



mito 
ACTION.ORG



What is Mitochondrial Disease (Mito)?

Mitochondrial disease is an inherited condition that causes debilitating physical, developmental, and mental disabilities. You can be born with it or it can develop later in life. It's progressive and there is no cure. About 1 in 2,000 people has Mito, making mitochondrial disease nearly five times more common in children than cancer.

Symptoms include fatigue, poor growth, loss of muscle strength and coordination, pain, seizures, vision and/or hearing loss, gastrointestinal issues, learning disabilities, and organ failure.

Diagnosis, treatment and care are challenging

There is no single laboratory or diagnostic test that confirms a diagnosis of Mito. Blood DNA and/or muscle biopsies are the best means of diagnosing patients. Treatment options are limited and include vitamin supplementation and energy management strategies as well as nutrition and hydration. In some cases, supportive care can help reduce symptoms and may stall progression of the disease.

Living with mitochondrial disease affects the entire family on a daily basis. It is not uncommon for children and adults with Mito to be frequently in the hospital, to miss school or work regularly, and to need supportive care in multiple ways.



What is MitoAction?

MitoAction is a non-profit organization dedicated to providing education, support, and advocacy, to improve quality of life for patients and families affected by mitochondrial disorders. Committed to making the largest impact possible with limited resources, MitoAction serves more than 14,000 individuals annually around the world. More than 94% of all donations go directly to patient-focused programs.

Our Mission

MitoAction's mission is to improve quality of life for all who are affected by mitochondrial disorders through support, education, clinical research and advocacy initiatives.

Reaching Patients Worldwide

14,000 patients and families



over **328,000**
visitors annually

“The MitoAction website is the most comprehensive source of information that I have found. Your site is easy to use and always has the information that I am looking for.”

“MitoAction’s website gave me an interactive place to start when I was diagnosed. I did not know how to talk to my family or doctors effectively. The education packet was a lifesaver!”

ADVOCACY TASK FORCE

Within the the first **10 days of publication**, **700 unique users** downloaded the critical resources on medical child abuse and navigating the health care system, written by a collaborative team of medical/legal professionals.

Clinical Conferences

With a shortage of mitochondrial disease specialists across the country, pediatric and general practitioners need to be able to recognize these patients, recommend appropriate diagnostic testing, interpret genetic and metabolic test results, offer effective supportive and preventive care, and coordinate care among specialists during periods of acute illness.

MitoAction is addressing this issue by offering medical outreach programs to physicians and nurses around the country, focusing on real **strategies for taking better care of those who suffer from Mito.**

240 doctors and nurses educated in 2014.

75% of physicians said attending made them “more confident” and better able to care for the mitochondrial disease patient.

“One of the best conferences. A great balance of basic science, practical diagnosis instruction, therapy and future!”

Creating a Global Community

47 States and 6 Countries



First Friday Speaker Series and Podcasts

95 free podcasts available in itunes

Average download 553 times a month... 18 times a day

Overall, users have downloaded individual podcasts from the iTunes library over 54,800 times since beginning in 2007.

"MitoAction's website has been invaluable in trying to make sense of diagnosis and treatment. The Webinars (First Friday Speaker Conferences) are great because they give me access to people who are tops in their areas and include a lot of specific information. Since they are also available on podcast I can listen to them again to clarify information."



Mito 411 Support Hotline

Supports an average of 30 callers a month

"...I found having a 'mentor' guide me through the day to day stuff the first year of my diagnosis [to be] very helpful."

"I was in a really dark place when my disease had progressed to where I could no longer work after being with my employer for 20 years. No one, including my family seems to understand this disease and the impact. I had just learned of your Friday calls and joined one of the adult calls. It was reassuring to hear other patients speak of the frustrating journey to get a diagnosis, how they had also questioned their sanity.. lost faith in themselves, but it was up to us to continue to battle for us! It was exactly what I needed to hear. A community of caring people that knew exactly what I was feeling... Please keep doing what you're doing!!!"

