

HOPE. ENERGY. LIFE.



**UNITED
MITOCHONDRIAL
DISEASE
FOUNDATION®**

HOPE. ENERGY. LIFE.

ANNUAL REPORT

July 1, 2011 - June 30, 2012



A DECADE OF DIFFERENCE

- ➔ ***In 2003, our cumulative dollars spent on mitochondrial research had not yet reached a million. Today, UMDF has contributed more than \$10,000,000 leading to new clinical trials and potential treatments.***
- ➔ ***In 2003, there were three clinical trials related to mitochondrial disorders. Today, there are 305 mitochondrial-related clinical trials ongoing.***
- ➔ ***In 2003, researchers were just beginning to understand the link between mitochondrial dysfunction and other more common diseases. Today, a clear link has been established between dysfunctional mitochondria and Alzheimer's, Parkinson's, diabetes, certain cancers, and even the aging process itself.***
- ➔ ***In 2003, UMDF had six chapters and 20 support groups. Today, UMDF has representation in every state and in 152 countries.***
- ➔ ***In 2003, only two members of Congress knew about mitochondrial disease. Today, 372 members of the House and Senate have been informed. When they make decisions about how to spend significant federal money on health-related issues, mitochondrial disease will be on their minds.***
- ➔ ***In 2003, there were 124 participants at the UMDF symposium, including only three from other nations. Today, more than 500 scientists, clinicians, allied health professionals, and family members attend each year, representing 16 countries.***
- ➔ ***In 2003, gene sequencing was just a dream. Today, gene sequencing is a reality, identifying areas where mutations occur and targeting potential treatments.***
- ➔ ***In 2003, 36 researchers applied to UMDF with research proposals. Today, over 200 new research proposals are received annually.***
- ➔ ***In 2003, there were no UMDF "Grand Rounds" (programs where mitochondrial specialists travel to different hospitals to brief medical personnel on mitochondrial disease). Today, over 80 grand rounds have taken place, serving approximately 50 people each time, leading to 4,000 medical professionals being informed about the diagnosis and treatment of mitochondrial disorders.***
- ➔ ***In 2003, there were only 21 identified "mito docs" worldwide. Today, there are nearly 400 identified mito docs worldwide.***

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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On the cover: Wyatt Winternheimer, age 7 in the photo, has mitochondrial disease and lives in Evansville, Indiana, with his mom, dad, and brother who are in the photograph with him.



MESSAGE FROM THE EXECUTIVE DIRECTOR

Peter Ferdinand Drucker (November 19, 1909 – November 11, 2005) was an Austrian-born American management consultant, educator, and author, whose writings contributed to the philosophical and practical foundations of the modern business corporation. He was also a leader in the development of management education, and he invented the concept known as management by objectives.¹ His quote, *“Efficiency is doing things right; effectiveness is doing the right things,”* will be the United Mitochondrial Disease Foundation (UMDF) mantra as we move forward with our next strategic plan update.

UMDF strategic plans have been professionally facilitated by Kelley Management Consulting Inc. (KMC). KMC President and UMDF Trustee, Patrick Kelley, has donated his services and is committed to promoting and supporting the UMDF Mission: “Promoting research and education for the diagnosis, treatment and cure of mitochondrial disorders and providing support to affected individuals and families.”

Over the years, UMDF has efficiently provided many services and benefits to our members and scientific communities. This past year, we began to identify the areas where we have the greatest “mission potential” and started sharpening our focus and developing strategies that will accelerate mission success.

Strategically focused on the future, UMDF now has regional coordinators in three regions representing 24 states. Our coordinators are our eyes and ears identifying member needs and connecting them with the national office. They are engaging our members in four key areas: education, support, special events/Energy for Life Walks and advocacy.

We realize the need and value in taking a global approach to mission success, and are working to engage our European counterparts by supporting the formation of the International Mitochondrial Patients (IMP) group. We are now partnering with other stakeholders from Canada, Australia, Germany, Belgium, The Netherlands, France, Spain, United Kingdom and Italy. We believe that by combining forces we can be a stronger voice and research supporter for the mitochondrial community. A result of this collaboration is recent participation by our Italian friends at Mitocon who co-sponsored a research grant selected by our grant review committee.

