



Guide to Starting an axSpA Patient Organisation



Living up to our mission

ASIF's mission is:

- To advocate globally to improve the lives of people affected by axial Spondyloarthritis and related conditions
- To grow, strengthen and empower our community, and to raise awareness around the world.

We want to help you do that too.

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Introduction

Almost every patient organisation starts out because someone wants to make important change happen.

Patient organisations can be powerful and can help people better manage their health or the health of their loved ones. They can support and connect people with shared experiences, improve lives through education and awareness, or tackle policy issues to improve diagnosis and treatment.

There are so many things to consider when establishing a patient organisation, and it can be difficult to know where to start. This guide has been created to support your ambition to set up an axSpA patient group.



Finding your community

Building a community takes time and commitment. Your axSpA community will be crucial to the success of your organisation.

Find your community and tell them about wanting to start a patient group.

Your community is likely to start off as a small group of people, either living with axSpA or connected in some way to the disease. It could be a small Facebook Group to start with. Connecting with, and growing your relationships with your community, including patients, rheumatologists and other healthcare professionals is an important first step to establishing a community base.

To do this:

- You can use social media to connect with patients; try finding relevant groups – there may be rheumatoid disease groups already established in your country
- You can also write emails to specialist healthcare professionals, especially rheumatologists, asking them to let their patients know you are establishing a patient group and passing on your contact details (you can produce a simple electronic flyer for them)
- It is crucial to connect with healthcare professionals and ask them to be involved in your community. They have a unique perspective, can help to guide your work and will help to build credibility.

We have created a separate, detailed guide called *Building your membership*, which can be found on our resources webpage.



Setting up your organisation

Continue to build your community and talk to them before you establish your goals. The first gathering of patients and caregivers, whether virtual or in person, is usually passionate and exhilarating — especially if the attendees have never met other people living with the same disease. This is a critical opportunity to ensure you have a good understanding of the needs of your community, which will help you identify the goals of your organisation.

Identify your team. Why do it alone? You can grow and reach more people as a team and people will have different sets of skills and expertise that can complement each other. As you establish your group, seek out individuals who are passionate about changing the lives of people with axSpA.

Name your group. You can decide on the name of your organisation with your team or community. Once this is decided, the name can usually be registered as a non-profit organisation with the government in your country.

Build your database of members. As people ask to be involved with your group, start to build a list of who they are, their contact details and what their interest is (for example, patient, healthcare professional). Having this information is crucial to be able to communicate with your members. When you start applying for funding, having a database of members is important. You should ask for their permission to keep this information and ensure you are complying with local data protection laws.

Ask ASIF to connect you with other patient groups that can help with advice and sharing their experience.



Your organisation's identity

Some of the most important parts of establishing your group's identity include your name, logo, vision and mission, as well as your online presence (website and social media).

- **Logo.** A logo can be a helpful identifier of your group. It can be used on your organisation's social media channels, website and materials to help build familiarity with the organisation
- **Tagline.** This is usually one line that describes your vision or mission — something that tells people what you are all about. For example, "To educate and support people living with axSpA"
- **Website.** There are many free or low-cost website platforms, like WordPress. This can be basic at first and grow over time
- **Materials.** A one-page leaflet (electronic or printed) is an effective way to introduce people to your organisation
- **Social media.** Decide which social media channels will be most effective for your organisation – perhaps start with one if your resources are limited. Consider creating a private group for members to talk openly.

We have created separate, detailed guides called *Creating and managing a website* and *How to make the most of social media*, which can be found on our resources webpage.

ASIF
AXIAL SPONDYLOARTHRITIS
INTERNATIONAL FEDERATION

Giving an international voice to patients with Axial Spondyloarthritis (axSpA) and related conditions.
(including Ankylosing Spondylitis)

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World AS Day
8 May 2021

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

CORPORATE SPONSORS ASIF is grateful for the support of its industry partners:
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Creating a leadership team

Is it really needed?

A leadership team plays an important role in guiding your organisation.

It also provides a group of individuals with different skills and experiences to share roles and responsibilities – and, therefore, make better decisions for the organisation. Your team might be very small to start with and grow, as you find you need additional experience, expertise or capacity.

