

PERSONAL FUNDRAISING

A guide for our community

Information for families raising money to meet their own medical, care or accessibility needs



Top tips

before you start your personal fundraising

Thinking about fundraising

Some families affected by MPS, Fabry or a related condition choose to fundraise to help meet costs that arise throughout their lives.

If you are thinking about fundraising, whatever your goal, taking some time to plan before launching your appeal can help ensure that the money raised has the greatest possible impact and can be used in the way you intend.

This guide highlights some practical considerations to keep in mind when exploring fundraising options.

- **Explore** grants and statutory funding first as you may not be eligible once you launch an appeal
- **Fundraise** for the outcome you want, not a specific item
- **Plan** for changing circumstances and be open with your supporters
- **Check** how your chosen fundraising platform manages and releases funds
- **Speak** to your clinical team before fundraising for specialist equipment or treatment

How we can help

While individual fundraising often focuses on the needs of one person or family, the MPS Society works on behalf of the whole MPS, Fabry and related disease community.

We provide support services, fund research, influence policy, work alongside clinicians, researchers, regulators and decision-makers and advocate for improved access to treatments and services. **Our aim is to ensure that no family faces MPS, Fabry or a related condition alone.**

Both individual fundraising and supporting the wider work of the MPS Society play an important role in improving the lives of people affected by these conditions.

Reasons to fundraise

Every fundraising campaign is different. Families may choose to fundraise for:

- specialist equipment
- wheelchairs or assistive technology
- communication aids
- home adaptations
- accessible housing
- education or independence support
- therapies or rehabilitation
- respite care
- travel and accommodation
- additional care costs

Some families also fundraise to access emerging treatments. They may seek treatments available in another country or raise money to cover the costs of participating in a clinical trial or accessing another emerging therapy.

As new treatments continue to be developed, the MPS Society is working with clinicians, researchers and other partners to better understand the practical, clinical and regulatory considerations surrounding access to them.



Check existing funding options

Before starting a fundraising campaign, consider whether there are other sources of funding or support already available.

Depending on what you are fundraising for, support may be available through:

- statutory services
- your local authority
- NHS
- charitable grant-making organisations

Fundraising can often work alongside these sources of funding, helping to cover additional costs or provide items and services that are not routinely funded.

Potential funding sources

Families seeking support for home adaptations may be eligible for a **Disabled Facilities Grant**.

Charities such as **REACT, Family Fund, Children Today** and others may offer grants towards specialist equipment or other practical support.

You may not be able to apply for other funding sources if you have already started a crowdfunder.

If you are unsure what support is available to you, your healthcare team or the MPS Society will be able to signpost you to appropriate organisations.

Focus on the outcome

Many fundraising campaigns last for several months and sometimes much longer. During that time, circumstances can change. A child's needs shift as they grow:

- new assessments may recommend different equipment
- funding may become available from another source
- priorities for the family may evolve

For this reason, it can be helpful to think about the overall outcome you are hoping to achieve rather than focusing on a specific item.

For example, rather than fundraising solely for a particular wheelchair or piece of equipment, you may wish to describe your appeal as helping to improve mobility, independence, comfort or quality of life, where this accurately reflects your intentions.

This can provide greater flexibility if recommendations change while remaining transparent with your supporters.



Choose the right equipment

If you are fundraising for specialist equipment, it is important that the equipment has been recommended following an assessment by the relevant healthcare or education professional.

This helps ensure the equipment is suitable for the individual's current needs and is the most appropriate option.

As needs can change over time, particularly for children or people with progressive conditions, the equipment recommended at the start of a campaign may not be the same as the equipment recommended several months later.

Considering this before launching your appeal can help you plan ahead and avoid disappointment.

Plan for changing circumstances

Whatever you are fundraising for, it is worth thinking about what might happen if circumstances change. For example:

- a different piece of equipment is recommended following assessment
- treatment plans change
- a clinical trial opens or closes
- statutory funding becomes available
- your fundraising appeal raises more money than expected
- your family's priorities change

It is also important to understand whether your chosen fundraising platform allows donations to be used for a different purpose from the one originally described. Being open with supporters helps maintain trust and ensures donations continue to make a meaningful difference.



Circumstances can change over time. Keep your supporters updated on how funds will be used.

Selecting a fundraising platform

Different fundraising platforms and organisations manage donations in different ways.

Some platforms release funds directly to the campaign organiser, who is responsible for managing the money.

Other organisations may hold funds on behalf of families and release them in line with their charitable objectives and campaign terms.

Some organisations may have restrictions on how funds can be used or whether donations can be redirected if your circumstances change. For example, they may not release funds for treatments that have not yet been approved. Before launching your campaign, make sure

you are clear on:

- how funds will be managed
- whether there are restrictions on how funds can be used
- what evidence may be required before payments are made
- what happens if your plans change
- whether funds can be used for an alternative purpose if your original goal is no longer appropriate
- whether the platform you choose allows you to fundraise through multiple channels

Fundraising for treatment

We understand why families want to explore every possible opportunity when new treatments are being developed.

If your fundraising involves access to an emerging treatment or participation in a clinical trial, there are some additional things to consider.

Clinical trials have strict eligibility criteria designed to protect participants and answer important scientific questions.

Eligibility may depend on diagnosis, age, disease progression, previous treatments and overall health. There may also be limited places available or recruitment may have closed.



Raising sufficient funds does not necessarily mean that treatment will be available.

Similarly, hospitals or treatment centres offering therapies outside clinical trials will usually carry out their own assessment before deciding whether treatment is appropriate.

Wherever possible, speak to your specialist clinical team before launching your fundraising campaign.

They can help you understand whether a treatment is likely to be appropriate for your individual circumstances and whether opportunities to access it are likely to exist.

Managing donations responsibly

Many fundraising campaigns raise substantial sums of money through the generosity of family, friends and the wider community.

Thinking about how funds will be managed from the outset can help avoid difficult decisions later.

Being honest and transparent about how funds are managed can help maintain the trust and confidence of your supporters.

We are here to support you

Deciding whether to launch a fundraising appeal is a personal decision and every family's circumstances are different.

The MPS Society does not endorse or verify individual fundraising campaigns.

However, we are here to help you understand the wider considerations, discuss practical issues, signpost reliable sources of information and help you explore the options available to you.

Considerations for overseas treatment

If you are considering treatment overseas, it is also important to think about the **whole treatment journey**, including **medical costs** and **insurance, visas, travel, accommodation**, ongoing **monitoring, follow-up care** and how any complications would be managed once you **return home**.

You should consider:

- who will manage the funds
- how spending decisions will be recorded
- how supporters will be kept informed
- whether independent financial, legal or tax advice may be appropriate if substantial sums are raised
- what will happen to any remaining funds if your circumstances change



MPS Society
transforming lives through
support, research & awareness

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