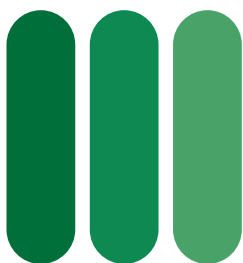




# Communicating our Message



**UNITED  
MITOCHONDRIAL  
DISEASE  
FOUNDATION®**



**Sydney Harris said, “Communication and information are often used interchangeably, but they signify two quite different meanings. Information is giving it out and communication is getting it through.”**

This information is designed to **communicate** important facts about mitochondrial disease to the many people we come in contact with. It will help us speak with one voice about mitochondrial disease and the mission of the United Mitochondrial Disease Foundation (UMDF).

The UMDF’s mission is to promote research and education for the diagnosis, treatment and cure of mitochondrial disease, and to provide support to affected individuals and families.

The UMDF is about **coordination**, **communication** and **collaboration**; **coordinating** our efforts and resources, **communicating** our needs and abilities and forming **collaborations** to bring information, patients, medical professionals and resources together to enhance progress for treatments and cures.

Since our formation in 1996, we have made significant progress in raising awareness of primary mitochondrial disease, empowering those affected and identifying those providing and investigating treatments, all leading to quicker and less invasive diagnoses, improved treatments and better **coordinated** research efforts.

These talking points are a resource to help you speak to potential donors, elected officials, the media, or anyone not familiar with the UMDF or mitochondrial disease. For further information and materials, please contact the UMDF at 888-317-UMDF (8633) or email us at [news@umdf.org](mailto:news@umdf.org).





***What if you were in an elevator and someone asked you about mitochondrial disease and the UMDF?***

***What would you say?***

#### **UMDF Elevator Speech -**

The United Mitochondrial Disease Foundation (UMDF) focuses on ***coordination, communication and collaboration.***

We bring people and resources together creating an impact on diagnoses, treatments and cures for mitochondrial disease.

Mitochondria are in the cells throughout our bodies that change food and oxygen into energy. When mitochondria malfunction, organs start to fail and people, including children, get sick and even die. The disease is difficult to diagnose because it affects every person differently; everything from seizures and strokes to blindness and muscle weakness.

The UMDF provides support and information to patients and medical professionals, working tirelessly to get donors and decision-makers, like Congress, to back our efforts to fund research.

Our role has become even more urgent with the scientific linkage between mitochondrial dysfunction and diseases like Alzheimer's, Parkinson's, diabetes and autism, even the aging process itself. Like the enormous impact on mortality that bone marrow transplants have had for those suffering blood cancers ... like the life-sustaining maintenance medications that have changed the course for AIDS patients ... if we could breakthrough and unlock the secrets to prevention and cures for mitochondrial disease, it would truly be a game-changer for millions.

# UMDF

## Core Messages -



There may be a time when you will have an opportunity to meet with a potential donor, walk sponsor, elected official or a member of the media. They will want to know about the UMDF, our mission and goals. Using these core messages, you will be able to **communicate** valuable information about the UMDF and help them better understand our mission.

- UMDF's mission is to promote research and education for the diagnosis, treatment and cure of mitochondrial disease, and to provide support to affected individuals and families.
- UMDF is about **coordination**, **communication** and **collaboration** bringing information, patients, medical professionals and resources together to make progress on therapies and cures.
- UMDF is impactful. Since our founding in 1996, we have made significant progress in raising awareness of primary mitochondrial disease, empowering those affected and those providing treatments. Our impact is leading to quicker diagnoses, improved treatments and better **coordinated** research efforts.

- UMDF is represented across the United States and around the world. We created the first-ever Congressional Caucus on Mitochondrial Disease, focused on securing significant federal research funding. We currently host Energy for Life Walkathons across the country.
- UMDF is the largest non-governmental funder of scientific and clinical research grants in the world, leading to current clinical trials of new drugs and other potential therapies.
- UMDF has funded clinical fellowships, represented patients in the North American Mitochondrial Disease Consortium (NAMDC) and recently launched the Mitochondrial Disease Community Registry, the first patient-populated registry to collect data used to identify symptoms and guide research and the development of new treatments.
- UMDF's Grand Rounds program has already educated over 4,000 medical professionals at hospitals in 64 cities nationwide on the latest developments in diagnostics and treatments.
- UMDF's role has grown more urgent with research linking mitochondrial dysfunction to numerous secondary diseases like Alzheimer's, Parkinson's, and autism.

Your support of UMDF's mission can transform medicine for millions by unlocking treatments and cures for those afflicted with primary mitochondrial disease, as well as many other conditions.

***But I'm not an expert on mitochondrial disease...***



**You don't have to be -**

Many times we are asked about the disease, its causes, its severity and prognosis. The talking points on these pages are designed to help you speak with confidence about mitochondrial disease.

The best way to talk about the disease is how it impacts you personally. You can always refer people to [www.umdf.org](http://www.umdf.org) for additional information.

# Mitochondrial Disease

## Core Messages -

Mitochondria in the cells throughout our bodies are responsible for creating more than 90% of the energy needed to sustain life and support organ function. When it malfunctions, organs start to fail – people get sick and even die.

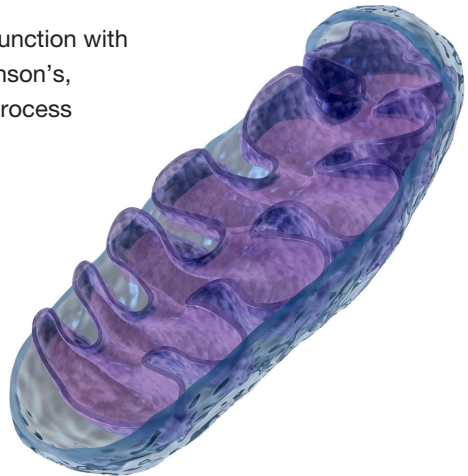
Every 30 minutes, a child is born with mitochondrial disease.

It's a difficult disease to diagnose because it affects every person differently. Children and adults can have seizures, strokes, severe developmental delays; inability to walk, talk, see, digest food and a host of other complications. If three or more organ systems are involved, mitochondrial disease should be suspected.

We need our breakthrough! Like the enormous impact on mortality that stem cell transplant has had for those suffering blood cancers ... like the life-sustaining maintenance medications that have changed the course for AIDS patients ... mitochondrial disease patients need a breakthrough that leads to treatments that alleviate symptoms and slow down progression and, ultimately, a cure.

Science has linked mitochondrial dysfunction with major diseases like Alzheimer's, Parkinson's, diabetes, autism and even the aging process itself.

Imagine if we unlock the secrets to prevention and a mitochondrial disease cure! It would truly be a game-changer for millions suffering from other major diseases associated with mitochondrial dysfunction.





*HOPE. ENERGY. LIFE.*

## **Our Mission**

*To promote research and education for the diagnosis, treatment and cure of mitochondrial disease, and to provide support to affected individuals and families.*

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**[www.umdf.org](http://www.umdf.org)  
[www.energyforlifewalk.org](http://www.energyforlifewalk.org)**

