



international mito patients



# Guide to starting a mito patient organisation



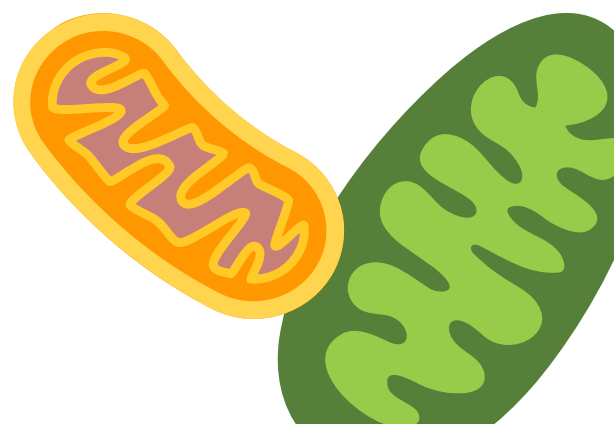
## Living up to our mission

### IMP's mission is to

*Increase quality of life for people with mitochondrial diseases (mito) by facilitating cross-border cooperation and collaboration among national patient organisations.*

### Our objectives are to:

- share best practices, information and knowledge, in order to:
  - promote early diagnosis;
  - develop appropriate care pathways;
  - clinically manage the disease;
- be an international bridge between patients, clinicians, scientists, industry and policy-makers; and
- promote and advocate for speedy development of treatments and cures.



# Contents

• Introduction	5
• Finding your community	6
• Setting up the organisation	7
• Your organisation's identity	8
• Creating a leadership team	9
• Engaging healthcare professionals	10
• Governance	11
• Funding the organisation	12
• Stay connected with your community	13
• Meetings and conferences	14
• Education and engagement	15
• We're here to help	16

First published May 2024

This guide is based on a content originally created by the Axial Spondyloarthritis International Federation (ASIF). IMP is grateful for ASIF's generosity in sharing its resources.







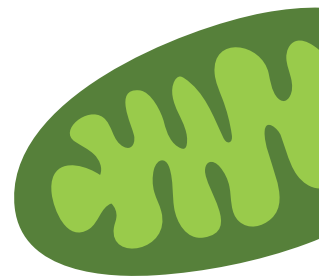
## Introduction

Patient organisations often start because there is a gap in support for those affected by a particular health condition - be them patients or carers.

Patient organisations connect people with shared experiences, improve lives through education and awareness, or tackle policy issues to improve diagnosis and treatment. They can help people better manage their health, and support them in their engagement with healthcare professionals.

There are many things to consider when establishing a patient organisation, and it can be difficult to know where to start.

At IMP we've lived that experience too, and this guide has been created to support you in creating your mitochondrial diseases patient group.



## Finding your community

Building a community takes time and commitment. Your mito 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 mito 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, mito specialists 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 and caregivers; try finding relevant groups. There may be mito related groups already established in your country.
- You can write emails to specialist healthcare professionals, 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 helpful 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.





## Setting up your organisation

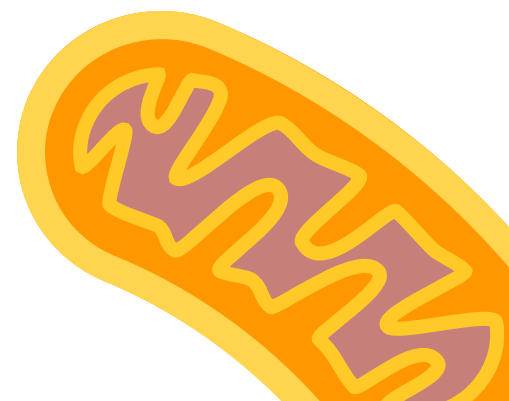
**Continue to build your community** and talk to them before you establish your goals. The first gathering of patients and caregivers, whether virtual or in person, is usually passionate and exhilarating — especially if the attendees have never met other people living with the same disease. This is a 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 mito.