We attended the most recent meeting of the International Rare Disease Research Consortium (IRDiRC). This is a global consortium teaming researchers and organizations committed to investing in rare diseases research in order to achieve two main objectives by the year 2020, namely to deliver 200 new therapies for rare diseases and means to diagnose most rare diseases. We will be working diligently making sure mitochondrial disorders are included in their objectives. Working across borders is not an option, it is an imperative; the IRDiRC consists of 30 country members on three continents.

The North American Mitochondrial Disease Consortium (NAMDC) continues to gain momentum. With your support there are now 13 active sites across the US with over 317 patients entered in the registry producing clinical trials, a scientific populated patient registry, establishment of diagnostic standards and a certified NAMDC Diagnosis. The NAMDC registry will continue to grow and support opportunities for more clinical trials and ultimately treatments.

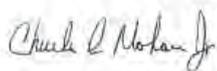
The Euromit Conference is a European based conference that is the largest scientific conference in the world dedicated to understanding how mitochondria are involved in disease. Euromit Conference 2014 will be the ninth in a series of international conferences and for the first time, Euromit 2014, in Finland, will be held alongside a parallel meeting for mitochondrial families, patients, caregivers and support organizations from many countries. Because of the recognized success of the UMDF Symposia, we have been asked to guide the patient platform and have involved members of the IMP to support this new initiative.

Because of your continued help and support UMDF is truly becoming a global voice and advocate accelerating the focus on research and treatments for mitochondrial diseases.

Our future is bright, but we need your continued support to get results bringing the future into the present.

I began with a quote by Peter Drucker and I will end with another:
“Effective leadership is not about making speeches or being liked; leadership is defined by results not attributes.”

