

## About the UMDF

Since 1996, the UMDF has funded nearly \$11 million in research projects aimed at finding better treatments for mitochondrial diseases, with the ultimate goal of a cure.

Not all physicians and medical professionals are aware of mitochondrial disease. Through our **Grand Rounds Program**, our annual symposium, and our patient and family meetings, the UMDF provides information about the disease, diagnostic testing, potential treatments and therapies.

The UMDF connects patients with mitochondrial disease experts and provides support to both the newly diagnosed and those living with mitochondrial disease. Information, local referrals, publications, programs, and volunteer opportunities are available from the UMDF and our national network of chapters, groups, and ambassadors.

### UMDF MISSION

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

*Become part of the cure.  
Call the UMDF at 888.317.UMDF  
or the local contact and number  
provided below:*

8085 Saltsburg Road, Suite 201  
Pittsburgh, PA 15239

Phone: 888.317.UMDF (8633)

Fax: 412.793.6477

Email: [info@umdf.org](mailto:info@umdf.org)

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

**UNITED  
MITOCHONDRIAL  
DISEASE  
FOUNDATION®**



**UNITED  
MITOCHONDRIAL  
DISEASE  
FOUNDATION®**

*HOPE. ENERGY. LIFE.*



**LIVING WITH  
MITOCHONDRIAL DISEASE**

### **We all have mitochondria.**

They exist in nearly every cell of the human body. They are like tiny batteries within our cells. Mitochondria generate 90 percent of the energy the body needs to see, hear, walk, and breathe.

### **Mitochondrial disease occurs when mitochondria fail.**

When the mitochondria fail, the body becomes unable to convert food and oxygen into energy. When these tiny power plants start to fail in the human body, the failure begins to affect organ systems, and the result is mitochondrial disease.

### **The parts of the body that need the most energy are the most affected.**

The heart, brain, muscles, and lungs are often the most affected by mitochondrial disease. The affected individual may have any combination of symptoms including the following: strokes, seizures, gastrointestinal problems (reflux, severe vomiting, constipation, diarrhea), swallowing difficulties, failure to thrive, blindness, deafness, heart and kidney problems, muscle failure, heat/cold intolerance, diabetes, lactic acidosis, immune system problems, and liver disease.

### **Research says one in 4,000 people are affected by mitochondrial disease.**

Mitochondrial medical experts believe that number is closer to one in 2,000.

Research tells us that every 30 minutes a child is born who will develop a mitochondrial disease by age 10. Further research indicates that one in 200 people carry a mutation that could develop into a mitochondrial disease in their lifetime. For many, mitochondrial disease is an inherited genetic condition. In some cases, the body's mitochondria have been affected by environmental factors. In other cases, mitochondrial disease seems to be a random occurrence.

### **Mitochondrial disease affects both children and adults.**

Mitochondrial disease affects people of all ages and races. Because symptoms vary, getting a diagnosis is difficult. Many affected adults have lived most of their lives not knowing what was wrong with them until they received a diagnosis of mitochondrial disease.

### **What is the prognosis of a mitochondrial disease patient?**

That is a tough question to answer because the prognosis depends upon the severity of the disease and other criteria. In some cases, patients are living fairly normal lives with the disease. In other cases, patients may not be able to see, hear, walk, or talk. Affected children may not survive beyond their teenage years. Adult onset can result in drastic changes from an active lifestyle to a debilitating illness in a short amount of time.

### **There is HOPE.**

You don't have to feel confused about what a diagnosis of mitochondrial disease means. The UMDF provides educational information to help you understand mitochondrial disease.

### **There is ENERGY**

You don't have to feel you are alone. The UMDF provides opportunities for you to connect with others facing similar challenges with mitochondrial disease.

### **There is LIFE**

You don't have to feel frustrated. The UMDF sponsors physician education and awareness activities; updates members on new, available treatments and clinical trials; advocates for funding mitochondrial medicine research; and is the largest, nongovernmental funder of research to investigate possible treatments and potential cures.

**Get involved!** Become a member of UMDF. Membership is free. Visit: [www.umdff.org](http://www.umdff.org).

Help us raise awareness and crucial dollars for research. **Participate in an Energy for Life Walkathon.** For details visit: [www.energyforlifewalk.org](http://www.energyforlifewalk.org).

### **Advocate on behalf of UMDF.**

Write to your elected officials and ask them to support funding for mitochondrial medicine research. For details, visit: [www.umdff.org](http://www.umdff.org) or call us at: 888.317.8633.