



international mito patients



# Guide to fundraising



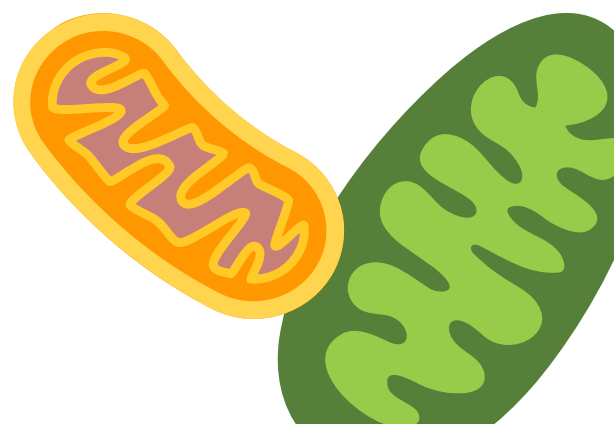
## Living up to our mission

### 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.



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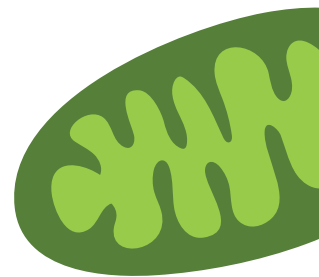


## What is fundraising?

The work that volunteers do to get an organisation started and to keep it going is critical, however there comes a time when you are going to need funds to carry out your work. Fundraising is the way an organisation asks for donations, or other financial support, from the public, businesses, government, foundations and others. There are many different ways to raise funds.

There are likely to be legal and/or tax regulations, specific to your country, related to fundraising. Therefore, the first thing to do it to check and follow those legal guidelines. For example, you may need to have a specific sort of bank account and funders may require you to be a registered organisation.

Fundraising not only raises vital funds – it can also be the main way that people hear about the work of your organisation and it can raise awareness and encourage further support such as volunteering. Fundraising can help to develop relationships with supporters.



## Questions to ask before you get started

- What are your fundraising goals and what will those goals allow your organisation to achieve?
- Who will you approach for funds?
- What resources, and people, do you have to help you fundraise?
- How will you go about it?
- Do you know the rules and best practice in your country for fundraising?
- Think about risks associated with a particular fundraising activity and consider how you might manage them.
- How will you keep your supporters engaged?
- How will you review, learn from, and improve your fundraising efforts?
- Consider talking to other organisations to find out about their fundraising experiences, what has worked and what hasn't.
- Think about doing some training in fundraising.



## Where will your funds come from?

### Community fundraising

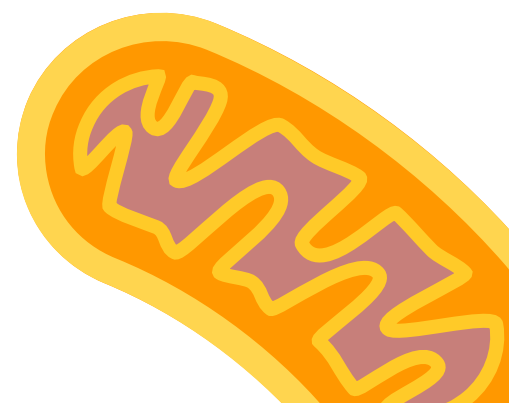
One of the best ways to raise money is through your mito community. They understand the need better than anyone and can be your greatest advocates. It's important to check the guidelines for fundraising in your country; a license may be required to hold a raffle for example, and it can be good practice to provide a letter of 'authority to fundraise' to those raising funds on your behalf.

There are many ways your community can fundraise, from selling home-made items or food at a fair or market, to doing a sponsored activity. Sponsored activities are a great way for your community to get involved and to raise awareness. You can also host events that raise funds through a registration fee, ticket sales or donations.

You can develop your own events throughout the year and use [World Mitochondrial Disease Week](#) as an opportunity to raise awareness as well as funds in September. Social media can be a useful tool to promote your events and to show your community how successful they have been by sharing photos afterwards.

### Membership Fees

When you are starting out, identifying members and creating your community will be the priority. As your organisation becomes more established, you may consider charging a membership fee to help cover basic costs. You may consider a lower fee or not charging those on a lower income.



### Advantages

- Membership fees provide a predictable and ongoing funding base
- Members might feel more personally connected to the organisation

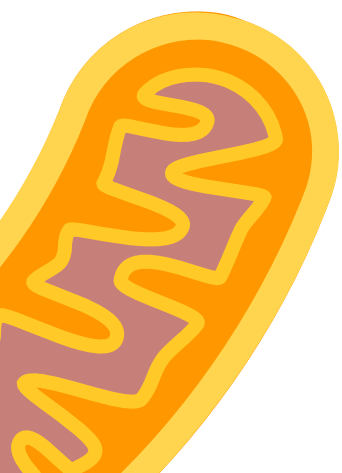


### Disadvantages

- Managing membership fees requires administrative work
- Losing prospective members who cannot afford to pay
- Some may be put off joining if they don't see the advantage of paying a fee.



You might consider some sort of 'welcome pack' or 'welcome to the association' letter including information about the association and about mitochondrial diseases.





