



MITOCHONDRIAL DISEASE AWARENESS WEEK

RESOURCE GUIDE



SEPTEMBER 18-24, 2022



5 WAYS YOU CAN RAISE AWARENESS



1

WEAR GREEN FOR MITO

Visit the MitoAction store on our website and order our latest awareness apparel to show everyone who you go green for during awareness week. Take a photo in your gear, or, download an awareness sign and post a photo to social media. Be sure to tag #greenformito and #mitoaction.



2

LIGHT UP GREEN FOR MITO

Light up your house or porch using green light bulbs, or try to get a monument or building in your local community to light up green for mito.



3

SPREAD THE WORD

Download awareness graphics and materials from the MitoAction website to distribute in your community and post on social media. You can personalize the MitoAction Press Release and share your story with your local media. Be sure to tag #greenformito and #mitoaction



4

LIGHT A LIGHT

Send MitoAction a photo and story of remembrance of a loved one lost to mito. We will share this on the Memories Facebook page and on the Light a Light page on our website.



5

HOST AN EVENT

Set up a table at your local grocery store, mall, church, school or library to share awareness materials. You can also host a walk, bowling event, restaurant night or other fundraiser to raise awareness of mito.



#GREENFORMITO #MITOAWARENESSWEEK #MITOACTION

For more details, visit:

www.mitoaction.org/awarenessweek2022



Press Release

FOR IMMEDIATE RELEASE
September 2022

Contact: Kira Mann, CEO

Kira@mitoaction.org
888-648-6228

MitoAction Launches Global Mitochondrial Disease Awareness Week

On September 18th, MitoAction kicks-off the annual Mitochondrial Disease Awareness Week. This global awareness initiative aims to raise awareness of the challenges faced by those affected by mitochondrial disease.

Mitochondrial disease is an inherited chronic illness that can be present at birth or develop later in life. It causes debilitating physical, developmental, and cognitive disabilities with symptoms including poor growth; loss of muscle coordination; muscle weakness and pain; seizures; vision and/or hearing loss; gastrointestinal issues; learning disabilities; and heart, liver, or kidney failure. About 1 in 4,000 people has Mito. It's progressive and there is no cure.

MitoAction encourages local communities to celebrate and honor the lives of every child, adult, and family who struggles with the devastating diagnosis of mitochondrial disease by spreading awareness, one voice at a time. Highlighting these issues during Mitochondrial Disease Awareness Week provides a time for people to come together and display the passion and strength of those working to improve the lives of those affected by Mito.

(Insert personal story)

Join MitoAction in its mission to raise awareness of this disabling disease. Learn more at www.MitoAction.org.

MitoAction is a Boston based nonprofit organization dedicated to improving the quality of life for children, adults, and families living with mitochondrial disease through support, education, outreach, advocacy, and clinical research initiatives. For more information, please visit www.mitoaction.org or email info@mitoaction.org.



<<date>>

<<Name>>

<<Job title>>

<<Street address>>

<<City>>, <<State>> <<Zip Code>>

Dear <<Name>>,

Be part of Light Up for Mito

I am writing to you on behalf of MitoAction and the local mitochondrial disease community.

Please consider illuminating <<proposed monument name>> in green on Saturday, September 24, 2022, to mark the close of World Mitochondrial Disease Week.

<https://mitochondrialdiseaseweek.org/>

We are trying to beat our record of 173 monuments lit up worldwide, and we need your help!

By lighting green, you'll be joining international landmarks and <<participating landmarks in your country>> to help raise awareness for mitochondrial disease (mito), a little known but devastating genetic disease with few effective treatments and no cure.

Mito is a debilitating genetic disorder that robs the body's cells of energy, causing multiple organ dysfunction or failure and potentially death. It can cause any symptom, in any organ, at any age. Although 1 in 200 people may carry the genetic changes that could lead to mito, few have heard of it. That's why events like Light Up for Mito are so important.

<<Personal statement on connection to mitochondrial disease – if applicable>>.

Thank you for your consideration. If you require more information please contact me on the details below or <<mitochondrial disease organisation details>>

Yours sincerely,

<<Your name and contact details>>

Light a Light

*Remembering what we have
loved and lost*



Each year, the Wednesday of Mitochondrial Disease Awareness Week, we remember those who have lost the battle with mitochondrial disease and ask that friends and family "Light a Light" in their memory.

Please send your photos and memory wishes to us at info@mitoaction.org

***For the angels we miss so dearly, we light
a light and remember you.***

www.mitoaction.org/light-light-mito



THIRD-PARTY FUNDRAISING

You inspire hope in so many – thank you!