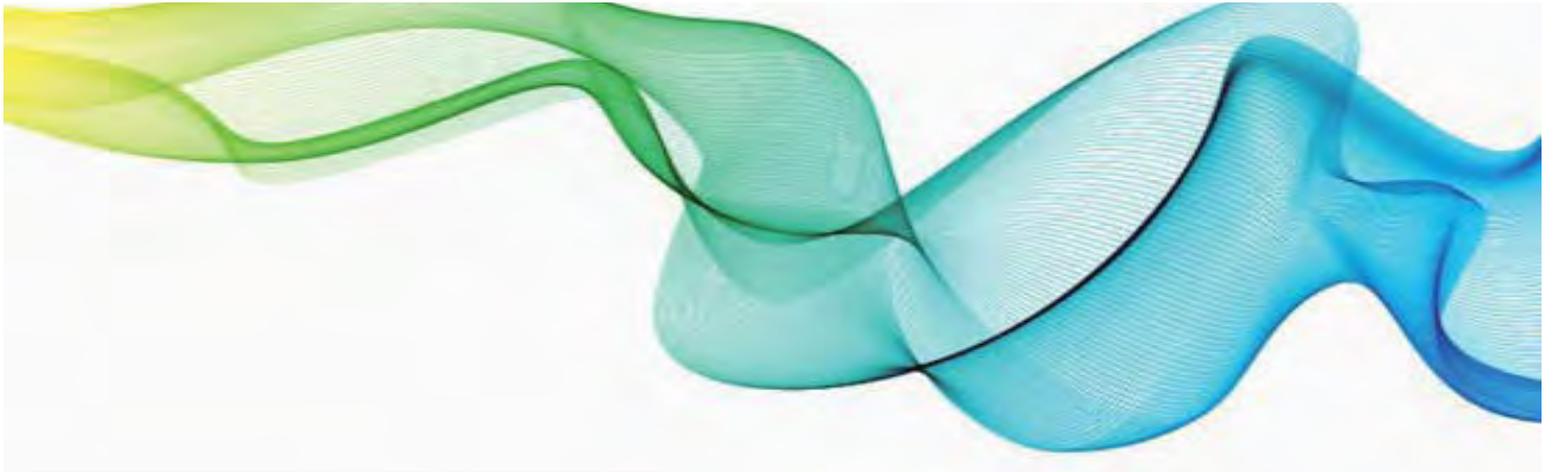
Towards a cure,

4 



Charles A. Mohan, Jr.
**Chief Executive Officer/
Executive Director**

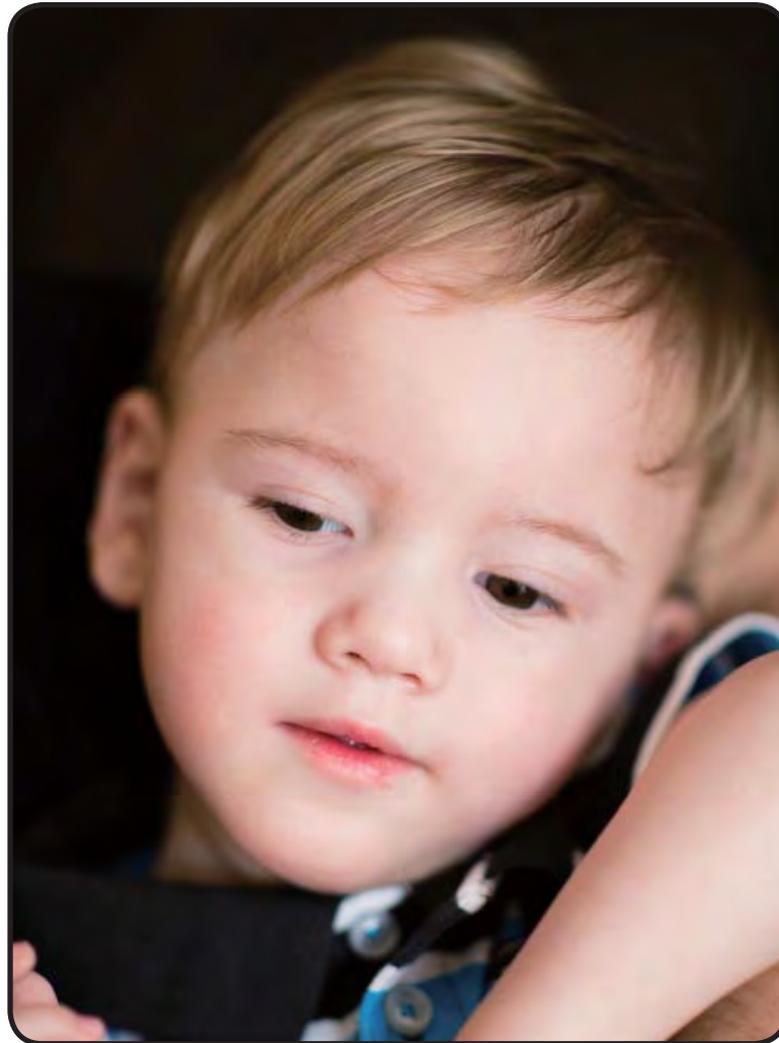
1 <ref> https://en.wikipedia.org/wiki/Peter_Drucker, 2013



Sharon Shaw said, "I have no other way to put it...those of us living with mitochondrial disease are WARRIORS... plain and simple. Warriors are not born my friends, they are made.....'Warriors are made by the paths they choose, not the powers they are graced with.'"



Sharon Shaw, UMDF Vice Chairman of the Board of Trustees



This is Jagger Peyton Cotte. He and his parents, Sebastien and Annett, have found HOPE at the United Mitochondrial Disease Foundation.

How the UMDF Has Helped Us

by Sebastien and Annett Cotte

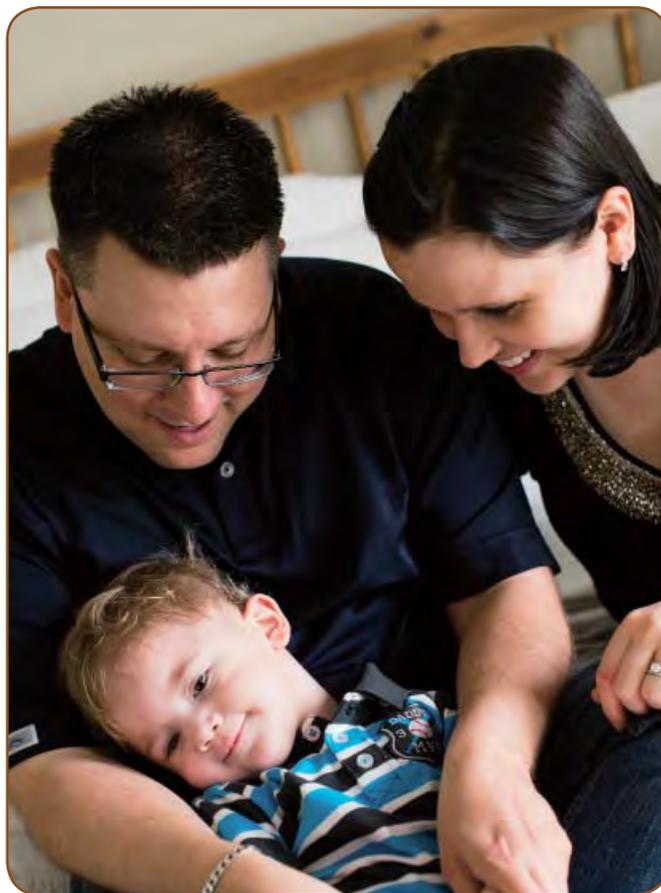
In August 2011, one month shy of his first birthday, Jagger had a muscle biopsy performed, which was ordered by a mito doctor, and a G-tube was placed. While the tube helped to give more nutrition to Jagger, he was still not well and started to lose some of the few skills he gained, such as holding objects in his hands, holding his head up, and even supported sitting. In November 2011, we received the results, based on the muscle biopsy, that Jagger has an undetermined mitochondrial disease; an MRI a few weeks later confirmed that he has Leigh Syndrome.

