



**UNITED
MITOCHONDRIAL
DISEASE
FOUNDATION®**

8085 Saltsburg Road - Suite 201
Pittsburgh, PA 15239
Toll Free: 888.317.UMDF (8633)
Fax: 412.793.6477
Email: info@umdf.org Web: www.umdf.org

UMDF MEMBERSHIP APPLICATION / CONTRIBUTION FORM

Member/Donor (please print - FAX or MAIL the following information to UMDF)

Name _____

Address _____

City _____ State _____ Zip Code _____

Phone _____ Email _____

Name of affected individual _____

Date of Birth ____/____/____ Male _____ Female _____

- Enclosed are my annual dues of \$50 (in US dollars) **within** the US/Canada (drawn on a US Bank)
- Enclosed are my annual dues of \$60 (in US dollars) **outside** the US/Canada (drawn on a US Bank)
- Enclosed is my gift to help sustain research and family support \$ _____
TOTAL ENCLOSED \$ _____

- Enclosed is a check made payable to - UMDF
- Please charge my: Visa Mastercard Discover American Express
Credit Card Number _____
Expiration Date _____ Signature of Cardholder _____

I am interested in membership but am unable to join at this time

This contribution is made In Honor of In Memory of
Name _____
On the Occasion of _____
(memorial, birthdate, deathdate, other)

Name _____
Address _____
City _____ State _____ Zip _____

Please send acknowledgement
of my gift to:

BECOME A MEMBER

Membership is open to patients, parents or guardians, friends, relatives, medical professionals, hospitals and other organizations.

Members Receive:

New Member Information Packet - includes valuable information on mitochondrial terms, frequently asked questions, resource materials and information.

Newsletters - The UMDF publishes a quarterly newsletter that is loaded with information about chapter events and fundraising, and the latest medical and scientific news about mitochondrial disease.

Exclusive Web Site Access - The UMDF offers a 'members only' area at www.umdf.org. In this area, members are able to post questions to a mitochondrial doctor and have access to other resources.

Member Discounts - members receive a discount on our annual symposium for families, physicians and clinicians.

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.

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Every 30 minutes a person is born with a Mitochondrial Disease.

There is no cure.

Many do not survive their teenage years.

Help us support the research that leads to a treatment or cure.



**UNITED
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DISEASE
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HOPE. ENERGY. LIFE.

WHO IS AFFECTED?



It is estimated that one in every 4,000 children will develop a mitochondrial disease by the age of 10. Because these diseases are often under-recognized or misdiagnosed, the real figure is probably closer to one in every 2,000 children. For the same reasons, it is difficult to estimate how many adults are affected.

WHAT IS MITOCHONDRIAL DISEASE?

Mitochondria are the power plants in almost every cell in the body. They produce 90% of the energy required for the body to function.

Mitochondrial disease is the result of failures or defects within these power plants. Defects in the mitochondria result in the body's inability to effectively convert food into life-sustaining energy. When the organs and systems of the body are deprived of energy, they begin to fail. Especially vulnerable are those which require large amounts of energy: the brain, the heart, the skeletal muscles, the kidney, the liver, and the endocrine and respiratory systems.

There are more than 40 known types of mitochondrial disorders and more than 200 inherited diseases of metabolism that are known to affect mitochondria. While the majority of cases are inherited, there are cases in which the disease seems to be a random occurrence.

WHEN TO SUSPECT MITOCHONDRIAL DISEASE

Mitochondrial disease should be considered when three or more organ systems are involved.

Patients present with a wide range of symptoms including strokes, seizures, gastrointestinal problems (reflux, severe vomiting, constipation, diarrhea), swallowing difficulties, failure-to-thrive, blindness, deafness, respiratory difficulties, lactic acidosis, immune system problems, autistic-like symptoms, and liver disease.

Many are misdiagnosed with atypical cerebral palsy, various seizure disorders or other diseases. Confirmation of diagnosis is possible through various means including blood and urine tests, brain MRI, muscle and skin biopsies.

THERE IS NO KNOWN CURE FOR MITOCHONDRIAL DISEASE.

Adult onset of mitochondrial disease can result in drastic changes from an active lifestyle to a debilitating illness in a short amount of time. Affected children may not survive beyond their teenage years.



Most treatments and medications address only the symptoms of the mitochondrial disease, not the disease itself.

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WHAT IS THE UMDF?

The United Mitochondrial Disease Foundation was founded in 1996 through the merger of several smaller foundations established by those who lost loved ones to the disease. Started as a volunteer organization based in a basement, the UMDF has grown into a nationally recognized non-profit organization. The UMDF staff responds to hundreds of inquiries a month about mitochondrial diseases and offer affected individuals and families information as well as resources, referrals to experts in the mitochondrial field and support. The UMDF is represented around the world by more than 60 chapters, groups and ambassadors.

The UMDF brings physicians who specialize in mitochondrial diseases to selected cities each year through our **Grand Rounds Program**. The program is designed to educate physicians about mitochondrial diseases. As part of the program, family meetings are held as well and include a group question and answer session.

The UMDF hosts an annual symposium dedicated to mitochondrial medicine. Physicians and researchers attending the symposium gather the latest resources and research information. Affected individuals and their families also attend to learn more about managing mitochondrial diseases and network with numerous physicians, researchers and allied health professionals.

The UMDF maintains the latest information on mitochondrial diseases and related issues at www.umdf.org. The UMDF also publishes a quarterly newsletter that includes medical, advocacy, insurance and support information.

FUNDING RESEARCH

The United Mitochondrial Disease Foundation is the leading non-governmental contributor of grants focused on mitochondrial disease research.

Since 1996, the UMDF has funded more than \$8 million as part of our Research Grant Program. ***The UMDF mission is to promote research and education for the diagnosis, treatment, and cure of mitochondrial disorders and to provide support to affected individuals and families.***

FINDING A CURE IS IMPORTANT



FOR ALL OF US.

Defects in mitochondrial function are linked to diseases of aging such as Parkinson's Disease, Alzheimer's Disease, heart disease and cancer. The UMDF funds cutting-edge biogenetic research that changes the way scientists look at many of these more common age-related diseases.