**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, parent or 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 IMP 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 connect and support people living with mitochondrial diseases".
- **Website.** There are many free or low-cost website platforms, like WordPress. This can be basic at first and grow over time.
  - Click here to see our guide [‘How to create and manage a website’](#)
- **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.
  - Click here to see our guide [‘Using social media’](#)





## 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 mito 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, or be a medical advisor.
- 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

There are many healthcare professionals that your organisation may work with, from fields including - but not limited to - cardiology, endocrinology, gastroenterology, neurology, ophthalmology and respiratory.





## 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.

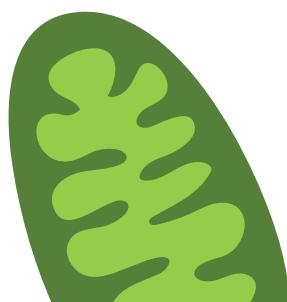
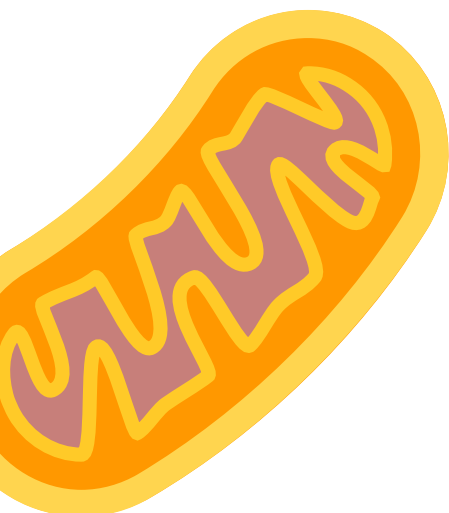
As the organisation becomes more established, you may also have salary costs or the costs of running specific projects.

### 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.

Click here to view and download our [Guide to fundriasing](#).





## 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.

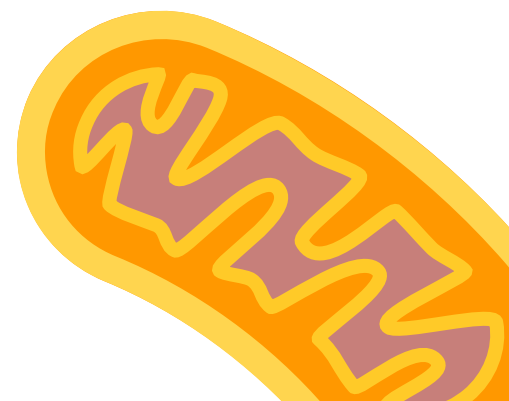
**Post on social media.** Sharing posts and information from IMP and other mito organisations is a great way to stay connected without always having to create new content.

**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 mito 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 IMP or other relevant organisations is a good way to engage with your community.



## 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 during awareness periods like World Mitochondrial Awareness Week
- 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.

### **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.





## We're here to help

We understand how daunting setting up your own organisation can be. IMP, and our member organisations, were started by people like you, often who were looking to find more support for themselves or their loved ones. They were driven to make a difference and help others affected by mito. They were created by one or two people, often from their home at weekends or in the evenings, around work, family and frequent medical appointments.

We understand that every country has different contexts and challenges. We might not always have the answers, but we are committed to supporting our global mito community and will do all we can to help you.

We believe in your capacity to do this! It is likely that there will be obstacles and frustrations - please reach out to us - there may be others who have experienced similar things and can offer advice. Contact us at [info@mitopatients.org](mailto:info@mitopatients.org) or find other useful guides on our website at [www.mitopatients.org](http://www.mitopatients.org).

### Online resources:

- [Guide to fundraising](#)
- [Guide to creating and managing a website](#)
- [Guide to using social media](#)





**international mito patients**



[www.mitopatients.org](http://www.mitopatients.org)  
[info@mitopatients.org](mailto:info@mitopatients.org)