



international mito patients



## How to make the best use of social media



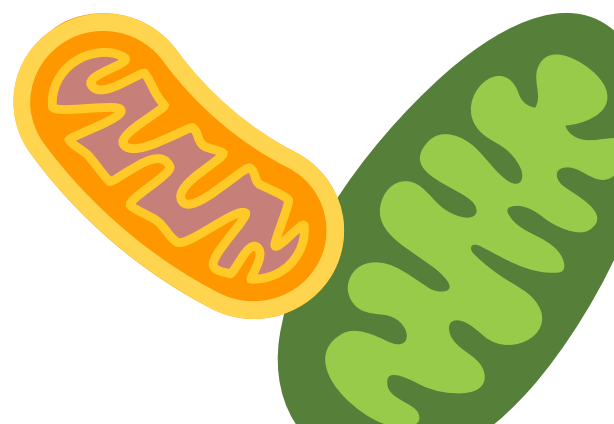
## Living up to our mission

### 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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## Getting started

Social media is a powerful tool that can give your organisation a voice; create awareness of mito and what your organisations does; connect with people affected by mito; and disseminate information quickly.

It is easy to get started and does not cost anything to create a social media presence. However, to maintain a strong social media presence takes dedication and a plan of action.

### Determine your goals

What are you trying to achieve through social media? Do you want to:

- Create and maintain an online presence?
- Drive traffic to your website?
- Attract members to your organisation?
- Share information about mito?

Identifying your goals and making them as detailed and specific as possible will make it easier to track and measure progress.

There are lots of articles online offering advice about social media. It is best to search for articles aimed at non-profits, ideally health or patient related.

### Evaluate your resources

A few things to keep in mind. For instance, who will:

- Create and post your content?
- Maintain your social media accounts?
- Respond to comments and messages?

Managing your social media accounts can be time consuming; consider the time and people you have available.



## Deciding which social media platform to use

Some of the most popular social media networks for sharing information are Facebook, Instagram, X (formally Twitter), YouTube, TikTok, LinkedIn and WhatsApp.

You don't need to be everywhere at once. When you are starting out, it is important to focus your efforts in places that will generate the most return, especially when resources are limited.

Consider **who you want to reach** and the type of content you want to share. For example, if you are targeting a younger audience and can produce lots of videos, **TikTok** might be the best platform for you.

If you are looking to connect with people living with mito and encourage conversations between people, **Facebook** could be a good option as you can have a page – and potentially create a private group that can act as a virtual support group.

Connecting with clinical mito specialists and other healthcare providers, as well as researchers could be done through **LinkedIn**.

**X** (formally known as Twitter) is great for short, frequent posts, whereas **Instagram** is perfect for more visual posts - either your own (ensure written consent is gained anyone you feature) or you can use stock images to illustrate your posts (there are some websites and tools that provide free images, for example **Unsplash** and **Canva**).

You can create your own **YouTube** channel, which people can subscribe to. This is a great way to share longer video content. **WhatsApp** is a messaging app, in which you can create groups. You can share information, including links, images and videos; and have group conversations.

Whilst it is not an exact science, you can make an assessment based on the demographic you want to reach. If your target group is broad, and you have the resources, you might consider being active on different platforms. It is worth doing some research to find the platform that is most relevant to your audience.

## Best practices

Getting started with social media doesn't need to be overwhelming. The following section sets out best practices. You can start small and grow your presence as your organisation grows.

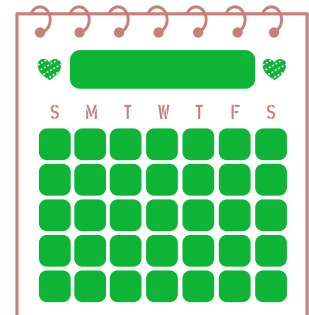
Remember, your objective is to be informative with the content you share, and to set your group up as a source of credible and important information.

Online tools like Buffer can be helpful for scheduling posts and can save time when posting or tweeting to different platforms. These types of tools often have free basic plans, regularly share helpful articles and have free templates and guides. Facebook and Instagram posts can both be scheduled through the Meta Business Suite, a tool that is available with Facebook pages.

### Create a social media calendar

Create a social media calendar to help you stay organised. It can be as simple as a spreadsheet to record the following for each post:

- Publication date and time
- The platform the post will be published on
- Text and creative assets (photos, videos, etc.)
- Links and hashtags

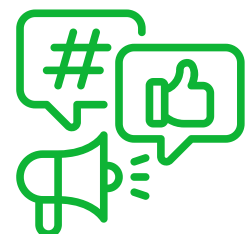


### Post a variety of content

Social media provides a range of opportunities to make a meaningful, positive impact on your followers, from educating to creating a sense of community.

The key to driving engagement is to use a variety of content types – from simple posts with image attachments to linked articles to video content.

- Educational content to provide valuable health information and answer common questions
- Content to raise awareness of current topics related to mito
- Inspirational and motivational content
- Content that people will want to share – infographics, videos, etc.



### **Post frequently**

When it comes to frequency of posting to social media, there is no exact science.

