



A low-friction path from clinic conversation to research participation.

Mito Discovery Alliance helps clinicians point patients and caregivers to a clear, consent-aware place to learn about participation, organize their story, and stay connected to mitochondrial disease research opportunities.

What this is

MDA helps people living with mitochondrial disease learn about research participation, consent choices, community programs, and future study opportunities. Mito Map is the secure profile tool patients may use to organize their health story, reduce repetitive retelling, and decide what they want to share.

Why refer a patient or caregiver

- Gives patients and families a clear, non-urgent place to learn about mitochondrial disease research participation.
- Lets patients decide whether to create a Mito Map profile for symptoms, diagnosis history, medications, labs, genetics, goals, and updates over time.
- May help patients prepare cleaner timelines or summaries for future appointments and care conversations.
- Keeps research contact and data-sharing decisions separate from routine clinical care.

Suggested referral language

Mito Discovery Alliance is a patient-led mitochondrial disease research participation community. You can review the public information first, then decide whether joining or creating a Mito Map profile feels useful for organizing your care story and research choices. If you send a referral note, keep it lightweight and patient-controlled; the Alliance reviews it before any follow-up.

What patients receive

- Plain-language education about participation, privacy, and consent.
- A path to join Mito Discovery Alliance and, if they choose, create a Mito Map profile.
- Research opportunity updates when relevant and available.
- Community updates, patient stories, events, and public impact reporting.
- A way to keep private updates in Mito Map while using the public site to learn and plan.

What this is not

- MDA is not a medical provider.
- MDA does not provide diagnosis, treatment advice, emergency support, or a replacement for clinical judgment.
- Participation does not guarantee study access, clinical trial access, treatment, payment, or other benefit.
- Clinicians do not need to manage a patient's MDA or Mito Map account.

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Clinician pathway and patient-facing context:
<https://mitodiscovery.org/clinicians>

Clinical boundary

This handout is informational and does not replace independent clinical judgment. For urgent symptoms or medical concerns, patients should contact their care team or emergency services.