Of course, it was an incredible shock to be told that your child, the love of our life, the center of our universe, has a 2-4 years life expectancy and there is nothing we can do about it. It is heartbreaking and frustrating and at times, we feel as if we are living in the twilight zone. Right away, we started to do as much research as possible on his disease, but it was very difficult to find any details and information that was scientifically sound. Fortunately, we found the United Mitochondrial Disease Foundation (UMDF) website and were able to connect with them and with other people dealing with this terrible disease. Their website offered us additional resources and guidance on our quest for more answers on how to best manage Jagger's progressive illness.

In early 2012, Sebastien attended his first UMDF chapter meeting in downtown Atlanta. Due to Jagger's weak immune system and his profound dislike of cars and car seats, family excursions are kept to a strict minimum and usually only involve doctor appointments. Any extracurricular activities are executed solo while the other person takes care of Jagger. During this chapter meeting, Sebastien was introduced to another mito doctor who informed us that Jagger might be eligible for a drug trial for a new medication specifically targeting patients with Leigh's disease. Thanks to this doctor's persistence and our patience, Jagger was finally able to receive the drug in October 2012.

Sebastien (again flying solo) was also able to attend the Day on the Hill and the UMDF Symposium in Washington, DC in June 2012. It was such a great event, as it is so rare to have the opportunity to talk to the best mito doctors from the USA and around the world, as well as, converse with families who understand what a mito parent goes thru every day. It is a never-ending battle with good and bad days. The program was so informative that Sebastien, along with three other attendees from Georgia, decided to hold a Symposium Synopsis meeting in Atlanta in September 2012. At the Symposium Synopsis, they shared information with those families who were not able to attend the meeting in Washington, DC. Twenty-four people attended the Symposium Synopsis in Atlanta and families came from all over the region, not just Georgia.

Sebastien also became very involved in the organizational aspects of the annual UMDF Energy for Life Walkathon, which was held in April in downtown Atlanta. And so our mission continues: providing the best possible care for Jagger while keeping up with current developments in mitochondrial disease research and treatment options and spreading awareness. Thank you UMDF for supporting us on this mission.



Sebastien and Annett Cotte with Jagger

THE STAFF AND VOLUNTEERS ARE PROUD TO SERVE UMDF AND ITS MEMBERS.

For the past five years, the UMDF has used 36 cents from every dollar donated for programs that benefit patients, families, and the medical community. These programs include the annual symposium, educational materials, such as Mito 101 and the MitoFirst Handbook, and the support of newly diagnosed and current patients.

UMDF's support team consists of employees in its Member Services Department, its Regional Coordinators, and numerous volunteers. Jean Bassett and Melinda O'Toole have worked in the Member Services Department for more than ten years and respond to the information requests received by UMDF. UMDF also offers support through Support Ambassadors, local support groups, and one-time meet and greet events. Volunteers are vital for all of these and other efforts. UMDF Support Ambassadors provide a listening ear for newly diagnosed patients and families whose situations have changed. They engage members who are interested in networking with others affected by mitochondrial disease. UMDF offers support groups in many locations, as well as educational meetings, social activities, annual meetings, webinars, clinical trial information, quarterly newsletters, and many other ways to get connected.



