

OUR FOCUS: help today for patients and families.

Living with mitochondrial disease requires support. All of MitoAction's programs are free. Please join us by visiting our website today: mitoaction.org

888-MITO-411

Call to connect with a volunteer ready to provide support via our peer-to-peer network.

Monthly International Teleconference Outreach (MITO Meetings)

Toll-free public meetings connecting leaders in the field to patients and their caregivers.

Support for Parents, Teens & Adults

Free membership, outreach and support for all Mito patients & caregivers, including support groups and tips for living with mitochondrial disease.

Energy 4 Education

Multimedia DVD and resources, to assist parents and educators to create successful school experiences for children with mitochondrial disease.

When Jeremy Jones Stomach Stopped Working

is our free illustrated book for children who may need a feeding tube (gastrostomy tube).

Online Community

Post questions and connect with others in our online forum, and stay informed with free email subscription.

Podcasts, Videos and Audio Programs

Take presentations by leading doctors to-go on iTunes, and watch the story of others who are affected by Mito.

Symptom Guide for Clinicians

Every aspect of mitochondrial disease is described, along with recommendations. Access is free online at www.MitoAction.org/guide.

Annual March for Mito Awareness

Join us every September in Boston and across the globe as we fight for awareness and support for mitochondrial disease.

PLEASE HELP support the mission of MitoAction!

Based in Boston, MA, our community is global and our primary communication tool is the web. Visit us online at www.mitoaction.org. We sponsor a variety of events to raise awareness and support for this "invisible" disease. We need your help – please join us!

Donations gratefully accepted:

- mitoaction.org/donate
- 888.MITOACTION (648.6228)
- PO Box 51474 Boston, MA 02205

MitoAction is a public 501(c)(3) charity. Tax ID number 55-0899427

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MitoAction's partners include:



Children's Hospital Boston



MASSACHUSETTS GENERAL HOSPITAL

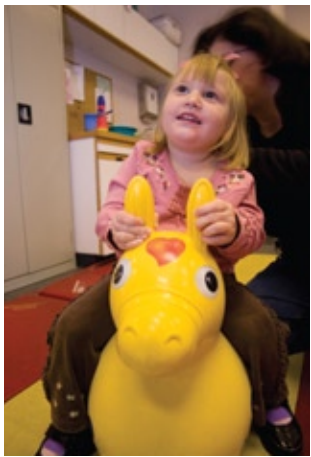


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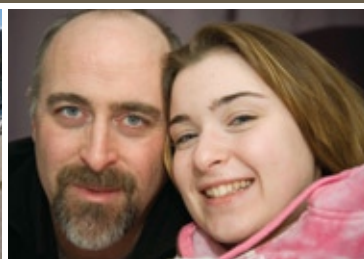
OUR MISSION: to improve quality of life for all people affected by **mitochondrial disease** through support, education and advocacy initiatives. mitoaction.org





“It’s just so reassuring to talk to someone who understands what it’s like to have a cabinet full of medicines instead of dishes. I’m so thankful that I have a community who understands with MitoAction”

-Heidi, Mito patient and mom of 2 children with Complex I & III



Mitochondrial Disease: frequently asked questions

What are Mitochondria?

- Mitochondria are tiny organelles found in almost every cell in the body.
- They are known as the “powerhouse of the cell.”
- They are necessary in the body to sustain life and support growth.

What is mitochondrial disease (“Mito”)?

- “Mito” is a chronic, progressive disorder that occurs when the mitochondria of the cell cannot produce enough energy for cell or organ function.
- The incidence of Mito is about 1 in 4000 individuals in the U.S., similar to the incidence of cystic fibrosis. Adults and children of all races and genders may be afflicted.
- In some cases, mitochondrial disease may be inherited. Symptoms and severity of the disease vary widely amongst patients.

How is Mito diagnosed?

Diagnosis is not easy. Many symptoms are similar to those of other disorders, and symptoms may be intermittent. There is no single laboratory or diagnostic test that confirms a diagnosis of mitochondrial disease. Blood DNA and/or muscle biopsy are the best diagnostic tools for Mito. The road to diagnosis can be long and difficult.

What does Mito look like?

The severity of mitochondrial disease symptoms differs from person to person and symptoms can first appear in infants, children, teens and adults. The most common symptoms are:

- Poor Growth
- Loss of muscle coordination, muscle weakness, pain
- Neurological problems, seizures

(continued)

- Autism, autistic spectrum, autistic-like features
- Vision and/or hearing loss
- Developmental delays, learning disabilities
- Heart, liver or kidney disease or failure
- Gastrointestinal disorders, dysmotility
- Diabetes
- Increased risk of infection, difficulty recovering from a minor illness such as a cold, flu or virus
- Thyroid and/or adrenal dysfunction
- Autonomic dysfunction
- Neuropsychological changes characterized by confusion, disorientation and memory loss

Sometimes a person with Mito may “look normal” but face great challenges and potential health issues due to their defect in energy metabolism.

Is there treatment for Mito?

Treatment involves balancing “energy demand” with “energy supply”. Hydration, nutrition, rest, and vitamin supplements allow one to maximize the “energy in”. Pacing daily life, controlling body temperature, preventing infection, and managing treatable symptoms or complications allow one to minimize the “energy out”. Living with mitochondrial disease is very difficult physically, psychologically, and emotionally.

Is there a cure for Mito?

Today, there is not a cure for mitochondrial disease. MitoAction’s mission is to help affected individuals find support and learn to live a full life *today* by understanding and managing symptoms and challenges of Mito.

Learn more at mitoaction.org