionals' Perceptions on Weight Reduction in the Treatment of Knee Osteoarthritis presenting a systematic literature review's* conclusion on the matter, was also presented. Weight reduction is considered a first-line treatment option for knee OA (KOA) patients, but both patients and HCPs reported significant barriers to managing weight loss. Modifying HCPs education and practice and the use of anti-obesity medications could become a solution, while addressing the underlying fear-pain cognitive cycle.

*The road to inclusion for axial spondyloarthritis in South Africa* presentation highlighted the need for axSpA being equally considered and included in the Prescribed Minimum Benefits (PMBs) available in South Africa for people living with RMDs (such as RA, juvenile idiopathic arthritis but not axSpA). This poster presentation gave us the ability to discuss the health inequities that people face in different parts of the world.

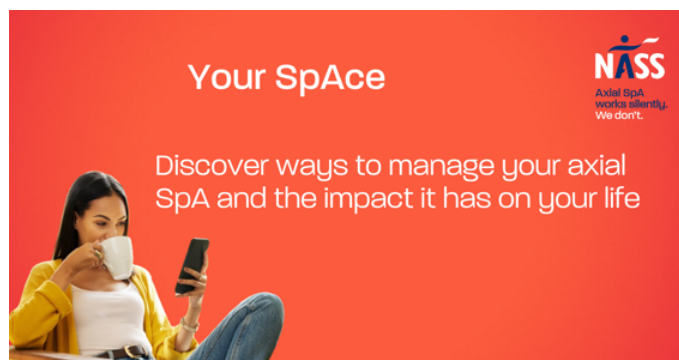
We continued with a presentation on range of emotions parents exhibit following their child's diagnosis of JIA. Results of a survey highlighted the range of emotions that families experience when they are initially informed that their child has a chronic debilitating autoimmune condition. Most parents experienced negative emotions (shock, anxiety and sadness and even guilt). It was obvious from the discussion that took place in the room that support, education and more data are needed for families and caregivers of children, young adults but also adults living with RMDs.

During the session: *Cognitive difficulties in everyday life: an extra challenge when living with an RMD*, Ingrid de Groot presented: *The Big Challenge: living with an RMD and experiencing cognitive dysfunction*. Ingrid de Groot showcased the number of difficulties in cognitive functioning that we may face in our daily lives, some without even realising. She explained that confusion and distraction may be signals of our cognitive dysfunction. She added that it is a myth that cognitive dysfunction is only experienced by older people, those living with dementia or other cognitive disabilities. Fatigue, loss of concentration and difficulties with our memory might be daily symptoms that we dismiss.

Training our minds, doing puzzles, keeping a diary and *to do* lists, creating a daily routine, being open and asking for help, resting, and pausing when we notice the symptoms can all help to tackle cognitive dysfunction. There is a stigma around RMDs and cognitive dysfunction, but discussion is needed to help improved our quality of life and alleviate the burden of yet another symptom. Being aware and understanding cognitive dysfunction is essential in managing the depression and anxiety that often accompany it.

## **NASS, UK**

The National Axial Spondyloarthritis Society (NASS) was delighted to present the abstract *Online patient education for axial spondyloarthritis self-management* at EULAR. Zoë Clark, Programme Manager, presented the results of the Your SpAce online supported self-management programme for people living with axSpA. The abstract was awarded best abstract in the PARE category.



NASS ran consultations with people living with axSpA and HCPs involved in their care to co-produce Your SpAce. It comprises short information videos, lived experience videos, downloadable resources, and online peer support meetups, freely available on the NASS website. The consultation identified the need to support people who were recently diagnosed, as well as those who have been diagnosed for longer but were struggling with their symptoms.

Launched in March 2023, the programme supports people to build confidence and skills in managing their axSpA pain, fatigue, and flares. Your SpAce was promoted across NASS channels, via partner organisations, and HCPs. The abstract shared that since launch, the webpages have been visited over 22,000 times, videos viewed over 11,500 times, and resources downloaded over 1300 times.

