



Working with the Pharmaceutical Industry



Contents

- How can pharmaceutical companies support your organisation?
- How to find a pharmaceutical company with an interest in axSpA
- How to connect with a pharmaceutical company
- Establishing and building a relationship
- Types of support
- Process of requesting funding
- Once you have your grant



How can pharmaceutical companies support your organisation?

There are many pharmaceutical companies that work in the field of axial Spondyloarthritis and related conditions. The pharmaceutical industry values the vital role patient organisations play, not least because patient communities are an invaluable source of information that helps them to better understand the patient experience. This in turn, is valuable in the development of treatments.

They often work closely with patient organisations because of a shared common interest – to improve patient experience and care. Pharmaceutical companies can be an important resource for your organisation, both in terms of funding and information.

How to find a pharmaceutical company with an interest in axSpA

How do you know which companies have a presence in your country and work in axSpA? There are a few ways to find this information:

- Research the axSpA treatments, in particular biologics and biosimilars that are available in your country and the pharmaceutical companies that manufacture them
- You can ask a rheumatologist. They will know either because they are connected to a pharmaceutical representative or are familiar with the company through a treatment
- You can also ask other patient organisations whether they are supported by pharmaceutical companies.

How to connect with a pharmaceutical company

Normally a pharmaceutical company will have a main point of contact for patient organisations, often different people for different therapeutic areas. The title may vary from country to country, but it helps to look for the individual with 'patient engagement' or 'patient advocacy' in their title. You can contact the person with an introductory email or by phone. If the company is one that ASIF has a relationship with at a global level, we should be able to help to find the name of the person responsible for axSpA at a national level and hopefully set up an email introduction.

The initial conversation will often focus on your organisation's work and what is important to you, as well as learning more about the pharmaceutical company's strategic priorities.

Establishing and building a relationship

When it comes to working with pharmaceutical companies, establishing a relationship is important. From the moment you make contact, there should be transparency, honesty, and integrity on both sides. Your contact should be able to provide information and insights about the organisation. They may be able to help you understand the types of projects that they will likely fund.

Something to be aware of:

Pharmaceutical companies have strict guidelines or codes of practice that comply with local laws and dictate what their relationship with patient organisations can look like. This ensures industry-patient organisation collaborations are open and transparent. Most importantly, industry guidelines are there to preserve the independence of patient organisations, so that the integrity of your association is not questioned. It is also worth knowing that many pharmaceutical companies will only fund organisations that are registered.

Once you have established contact with the right person, you may choose to meet. A meeting will give you the opportunity to go into more detail about your work and their priorities. Preparation will help your organisation come across as credible.

To prepare well for the meeting outline, your vision and objectives for the near future. List other organisations or healthcare professionals you are aligned with. These might be other patient advocacy groups, other pharmaceutical companies, or a group of rheumatologists. Showing that you have established a network helps to add credibility to your organisation and any future request for support.

Some questions you may get asked:

- What is your membership base?
- What are your short/long term goals?
- Are you affiliated with a global group(s) or other patient groups?
- What projects or campaigns are you working on, or have you done in the past?
- What work are you seeking funding for or would like to collaborate on together?

You will also want to understand more about the company's axSpA priorities and strategy. It is very useful to know what they are, so that you can check whether they align with the work you are doing – or want to do.

It is likely that you have a personal connection to axSpA, but if you don't, consider inviting someone living with axSpA to join you. It can be really powerful to have someone there who can speak from personal experience.



Types of support

Financial support is available for patient organisations whose work aligns with companies' therapeutic areas of interest. Each company has its own guidelines and having a relationship is the best way to understand what support is available.

Grants

Grants (sometimes called restricted grants) are for a specific project or activity and must be spent in this way. The application process might require you to fill out a form, write a letter or apply online. Regardless of how you apply, you will need to provide details of the project or activity you are requesting funding for.

Donations and unrestricted grants

You may also be able to get a donation or unrestricted grant, which is not for a specific project or activity; however, these are far less common.

In-kind support

It may also be possible to obtain 'in-kind' support. This is a non-monetary contribution and can be very useful for a variety of projects and tasks. For example, a company might offer some graphic design work, printing or translations.

Collaboration

You might decide that working on a project collaboratively is beneficial. Collaborations with pharmaceutical companies cover a range of activities that make a difference for the patients your organisation serves; these could include:

- Disease awareness or advocacy campaigns
- Producing information videos and other types of support for patients
- Meetings or events
- Research.

If you do embark on a collaboration, have a clear understanding about the purpose of the collaboration and the goal of the project or activity. When you enter a collaboration, you are two separate entities that are independent of each other and have come together to achieve a common goal or objective. Think about what you want to bring to the collaboration and what you hope to get out of it.

Before starting, be clear about the roles of each party and how much time and resources you will need to commit. Most importantly, a true collaboration is when two parties work closely together to share the decision making.

Sponsorship

This is normally funding for a specific event, publication or project for which in return the company will receive some benefit, usually branding of some kind.



Process of requesting funding

There are different ways to submit a funding request. Your contact is best to advise you on the process. You may be able to request funding through a letter or there may be an online form to complete. If there is not a form, your contact should be able to tell you what information to include.