The idea is to be active, yet not inundate your followers. Keep in mind your own personal social media experiences – if you are flooded with posts, it's difficult to follow information.

Some well-resourced organisations aim for one post a day on each platform. But, you can share the same or similar content to different platforms as you are likely to have different followers on each platform.

The exception is X. Sharing more is better on X so if you can post several times a day, it will increase your visibility; however, this can be time consuming and may not be practical for all organisations.

It's important to remember that quality is more important than quantity. If your posts are not relevant to your audience, they may unfollow you.





## Let's talk about hashtags!

When you want to get people talking about a certain subject or post, you can include a hashtag (#). It will allow others who are interested in your topic to easily find it.

The great thing about hashtags is that they can be conversation starters and encourage interaction.

However, when it comes to including a hashtag with your post, there is a right way and a wrong way! Here are a few tips:

- Using one or two hashtags in a single post is better than using a hashtag after every few words
- Try to keep it short so that people can remember your hashtag
- Try to be specific with your hashtag – simple is better!

Example hashtags:

#WorldMitoWeek #mitochondrialdiseases #mito

## Promote your social media accounts

Promoting your social media accounts is important if you want people to follow you.

People will often go to your website to see where you have a social media presence.

The social media icons on your website should link directly to your accounts (they should always open in a new window so you don't lose them from your website).

You can feature feeds from your social media accounts on your home page.

You can also link to your organisation's social media platforms in your email signature, emails and newsletter.



## Growing your presence and keeping your followers engaged

Follow other groups or individuals who are meaningful to your organisation or your cause.

They have their own followers and potentially great content you can share – they may even share some of the content you post which will increase your visibility among their followers.

For example, you can follow medical associations, a prominent researcher in your country or region, or other patient organisations with an interest in mito.

To find the right groups/individuals, you will have to do some social listening first. This means going to the platforms you plan to be on and searching mito-related terminology to see who or what comes up.

You can start by following IMP and sharing our posts.

There are lots of other ways to grow your following. Being proactive in responding to comments is important – even if it is simply liking a comment, you are showing your followers that you value them. There are lots of great articles online that give guidance on growing your social media audiences.