MitoAction is incredibly grateful to people and organizations who wish to make a difference by organizing events to support our unique mission. The time and effort that you put into your event will benefit patients and families living with mitochondrial disease. No matter how large or small, your contribution will make a big difference in the lives of families navigating the Mito journey. MitoAction will be here to support you every step of the way!

In this short guide you will find some basic tips, guidelines, and answers to common questions. If you need more information, please contact Kira Mann, CEO at kira@mitoaction.org.

What

A third-party fundraiser is an event or program organized and executed by a business, organization, community group, school, or individual hosts to benefit MitoAction.

Why

One in 4,000 people will be diagnosed with mitochondrial disease. MitoAction uniquely serves our Mito community. MitoAction is dedicated to improving the quality of life for children, adults, and families living with mitochondrial disease through support, education, outreach, advocacy, and clinical research initiatives. We are funded entirely by donations and grants. In order to serve more families, we need you!

There are many possibilities

The first step is to decide on an event. Here are a few examples:

Tournaments

Have a favorite sport? Or a favorite board game? Turn it into a fundraiser. Organize a tournament and donate the entry fees. For larger events, ask corporate sponsors to underwrite the costs in exchange for brand exposure. Don't forget to incorporate additional ways people can donate once at the event such as a raffle or silent auction.

Parties

Invite family, friends, and colleagues over for a sponsored event such as a Pampered Chef, Tupperware, or Silpada party. Or throw your own. Have a dinner or dessert event, theme party, or movie night. Sell tickets, raffles, or have a free-will offering. Or use games like bingo and poker to raise money.

Charity nights at local restaurants

Many restaurants will help nonprofits by giving a percentage of the sales on a designated day for all customers brought in by the organizer. MitoAction will help the event organizer publicize the event.

Be sure to understand the terms because they will vary by restaurant.



Some questions to ask

- What percentage of sales will our group get?
- What days and hours are available?
- Is the percentage of sales during a defined period? Or is it just for our group?
- Does takeout or drive-thru apply to our percentage?
- Can we use “celebrity” servers?
- Can we set up a display booth to raise awareness and solicit funds?