*The UMDF Staff poses with the 2012 award winners at the symposium.
Staff not in the photo: Janet Owens and Barb Podowski*

In FY 2011 - 2012...

UMDF PROMOTED AWARENESS ACROSS THE COUNTRY



Brandon Wees aka Professor B

September 18 - 24, 2011, marked Mitochondrial Awareness Week. The UMDF National Office sent more than 150 Awareness Week material orders to people across the country trying to raise awareness about mitochondrial disease. As part of Awareness Week 2011, the UMDF held a video awareness contest to spread awareness about mitochondrial disease. On September 19, 2011, the National Office of the UMDF announced the first, second, and third place winners of its video awareness contest. Brandon Wees, age 6 of Katy, Texas, won first place and received an iPad from the UMDF.

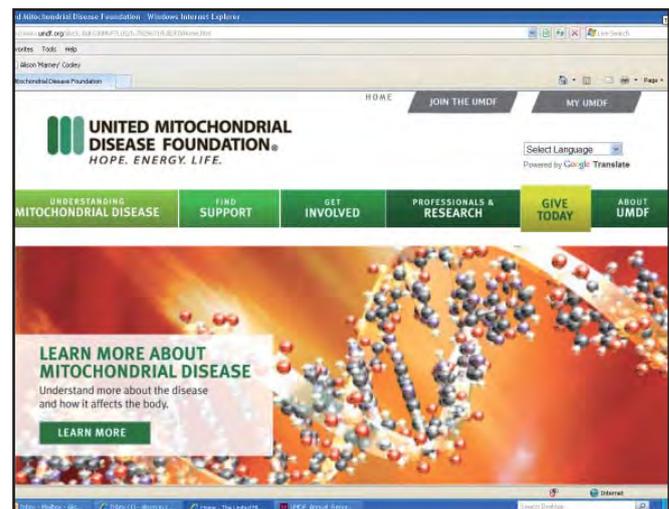
DAWGS FOR MITO

During Awareness Week 2011, Hannah Bossie who attends the University of Georgia (UGA) in Athens, Georgia, decided to start a club at the school to bring awareness of mitochondrial disease to the school. "Dawgs for Mito" created awareness of mitochondrial disease, and the new club on campus. They distributed more than 1,000 hand-made awareness ribbons and more than 1,500 flyers.

THE UMDF WOULD LIKE TO THANK ITS DONORS FOR THEIR SUPPORT ON THE DAY OF GIVING 2011

On October 4, 2011, the UMDF participated in The Pittsburgh Foundation's Day of Giving 2011. A total of 99 donors contributed \$8,337 to UMDF on that day.

THE UMDF WEBSITE RECEIVED A NEW LOOK IN THE WINTER OF 2012 AND THE UMDF NEWSLETTER WAS REDESIGNED IN THE SPRING OF 2012



UMDF INCREASED STAFF AND BOARD MEMBERS



Leslie Heilman, J.D.

In the fall of 2011, Leslie Heilman, J.D., joined the UMDF staff as Associate Director of Development. She was the Associate Director of Development and Communications for the University of Pittsburgh School of Law. Heilman was on the UMDF Board of Trustees for four years and served on the Donor Development Committee. She was UMDF's first Executive Director from 1999 to 2001.

In January of 2012, Margaret Moore was hired as the Regional Coordinator for the Southeast region. Margaret lives in Charlotte, North Carolina, and brought nearly two decades of experience as an allied health professional to the position. Prior to accepting her position, Moore was a longtime volunteer with the UMDF.



Margaret Moore



Carl Daniels

In the winter of 2012, Carl Daniels and Patrick Kelley joined the Board of Trustees. Carl Daniels is a Supply Chain Executive with operational experience across all aspects of retail including specialty, department store, off price, furniture, automotive, and discount store operations. Daniels and his wife, Noreen, live in Williamsburg, VA and plan to eventually retire to their home in Tennessee.

Patrick Kelley is the founder and President of Kelley Management Consulting (KMC), Inc., a general management consulting firm headquartered in Evanston, IL. Kelley lives in the Chicago area with his wife, Marybeth, and their six children. He has been an active member of the Chicago Chapter of the UMDF, including serving a three year term as Chapter President from 2007 – 2010. Kelley and his wife have a son, Patrick, who was born in 1998 and has a mitochondrial disease.