**Giving people a reason to follow you is key – think about your audience and what is relevant and important to them.**

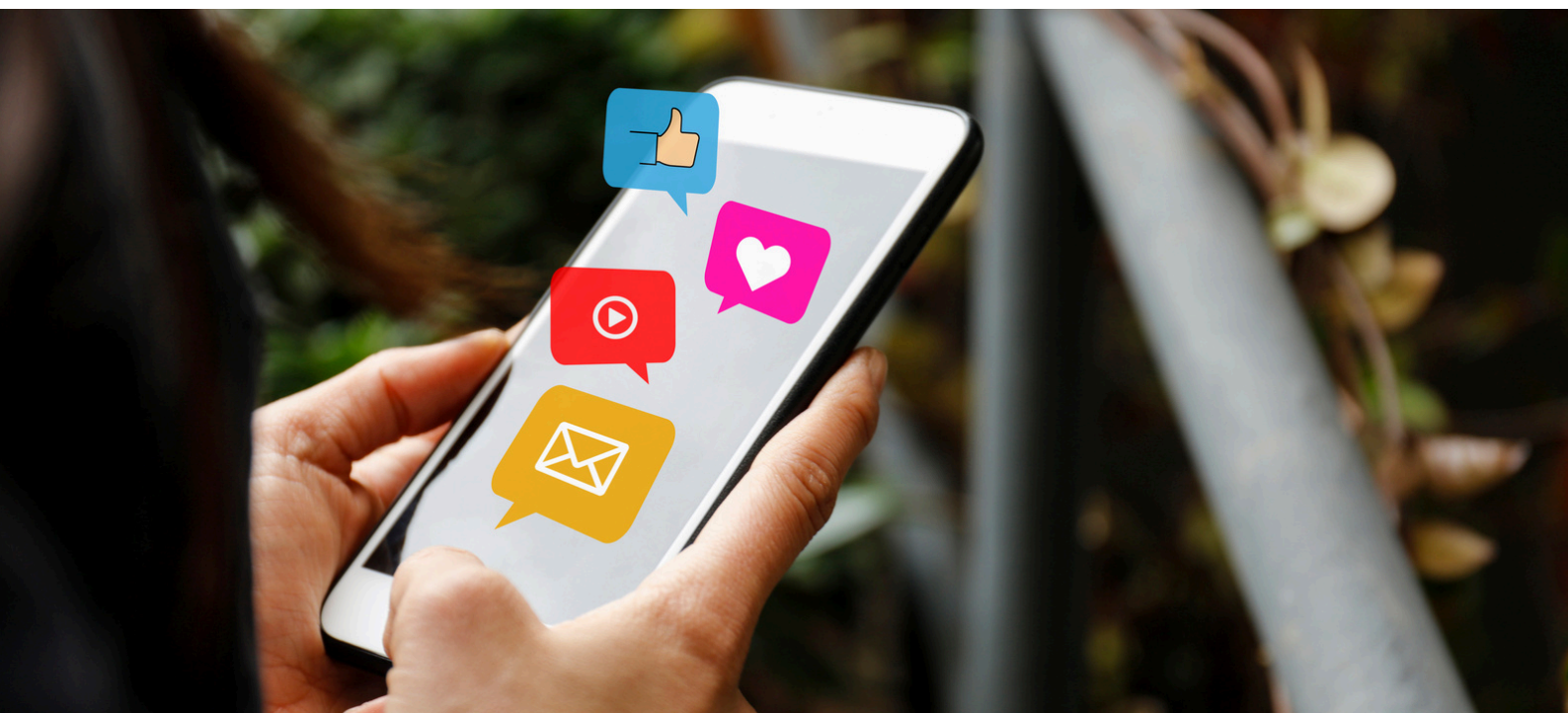
## Boosting and Ads

Complex social media algorithms mean that organic posts (posts that have not been 'boosted' - in other words not had any money added to them) will only ever reach a small number of people – regardless of the quality of the content. Occasionally an organic post will be liked, commented on and shared so much that it will be seen by a significant amount of people, but sadly it is not the norm. This is why many organisations invest in 'boosting'.

Boosting means paying the platform to amplify your post to reach more than the people who are already following you. It's a great tool that doesn't necessarily require investment of a significant amount of money. Sometimes a small amount will go a long way!

A good thing about boosting is that you can decide the amount you want to invest, the duration of your boost and who you want to reach. Be mindful that a boosted post will show up as 'sponsored' on your followers' feed. This isn't a bad thing – it just shows that you have put money behind the post to help it reach a wider audience.

Paid Ads are another way to get your content seen by more people. A Paid Ad is created differently to a boosted post. For example, in Facebook they are created in Ads Manager and they have more options and customisable features. Ads can be successful in getting more people to click through to your website. Each platform has guidance on creating Paid Ads.



### **Language**

Think about your audience and what resonates with them. Posts on Instagram might use informal language, whereas you might use a more professional formal tone on LinkedIn.

When talking to people affected by mito or trying to reach the general public, use terms that are familiar and not too complicated or clinical. Use references to support medically related statements.

### **Measurement**

Taking the time to measure your social media impact can help guide your future activity. If you are looking to measure awareness, it is useful to track:

- reach – number of people who see your content
- impressions – number of times your content appears on someone’s screen; impressions are likely to be higher than reach as content can appear on someone’s screen multiple times
- engagement – comments, retweets, likes, shares and clicks

Each social media platform has its own in-platform analytics. For example, on Facebook, they can be found in the Insights tab and on X, in X Analytics. There are also in-platform tools available to see how boosted posts and ads perform.



## Social media post examples to get you inspired!

Well-designed graphic cards get the message across clearly and simply.

Use tools such as [Canva](#) to create your own eye-catching posts, stories and reels. Canva is very easy to use, doesn't require any software and offers a free to use version. It also has a subscription option for registered charities that gives free access to their professional tools. It is a great platform for creating professional looking social media assets.



## More examples to get you inspired!

Use short attention statements to grab attention



**WORLD MITOCHONDRIAL DISEASE WEEK**  
18 - 24 SEPTEMBER 2023

**fatigue**

Mitochondria are our body's batteries.

mitochondrialdiseaseweek.org




MitoNews

**Cosa sta succedendo nel mondo Mito?**

Tutte le notizie di questo mese dal mondo delle malattie mitocondriali.

Scorri per leggere le news dell'ultimo numero



By updating mito education module for health professionals, we're improving their knowledge of mito.

mito+  
FOUNDATION



## Calling all POLG Patients!


Participate in the development of the Mitochondrial Video Assessment (MVA) as an outcome measure for the evaluation of patients with mitochondrial myopathies, conducted by research firm Casimir.


## Highlighting patient stories


Featuring real life people is a powerful way to share the reality of living with, or supporting a loved one who is living with mito.

This post reached over 7,000 and received nearly 500 engagements. Capturing a person's story in a short paragraph, that they can quickly read without having to click through increases the chance of people noticing the story. Even better if it is written by that person as it feels as if they are speaking directly to the reader.




 worldmitodiseaseweek · Follow ...

 worldmitodiseaseweek Edited · 28 w  
 Here's a story from our Faces of Mito campaign! Meet Sebastian 😊  
 I'm Sebastian, and LHON, or Leber's Hereditary Optic Neuropathy, became an unexpected presence in my life at the age of 21, in Sep '22, while living in Romania. It swiftly robbed my right eye of vision in just four days, followed by my left eye two weeks later. LHON's arrival brought confusion and uncertainty, culminating in an official diagnosis at the end of Nov '22. #LHON is a genetic disease that primarily affects the optic nerves, resulting in rapid vision loss. LHON left me with only peripheral vision, a limited window to the world, bringing a host of challenges I had never anticipated. Simple tasks like crossing the street, reading, or navigating crowded spaces

50 likes

17 September 2023

 Add a comment...



## We're here to help

We understand how daunting setting up your own organisation can be. IMP and our members 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 to help overcome them. 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](#)
- [Guide to fundraising](#)
- [Guide to creating and managing a website](#)







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[www.mitopatients.org](http://www.mitopatients.org)

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