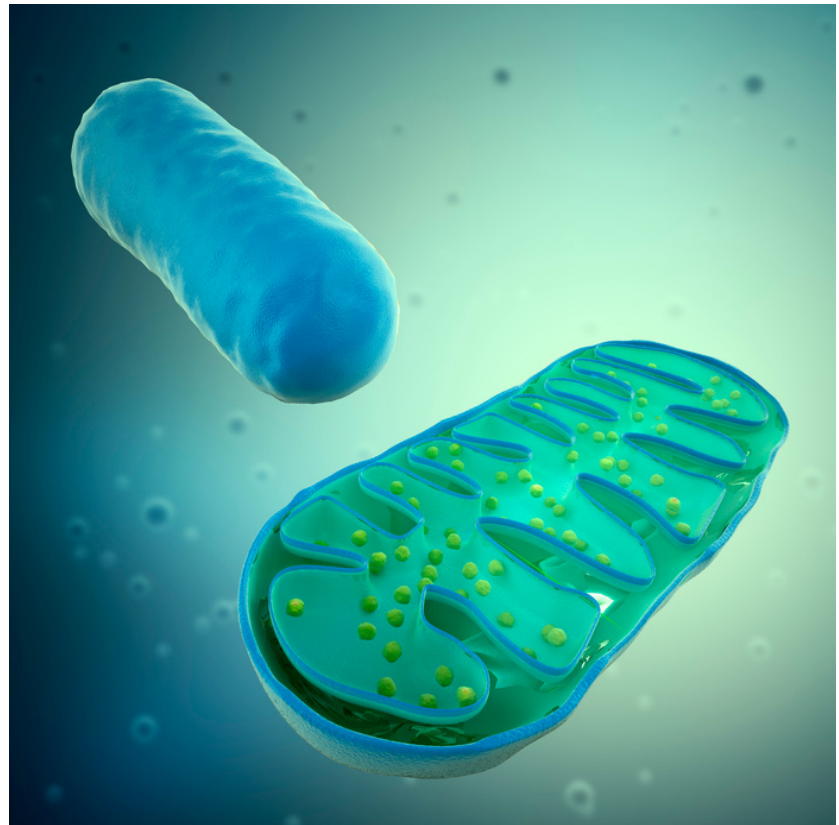


OTHER EVENT IDEAS

- “a-Thons” (bowl, walk, run, bike, dance, swim)
- Auctions: donated goods, art, silent
- Arts and Crafts Shows
- Bake Sale
- Birthday Parties or Personal Celebrations
- Bring Your Dog to Work Day
- Car Washes
- Church or Community Neighborhood Donation Drive
- Concession Stands
- Fashion Show
- Fitness Challenges
- 5Ks or Walks
- Galas
- Garage & Yard Sales
- Green Day: Ask friends and classmates to wear green and collect donations
- Holiday Wrapping
- Office “Jeans” Day
- Pet Washes
- Ticket Sales, Raffles and Entry Fees
- Raise money by creating a fundraising page online (www.mitoaction.org/getinvolved)
- School Events: raise a certain amount to make your teacher/principal do something unusual
- Sporting Events and Tournaments (golf outing, dodgeball tournament, fun run, etc.)
- “Taste of” Events
- Used Book Sale
- Wine Tasting

ABOUT MITO: FAQs

Mitochondrial disease is an inherited, chronic illness that can be present at birth or develop later in life. “Mito” is progressive and can cause physical, developmental, and cognitive disabilities. Symptoms can be mild, such as tiredness or weakness, or they can be severe, such as poor growth, loss of muscle coordination, muscle weakness and pain, seizures, vision and/or hearing loss, gastrointestinal issues, learning disabilities, and organ failure. Approximately 1 in 4,000 people have Mito. There is no cure, but there are treatments that can help with the symptoms.



What are Mitochondria?

- Mitochondria are tiny organelles found in every cell in the body except red blood cells. The number of mitochondria in a cell varies by tissue and cell type with higher numbers per cell found in high energy-requiring organs, such as the liver, heart, brain, muscles, pancreas, eyes, ears, kidney, and GI tract.
- Mitochondria are known as the “powerhouse of the cell.”
- Mitochondria are responsible for creating more than 90 percent of cellular energy which is necessary for the body to sustain life and support growth.
- Mitochondria turn nutrients into cellular energy in the respiratory chain cycle.
- Mitochondria have their own independent genome (mitochondrial DNA or mtDNA) that was likely derived from early bacteria.
- Mitochondrial failure causes cell injury that leads to cell death. When multiple organ cells die, organs begin to fail.

What is Mitochondrial Disease?

- Mitochondrial disease is a chronic, genetic disorder that occurs when the mitochondria of the cell fail to produce enough energy for cell or organ function.
- Many forms of mitochondrial disease are known, arising from defects in both the mtDNA and the cell’s nuclear DNA (nDNA).
- Mitochondrial disease can be inherited in a number of ways.
- Mitochondrial disease often presents very differently from individual to individual.
- One individual in a family or many individuals affected over a number of generations may be affected.

What are the Symptoms of Mitochondrial Disease?

- The severity of mitochondrial disease symptoms is different from person to person. The most common symptoms are:
- Poor growth and failure to thrive (in children)
- Loss of muscle coordination, muscle weakness and pain, low tone, exercise intolerance
- Neurological problems, seizures
- Autism, autistic spectrum, autism-like features
- Visual and/or hearing problems
- Developmental delays, learning disabilities
- Movement disorders
- Heart, liver or kidney disease
- Gastrointestinal disorders, including severe constipation, diarrhea, swallowing difficulty, repeated vomiting, cramping, reflux
- Diabetes
- Increased risk of infection
- Neurological issues, including difficult to treat seizures, migraines, and stroke or stroke like events
- Thyroid and/or adrenal dysfunction
- Autonomic dysfunction (may affect the functioning of the heart, bladder, intestines, sweat glands, pupils, and blood vessels)
- Respiratory issues
- Lactic acidosis (the buildup of lactate in the body, which results in an excessively low pH in the bloodstream)
- Neuropsychological changes characterized by confusion, disorientation, dementia, and memory loss

Detailed information about symptoms can be found at www.mitoaction.org/symptoms

How common are mitochondrial diseases?

- Infants, children, and adults may develop mitochondrial disorders. Experts in mitochondrial medicine describe a spectrum of disease, ranging from mild to severe. 1 in 4,000 people are estimated to have a genetically confirmed primary mitochondrial disease, yet many remain undiagnosed.
- In adults, many diseases of aging have been found to have defects of mitochondrial function, including, but not limited to, diabetes, Parkinson's disease, Huntington's disease, atherosclerotic heart disease, stroke, Alzheimer's disease, amyotrophic lateral sclerosis (ALS), autoimmune disorders, environmental toxicities, and cancer.