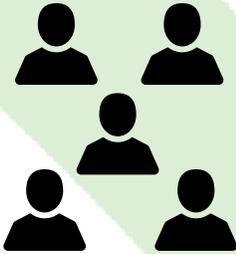
Matthew Harty Camper Fund



Dedicated to allowing every child with mitochondrial disease the chance to go to camp.

94% of funds directly supports programs

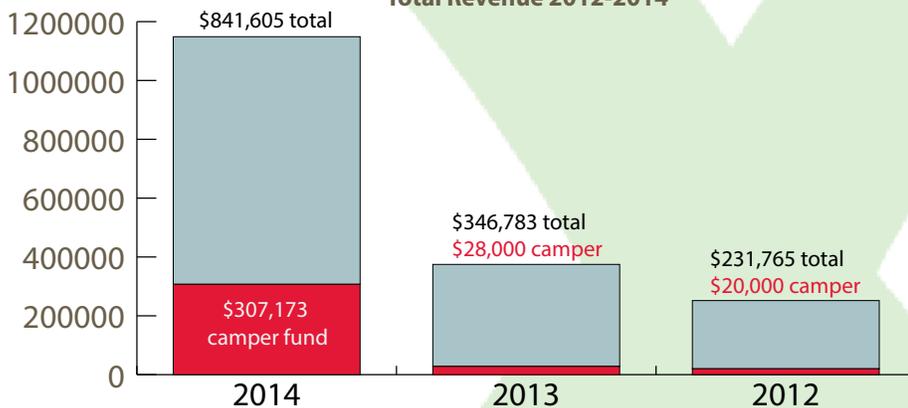
2005 127 served



2014 over 10,000 people served



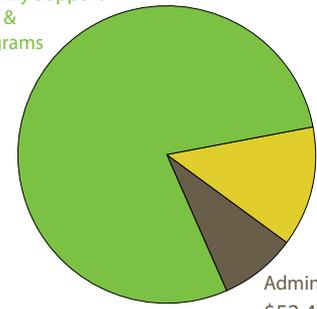
Total Revenue 2012-2014



2014 Expenses

(\$694,541)

Patient/Family Support
Awareness &
Camp Programs
\$506,389



Events &
Fundraising
\$83,556

Admin
\$52,414

MitoAction is a lean and strategic organization, building programs that transform the lives of patients and families with a sustainable impact. We harness accessible and inexpensive technology and recruit passionate, skilled from around the world in order to provide a programmatic impact that is much greater than our budget. MitoAction fills a gap, demonstrated by the growth rate in patients served and fundraising, doubling or tripling every year for the past five years. Next steps? Patient care initiatives, expanding national camper opportunities, new patient outreach, and broader physician education.

Your donation makes a difference when it is used wisely by an organization with minimal admin and overhead expenses, backed by a diverse Board of Directors and a Medical Advisory Board. We are the backbone of the patient community, a driving force behind change, and providing the necessary pressure and attention so that treatments become available and accessible in this decade.

Leading the Mito Community through Partnerships

MitoAction Staff

Cristy Balcells RN MSN, Executive Director
Christine Cox, JD, Director of Outreach and Advocacy
Ginger DeShaney, Membership & Support Coordinator
Shawney Lamm, Events & Program Manager

Leadership Volunteers

MaryBeth Hollinger, Mito411, Support Groups
Julie Gortze, Support Groups
Alyssa Davi, Mito-Autism Task Force
Wendy Helmka, M.S., P.T., Adult Advocacy
Jean Shepherd, Adult Advocacy
Maggie Orr FNP-BC MSN, Memories Group

2014 Board of Directors

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Patricia Cappucci, Treasurer
Theresa Couture, Chairperson Emeritus
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Marie Grant, Adelphic Mobile
Paul Harty, Seven Step Pro
Tom Keery, Frost Motors
Brad Lorimier, Philanthropist
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