

Guidance on submitting your Patient story

We invite you to share a short personal story (100–300 words) that reflects what it is really like to live with mitochondrial disease. Your story may be about your own experience, or your experience supporting someone with mito. We welcome stories from all countries and all stages of the mito journey – whether you are waiting for a diagnosis, you have been part of the mito community for many years, or whether you have lost a loved one to this devastating condition. Your story will celebrate your strength and will help to raise awareness of mito.

What to write about

Your story might include:

- Daily realities of living with mito
- Challenges you or your loved one face
- Moments of strength, connection, or resilience
- What you wish others understood about mitochondrial disease
- How mito affects family life, work, school, or identity

There is no “right” way to tell your story — honesty and lived experience are what matter most.

Privacy and confidentiality

To protect you and anyone you mention:

- Please do not include full names, specific locations, or any identifying details (e.g., hospitals, doctor’s names, schools, workplaces etc).
- Only share information that you or the person you’re writing about would feel comfortable being public.
- We ask for your full name and email address on the form so we can contact you if needed, but we will only publish your first name and your country (not your town or contact details).

How your story will be used

By submitting your story, you give IMP permission to **publish it** on our website, e-communications and social media channels as part of World Mitochondrial Disease Week, and other awareness raising activities. Our aim is to amplify real voices from around the world and deepen understanding of what it means to live with mito.

We might use a shortened version of your story, or use extracts on our social media channels.

Thank you

Thank you for sharing a piece of your life with us. Your story will help others feel less alone and will guide IMP's ongoing work to raise awareness and understanding of mitochondrial disease.