Of those surveyed, 63% had been diagnosed less than 5 years (of those, 23% were in the last year). A pop-up question on the topic webpages suggested that those accessing Your SpAce were currently struggling to manage their symptoms. When asked how well they were coping with each symptom from 0 to 100 (0 being not at all and 100 being extremely well), 62% of 862 respondents rated 0-40/100 for pain, 72% for fatigue, and 73% for flares.

In an anonymous feedback survey of 73 people who had accessed Your SpAce, 92% felt the Your SpAce videos had helped them understand more about their axSpA and 85% felt more confident managing. 87% felt they had more practical skills following watching the videos and 92% felt the resource sheets had increased their skills. Full results are available in the [abstract](#).

Since abstract submission, NASS have co-produced and launched modules on making medication decisions and getting the most out of appointments. [Visit Your SpAce](#) to learn more or book a place at an upcoming meetup. We'd love for HCPs to continue signposting their patients to the programme. UK-based HCPs can [order a free pack](#) of promotional

postcards and leaflets. If you have any questions about the programme or would like to share your work on self-management, please email [zoe@nass.co.uk](mailto:zoe@nass.co.uk).

## Spafo Norge, Norway

Spafo Norge's leader, Lillann Wermskog, presented their poster *Spondyloarthritis webinar series: diagnoses, physical activity, acceptance and coping with a chronic disease*, with the abstract available on the congress screens.

The poster addresses the webinar series on spondyloarthritis, where rheumatology experts talk about the different spondyloarthritis diagnoses and how to diagnose them. The series also has separate episodes on the topics of physical activity and coping and acceptance of one's own disease.

**Spondyloarthritis webinar series:  
diagnoses, physical activity, accept and coping with a cronic disease.**



Lillann Wermskog1, Lise Mette Eidet1, Ida Vindstad2  
*1Spondylitis association of Norway, Oslo, Norway, 2Spondylitis association of Norway, Larvik, Norway*

Abstract N: 5502

**Background:**  
When you get diagnosed with spondyloarthritis, you want to know everything about the disease. To find information about your own diagnose can be overwhelming and it may be difficult to find answers to the specific questions you have.

**Objectives:**  
The aim is to provide good and safe knowledge about spondyloarthritis diagnoses, symptoms of the different spondyloarthritis diagnoses. Rheumatologists, physiotherapists and a psychologist provides knowledge about living with a chronic disease.

**Methods:**  
We made webinar series with rheumatologists, physiotherapists and a psychologist. People were allowed to ask questions to the professionals in advance, and the questions were answered in the webinars. The questions that came in were about treatment, who should treat these patients, and symptoms of the different spondyloarthritis. We used a professional studio to film the webinars with the different professionals, each spondyloarthritis diagnosis received its own webinar, to show the difference between them.



One episode was about how to accept and live with spondyloarthritis. The reason we chose to film webinars was to be able to share them in social media, and on our website. And at the same time, this is a tool for explaining the symptoms and treatment of spondyloarthritis by a specialist.

**Results:**  
The webinars have reached: Axial spondyloarthritis: 7135, Psoriatic arthritis: 5930, Juvenile spondyloarthritis 3300, IBD associated arthritis: 4285, Accept and coping: 2457, Physical activity: 3645 = 26752. In total, including online articles about the webinars and spreads in social media the 6 webinars have reached ca. 40 000 people.

**Conclusion:**  
The webinar series includes safe and good knowledge about the different spondyloarthritis diagnoses, helps the patients understand the symptoms better, gives information about both medical and non-medical treatment. At the same time, they provide knowledge about coping and accepting a chronic illness. The webinars are easily accessible for patients and relatives to find, and the webinars are customized for patients to understand.

<https://spafo.no/prosjekter/webinarer/>



The report is supported by Novartis, AbbVie, Pfizer. Copyright © 2024 Lillann Wermskog lillann@spafo.no Lise Mette Eidet litemette@spafo.no

The webinar series provides those living with spondyloarthritis with reliable knowledge that can enable them to make better choices for their own health. Spafo Norway hopes that its success in offering information and knowledge in this way will inspire other patient organisations to do the same.

For more information about the work described above, please [contact us](#) or reach out to the specific organisation directly. To read about our Spotlight on IMAS event held immediately prior to EULAR [click here](#) and to see some more photos from EULAR [click here](#).