## Fundraising from individuals

- Charitable appeals can ask for donations from members, their families and other individuals. The request can be done via hard copy letters or digitally (email and social media). You can have an online donation page on your website; include options for one-off and regular donations. The link to your donation page could also be shared in your email signature and in any other materials you have.
- Fundraising events can range from balls, exhibitions, concerts or auctions, to bake sales and coffee mornings. These are opportunities to be creative, they can help supporters to understand more about your work and can bring together potential donors and beneficiaries.
- If there is an influential individual in your country that has a personal connection to mito, they may be willing to support your organisation and can be an important focal point for your fundraising activities and communications.
- Legacies can be a sensitive area of fundraising, but it can also be a positive opportunity to communicate with supporters about the impact they can have on the world after they are gone. You can integrate messaging about legacies across your communication channels.

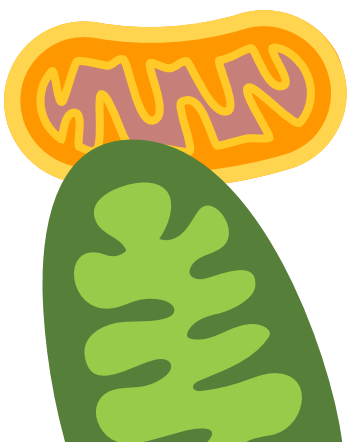


## Grants

Do some research into grant-making trusts and foundations, and government organisations, that fund patient associations and the type of work you do. These types of organisations tend to have specific guidelines for applying for funding, and may have an application form that asks for information including:

- Contact information
- Organisation overview
- Financial information
- Activity start and end dates
- Project details:
  - A brief description of the activity
  - Main aims and objectives
  - Target beneficiaries. Who will the project/activity aim to help?
  - Tangible and intangible benefits you expect from your activity, who will receive those benefits and how many will benefit?
  - Outputs and outcomes of the project/activity. This could be a service or product or could be the changes, benefits or learning
  - Any collaborators or partners in the project/activity
  - Potential risks that could affect the delivery of the project/activity and how you propose to manage them
  - How you will monitor progress and evaluate the success of your project/activity.

It is important to be clear about your fundraising objectives and the impact the grant could make.



## Corporate funding

Depending on the legal regulations in your country, you may or may not be able to access funding from corporations. There is normally specific ethical and legal guidance for working with pharmaceutical industry partners.

There may also be companies that have a role in the life of people living with mito; some examples might be pharmaceutical companies or manufacturers of disability equipment.

Businesses recognise the need to demonstrate social responsibility by investing in the community and might offer grants or donations. National or local companies may have a philanthropic department and want to do good in the community. They could be approached to ask for support for a specific project, either for funding or in-kind donations (non-monetary support, for example providing volunteers or printed materials).

Examples of things that could be funded:

- Printing and mailing costs
- Design work: for example, website and brochures
- Educational programmes
- Support groups
- Information sessions
- Awareness raising activities: for example if your organisation holds an event such as a sponsored walk, a company could provide catering, t-shirts, balloons or goody-bags etc.





## Relationships with funders

Establishing relationships with potential funding sources is important. This might take time and they may want to see how your activities are progressing before committing to funding, especially if it is for a large sum of money.

Before your first meeting, take the time to write out a brief description of what you want to communicate. Include what your organisation is trying to achieve, what funds you are looking for and how the person or group you are meeting can help.

Maintaining connections with funding sources or donors is key to keeping them engaged with your cause. It might be useful to provide updates on your projects and activities to help with this. If they are engaged and can see the benefits of their donation, the chances of them becoming a regular donor are higher.

It is good practice to send a note to say thank you. Including funders in your newsletter or other communications can also help to keep them engaged and updated.



## Telling a story

You know what your organisation stands for and why it's important, but do others?

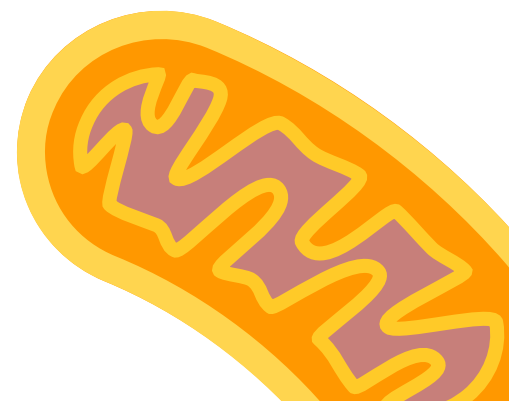
Getting potential funders to care about your cause is key to successful fundraising. When you raise funds, the best way to connect with people is to make it personal. Why? Because people give to people. Storytelling is powerful and memorable and helps to create an emotional connection to your cause.

Sharing stories of patients, caregivers, and volunteers within your organisation can inspire contributions. Ask people if they would be willing to tell their story or have it shared for the purposes of fundraising. It's important to have their written consent first.



## Principles of excellent fundraising

- Treat supporters fairly and with respect – take care not to pressurise anyone into giving.
- Be clear and truthful – make it clear what you are raising funds for. Take care not to exaggerate any facts.
- Handle donations safely and securely – It is important to protect your organisation from fraud or theft, or accusations of them.
- Honour your promises to supporters – if money is donated for a specific purpose, it has to be used for that purpose. You should consider informing donors from the start what will happen to their donation if that particular project does not go ahead – or if you exceed your fundraising target.
- Take responsibility for your fundraising – record your decision-making and be sure to handle any concerns or complaints promptly and sensitively.
- Be responsible with personal data – supporters and donors should be confident that you will use their data legally, fairly and responsibly.
- Think about your supporters – this applies to individuals, members and corporations. Nurture relationships and ensure they know how valued they are.
- Always say thank you!





## 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:

- [How to set up a mito patient organisation](#)
- [Guilde to creating and managing a website](#)
- [Guide to using social media](#)





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