Patrick Kelley

UMDF PARTICIPATED IN RARE DISEASE DAY



On February 29, 2011, the UMDF patients and families were represented at the 5th Annual Rare Disease Day. This was a two-day event that was held at the National Institutes of Health (NIH) campus in Bethesda, MD. Representatives from more than 400 patient advocacy groups, scientists, researchers, and clinicians attended.

UMDF PROVIDED FAMILY MEETINGS AND GRAND ROUNDS

UMDF has made Grand Rounds a top priority to reach out to physicians through introducing and/or broadening the knowledge base on mitochondrial diseases. The primary purpose of our Grand Rounds program is to provide continuing education to health care providers on topics specific to mitochondrial disorders, which also furthers the 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.

With the generous support from Transgenomic Labs, the UMDF hosts approximately 12-15 Grand Rounds per fiscal year throughout the United States. These meetings have received nothing but positive feedback from the medical community.

In addition to Grand Rounds, UMDF also schedules a special family meeting with our members during this time to not only help educate patients/families about mitochondrial disease but to allow them to speak one-on-one with a mitochondrial specialist. These family meetings are also suitable for outreach to nurses, therapists, educators, and various allied health professionals.

THE UMDF INCREASED COLLABORATION WITH THE NIH AND MITO PATIENTS IN EUROPE

On March 8-9, 2012, more than 80 clinicians, scientists, and researchers from leading medical institutions and universities gathered in Rockville, MD, for a first of a kind meeting with representatives from numerous institutes at the National Institutes of Health (NIH). The meeting, entitled, "Translational Research in Primary Mitochondrial Diseases: Obstacles and Opportunities," was developed and chaired by UMDF Scientific and Medical Advisory Board Chairman Carlos Moraes, Ph.D., of the University of Miami, and Vernon Anderson, Ph.D., of the National Institute of General Medical Sciences (NIGMS) at the NIH. The meeting between the UMDF and the NIH was the result of a request from Sen. Barbara Boxer (D-CA). Sen. Boxer introduced legislation in the Senate and asked, among other things, for better collaboration between researchers around the country and at the NIH.



Workshop organizers: Charles Mohan, Jr.; Vernon Anderson, Ph.D.; David Eckstein, Ph.D.; Carlos Moraes, Ph.D.; and Stephen Groft, Pharm.D.

In April of 2012, UMDF CEO/Executive Director Charles A. Mohan, Jr., attended an International Mito Patients (IMP) group meeting in Paris, France. He presented meeting information about the UMDF and the status of mitochondrial disease and research in the United States.

UMDF OFFERED MEMBERS EDUCATION AND NETWORKING AT THE UMDF'S ANNUAL SYMPOSIUM

Every year, the United Mitochondrial Disease Foundation (UMDF) holds a symposium, which is organized by staff with input from volunteers. Researchers and clinicians from all over the world, representing many scientific and medical disciplines, attend research and clinical sessions. At the same time, patients and families attend family sessions and meet some of the top clinical mitochondrial specialists. There are many opportunities for networking and the exchange of information among physicians, researchers, patients and families. The symposium includes a four-day scientific/clinical program and a two-day patient/family program. This past year, the symposium was held from June 13 - 16, 2012, in Bethesda, MD.

Donors' gifts not only helped UMDF offer this one-of-a-kind conference, but it also helped people like Sonya Murray go, who would not otherwise be able to attend. Sonya was among 25 people who received a scholarship to attend the 2012 symposium. Sonya Murray of Smyrna, Tennessee, said, "What was so special to me about attending the symposium is that there are famous doctors right in front of you, and you can talk to them. It's not like seeing a superstar in Nashville and not being able to talk to them because you want to respect their privacy. These doctors are superstars to us, and yet they are there to talk to us."



Stephen Groft, Director of the Office of Rare Diseases at the National Institutes of Health, and his wife mingling at the 2012 symposium.