Points to consider

- You may be required to disclose what percentage of your organisation's annual income the funding request represents.
- When applying for funding, include the direct costs and overheads associated with the project or activity. Also consider including an amount that will contribute to the day-to-day running of the organisation.
- Successful funding for a project in any one year does not guarantee it will be renewed in a subsequent year. It is important to maintain good relationships with funders, by keeping them updated on the project and making regular contact. Asking if they would like to receive your newsletter or other communications can be a really simple way to keep them informed about your work and events.
- You might consider setting up annual partnership levels of funding; for example, Gold, Silver and Bronze, each with a different funding value and each offering different benefits to the organisation.

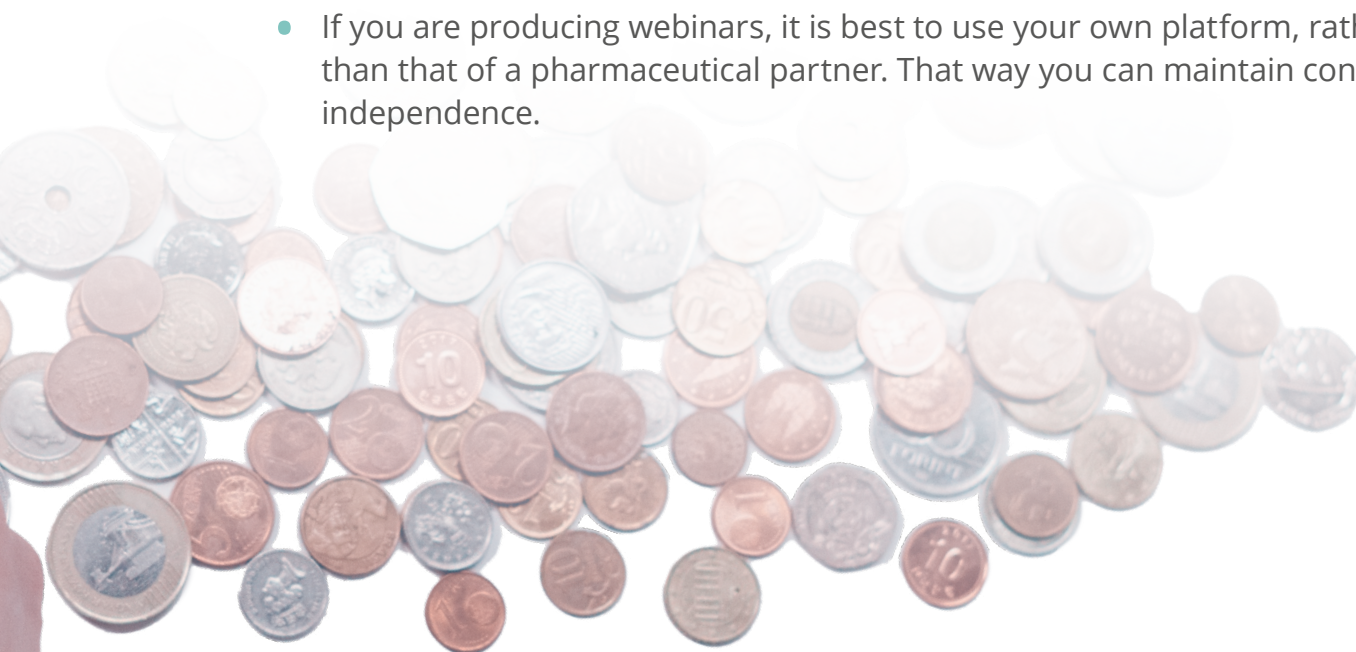


Once you have your grant

You will be required to report on the progress of your project or activity and you may need to do that by a specific date. There should be clear guidance included with your offer letter.

Things to be aware of

- Pharmaceutical companies should not promote their products or services. Ensure they do not do so in any part of your materials.
- The company should not have any undue influence over the content or editing of the materials unless you have agreed to this as part of a collaboration agreement.
- Do not include any text that recommends a specific company or its products.
- Avoid sending out joint emails or invitations from you and a pharmaceutical company. This can be perceived as them having undue influence and can damage your reputation.
- If you are producing webinars, it is best to use your own platform, rather than that of a pharmaceutical partner. That way you can maintain control and independence.





Acknowledging support for funding

When you acknowledge a pharmaceutical company on materials or content, you will need to comply with local guidelines.

Be cautious that there is no undue influence from a company on your work. Consider these tips:

- Try to have more than one company funding a project where possible; this will help to maintain your independence
- Discuss branding with your funders. Manage their expectations with regards to prominence and size of their logo on your materials. Have a consistent approach to branding
- Have a written agreement with the company outlining what you have agreed, which should include where their logo must appear and with what wording
- Ensure your own logo is on all materials and is the most prominent
- Consider a statement to accompany the company logo – for example: *We are grateful to x for their support of this project. X has had no influence on or involvement in the delivery of this project.*

Other possible suggestions for crediting company partners:

- The publication of this xxx was made possible by a grant from x
- This webinar was supported by a grant from x
- We thank x for their support.



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