

- Spondylitis ankylosans • Spondylarthritis ankylosante
- Spondiloarthritis anchilosante • Espondilite anquilosante • Espondilitis anquilosante
- Behterevova nemoc • Ankilozan Spondilit • болезни Бехтерева



## ASIF'S MISSION

To increase awareness of Axial Spondyloarthritis (axSpA) and knowledge of the disease around the world to all key stakeholders be they people living with axSpA, health care professionals, researchers, pharmaceutical organisations, policy makers or the general public.

### WHO WE ARE

**ASIF** is an international membership organisation representing more than 50 patient organisations from over 40 countries specialising in the support of patients with axSpA.

**ASIF** is proud to work on important projects aimed at improving the lives of the global axSpA community. These include the International Map of axSpA (IMAS) and Delay to Diagnosis.

**ASIF** coordinates World AS Day - annual day dedicated to people with axSpA. It is celebrated globally on the first Saturday after 1 May.

**ASIF** cooperates with the Assessment of SpondyloArthritis International Society (ASAS), an international group of experts in the field of spondyloarthritis.

### PATIENT ORGANISATIONS

If you know of an association that would like to join ASIF, or if you live in a country that does not have a national association, please contact us.

We encourage the formation and development of disease-specific axSpA societies, separate from general arthritis organisations to better represent, educate and advocate for people living with the condition.

New associations need willing and capable rheumatologists and patients to be successful. ASIF can support the creation of new associations.

For more information on how to set up an axSpA society in your country, contact us.

*Our members can be found on our website [www.asif.info](http://www.asif.info)*



**CORPORATE SPONSORS** ASIF is grateful for the support of its industry partners:



**“You are not alone, there are patient organisations around the world who can support you and who work with ASIF to ensure our voice, as patients, is heard in a global arena.”**

– Zhivko Yankov, President of ASIF

## WHAT IS AXIAL SPONDYLOARTHRITIS

**Axial Spondyloarthritis** (axSpA) is a chronic inflammatory disease that encompasses radiographic (Ankylosing Spondylitis or AS) and non-radiographic (nr-axSpA) forms. It is a rheumatic inflammatory disease primarily affecting the spine and sacroiliac joints. It can lead to chronic pain, structural damage and disability.

**LEADING SYMPTOM:** Inflammatory back pain that improves with exercise but not with rest

**DISEASE ONSET:** Usually before the age of 45, often in the 20's

**PREVALENCE:** Varies between populations and could be as many as 1 in 150

**OTHER SYMPTOMS:** Patients may also experience uveitis, psoriasis, enthesitis and colitis

**GENDER:** Affects both men and women equally

### DIAGNOSING AXSPA

If a patient:

- is under 45 years old and...
- has had persistent backpain for more than three months and...
- has morning back stiffness that eases with movement

investigations into Inflammatory Lower Back Pain should be done.

We recommend patients are referred to the axSpA/AS Society in their country, find details on [www.asif.info](http://www.asif.info)

### PATIENTS BENEFIT FROM JOINING PATIENT ORGANISATIONS

ASAS recommends patients join their national axSpa/AS patient association, as they:

- help patients feel less isolated
- provide education via newsletters, symposia, websites and social media
- help motivate patients to exercise in group physiotherapy/exercise sessions
- share information about the disease and research taking place
- help patients learn to self-manage and cope with their condition



**axSpA** places a huge physical impact and psychological stress on patients which can disrupt every aspect of their life and its quality, including mobility, sleep, work and relationships. It is a poorly understood disease that causes patients to worry for their future.

**7+** years on average to be diagnosed and women often wait longer than men

**69%** of participants struggled to get dressed

**74%** reported difficulties finding a job due to their condition

**50%** reported sleep problems

**39%** reported anxiety

**34%** reported depression

\*data from IMAS