What causes mitochondrial disease?

- For many patients, mitochondrial disease is an inherited genetic condition. Mutations can also be spontaneous as well as be induced.
- A patient may be found to have a de novo variant, or new mutation, meaning that the mutation arose in this patient early in development and was not passed down from a parent or previous generations.

- An uncertain percentage of patients acquire symptoms due to other factors, including mitochondrial toxins.

It is important to determine which type of mitochondrial disease inheritance is present in order to predict the risk of recurrence for future children. The types of mitochondrial disease inheritance include:

Nuclear DNA (nDNA) inheritance. nDNA is contained in the nucleus of the cell. This type of inheritance is also called autosomal inheritance.

- If the gene trait is recessive (one gene needed from each parent to have the disease), often no other family members appear to be affected. Two recessive mutations, one from each parent, are needed to express the disease. If parents both share the same recessive gene for a particular type of mitochondrial disease, 25% of children will get both mutated genes and have the disease, 25% will get no mutated genes and be healthy, and 50% will get a single mutation and be considered a “carrier,” like their parents, also be healthy, but could pass the mutation to their offspring.
- If the gene trait is dominant (a gene from either parent can express disease), the disease often occurs in other family members. There is a 50 percent chance of the trait occurring in other siblings/offspring.

Mitochondrial DNA (mtDNA) inheritance. mtDNA is contained in the mitochondria of the cell.

- There is a 100 percent chance of the trait occurring in other siblings, since all mitochondria are inherited from the mother, although symptoms might be either more or less severe due to heteroplasmy (the percent of mutated cells). Higher rates of heteroplasmy are typically associated with more severe disease.

Combination of mtDNA and nDNA defects:

- The relationship between nDNA and mtDNA and their correlation in mitochondrial formation is a new area of study. MtDNA and nDNA communicate with each other. Researchers believe that such interactions may regulate the expression of particular sets of genes. This communication may explain how mitochondria are involved in cellular processes not related to energy generation, such as cell growth and death.

Random occurrences:

- Diseases specifically from deletions of large parts of the mtDNA molecule are usually sporadic without affecting other family members.
- Medicines or other toxic substances can trigger mitochondrial disease.

How is mitochondrial disease diagnosed?

- No reliable and consistent means of diagnosis currently exist. The road to diagnosis is often personalized based on symptoms. Clinicians are working to create diagnostic and treatment standards for mitochondrial medicine.
- Diagnosis usually is made by DNA testing. Although it is no longer the primary diagnosis method, a muscle biopsy could be an option.

How is mitochondrial disease treated?

- The goals of treatment are to improve symptoms and slow progression of the disease. Patients are advised to:
- Use vitamin and supplement therapy
- Conserve energy
- Pace activities
- Avoid exposure to extreme temperatures
- Avoid exposure to illness
- Ensure adequate nutrition and hydration

Misdiagnosis

- Lack of understanding of the disease and misinterpretation of symptoms can lead to misdiagnosis.
- Further progression of symptoms can occur if the symptoms are missed and opportunities for treatment and support are not recognized.

What are the challenges of living with mitochondrial disease?

- Mitochondrial disease can affect multiple organs, multiple family members, and multiple generations.
- Lack of awareness and understanding of the disease can delay treatment and diagnosis.
- Families are continuously forced to expend energy to explain their disease, advocate for themselves, and fight for services.
- Mitochondrial disease is often an “invisible disease.” On a good day, a patient may look fine and healthy, with more energy and appear rested. But on a bad day, patients can appear tired or even significantly ill. Repeated bad days may lead to decompensation and patients may have difficulty returning to baseline.
- Mitochondrial disease is unpredictable. Symptoms can vary day to day or even hour to hour.
- Mitochondrial disease is difficult to diagnose. Difficulties establishing a diagnosis interfere with a patient’s ability to obtain adequate recognition and appropriate medical care.
- An individual can become symptomatic at any time in life despite the fact that mitochondrial disease is inherited.

To connect with others facing the challenges of mitochondrial disease, visit the MitoAction closed Facebook group or join our weekly support teleconferences.

What is the prognosis for someone with mitochondrial disease?

- The prognosis is variable. Some people live a normal life and are minimally affected; others can be severely compromised with the disease.
- The progression of mitochondrial disease is unpredictable and different for each person.

For more specific details about mitochondrial disease visit www.mitoaction.org