There are no rigid rules about who the team should be made up of, but you might want to consider:

- **Chair or President:** This person leads the team and meetings; and ensures everyone gets chance to have input
- **Treasurer:** If your association will be handling funds (donations, grants, etc.), it is good governance to have someone who oversees the organisation's finances
- **Patients**
- **Healthcare professionals**



Engaging healthcare professionals

The value of clinical experts

The expertise of healthcare providers who specialise in axSpA is a valuable resource. Their role could be to validate that the information you are providing patients is accurate or to use their experience to help the organisation make decisions.

Building strong relationships with disease experts will help establish your organisation among the medical community, while also helping you to reach patients.

Ways to involve healthcare professionals:

- Invite a medical expert to join your leadership team
- Invite medical experts to share new research and disease developments at events, in your newsletter, website or social media
- You can ask them to share your social media posts.

Healthcare professionals to engage

Rheumatologists are the main healthcare professionals that you are likely to involve. However, as your organisation grows you may benefit from engaging with physiotherapists, GPs and specialisms that treat associated conditions, such as ophthalmologists, gastroenterologists and dermatologists.



Good governance

What is it?

A set of guidelines and regulations that says how your organisation will be run and outlines its structure. This gives an organisation direction and a purpose and provides a framework and a strong foundation. Again, this can be basic at first and grow over time.

What is included?

- Vision, mission and purpose
- Team roles (include responsibilities)
- Team structure
- How decisions are taken
- Board effectiveness
- Risk and financial planning
- Compliance with legislation
- Accountability, openness
- Equality and diversity



Funding your organisation

Running a successful patient organisation costs money. There could be office expenses, fees to design and host a website or costs associated with printing flyers and brochures.

As the organisation becomes more established, you may also have salary costs or the costs of running specific projects.

Funding can come from:

- Donations
- Membership fees
- Funds from pharmaceutical companies
- Grants for non-profit organisations
- Fundraising.

It is important to check local regulations on the funding of non-profit organisations.

We have created separate, detailed guides called *Getting support from pharmaceutical companies* and *Fundraising*, which can be found on our resources webpage.



Stay connected with your community

Build a database. Include your members, volunteers and supporters (healthcare professionals, pharmaceutical industry contacts) to make it easy to find their information.

Post on social media. Sharing posts and information from ASIF and other axSpA organisations is a great way to stay connected without always having to create new content.

Write a newsletter. This can be a simple pdf that you attach to an email or consider a platform such as MailChimp that offers free or low-cost plans that make it easy to create and send newsletters.

Update content. Your website and newsletters are great places to provide links to recent axSpA news and interviews with medical experts and patients.

Increase subscribers. Encourage people to sign up for your newsletter by adding a sign-up link on your website and posting about it on social media.

Share campaigns. Sharing campaigns from ASIF or other relevant organisations is a good way to engage with your community.

We have created a separate, detailed guide called *Communicating with your members*, which can be found on our resources webpage.



Events

There are many ways to connect with patients, caregivers and healthcare professionals – either in-person or virtually.

- **Support groups** – patients only
- **Webinars** – invite speakers
- **Information sessions** – invite speakers
- **Attending conferences** – having a booth for your organisation or speaking at a conference can be a great way to connect with new individuals
- **Events on awareness days** like World AS Day
- **Podcasts** can also be a great way to share information with your community.

It is useful to record virtual events for those that cannot attend. It can also be a good reference point later and help to build a library of resources. You can consider setting up your own YouTube channel.



Education and engagement

A key strength of a patient organisation is its ability to keep its community engaged and educated.

The information available on your website, in newsletters and on social media, is important. Ensuring it is current and accurate helps to establish trust and credibility.

ASIF has a number of axSpA related guides that you can share using your own logo and contact details.

Some ideas to generate content:

- Interviews with doctors and other healthcare professionals
- Patient/caregiver stories
- ‘Explainer’ type stories that look at relevant lifestyle issues
- Reporting on articles from other organisations
- Profiles of leading researchers.

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