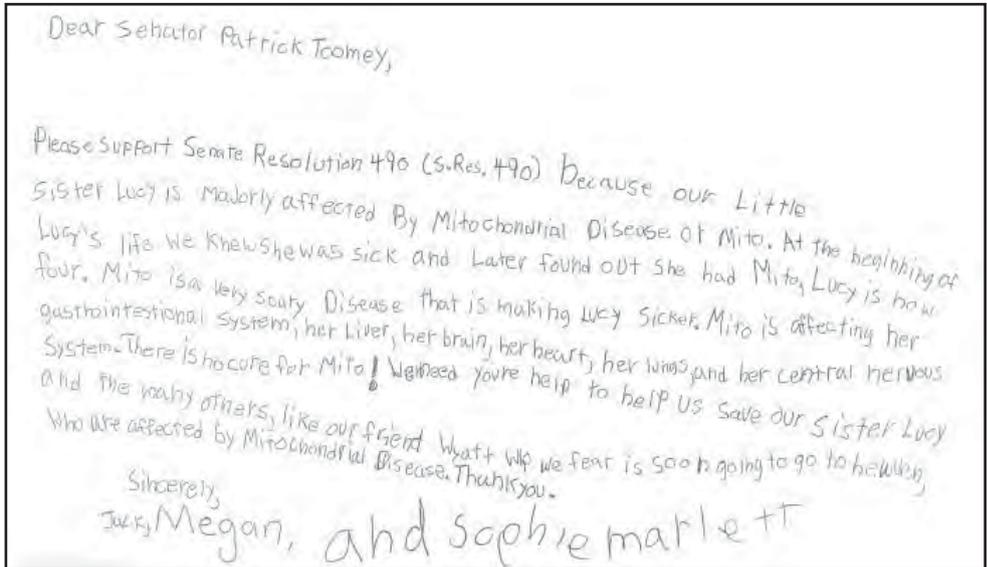
UMDF staff pose with Dr. Douglas Wallace, Director of the Center for Mitochondrial and Epigenomic Medicine at the Children's Hospital of Philadelphia.



MORE THAN 230 MEMBERS PARTICIPATED IN "DAY ON THE HILL"

June 14, 2012, was "Day on the Hill" during the UMDF's symposium, which was held in the Washington, D.C. area. During "Day on the Hill," patients and families had the opportunity to go to Capitol Hill, meet with their elected officials, and advocate for more government funding for mitochondrial disease research.

In June of 2012, Senator Barbara Boxer (D-CA) introduced Resolution 490. UMDF members were asked to talk to their Senators and ask them to cosponsor S. Res. 940 and encouraged to visit the UMDF Action Center online and send a letter to their Congressman asking him or her to join the newly formed Mitochondrial Disease Caucus.



Dear Senator Patrick Toomey,

Please support Senate Resolution 490 (S-Res. 490) because our little sister Lucy is majorly affected by Mitochondrial Disease of Mito. At the beginning of four, Mito is a very scary disease that is making Lucy sick. Mito is affecting her gastrointestinal system, her liver, her brain, her heart, her lungs, and her central nervous system. There is no cure for Mito! We need your help to help us save our sister Lucy and the many others, like our friend what we fear is soon going to go to heaven, who are affected by Mitochondrial Disease. Thanks you.

Sincerely,
Jack, Megan, and Sophie Marlett

Jack Marlett, age 11, wrote and read this letter to Senator Patrick Toomey on June 14, 2012 in the Senator's office on Capitol Hill. The letter brought tears to the Senator's eyes. Jack received a certificate of appreciation in honor of being a special advocate for the UMDF on "Day on the Hill" 2012.



Senator Barbara Boxer with her "UMDF Champion" plaque, Norma Gibson, UMDF California Chapter President, and Chuck Mohan, UMDF CEO/ED.



Drew and Nicole Marlett with Jack, Sophie, and Megan sporting their patriotic colors at "Day on the Hill." (Not pictured is Lucy, the Marlett's youngest child.)

THE UMDF HELD 18 ENERGY FOR LIFE WALKS



*Hunt Hollis of Team Hunt
at the Energy for Life
Walkathon in Nashville, TN.*



For every dollar donated to the UMDF over the last five years, 15 cents was allocated towards fundraising costs, covering all event related expenses, everything from brochures to rental fees. Volunteers generously give their time and energy to raise money for the United Mitochondrial Disease Foundation (UMDF) in various ways. Kids get involved by selling lemonade and cupcakes while some adults organize golf outings, galas, and walks. No matter what fundraiser volunteers want to do for the UMDF, every dollar counts.

In the fall of 2011, there were eight Energy for Life Walkathons held across the United States in these cities: Camden, NJ; Charlotte, NC; Chicago, IL; Bloomington, MN; Kansas City, KS; Murray City, UT; Sugar Grove, PA, and Williamsville, NY. These eight walks raised nearly \$380,000.

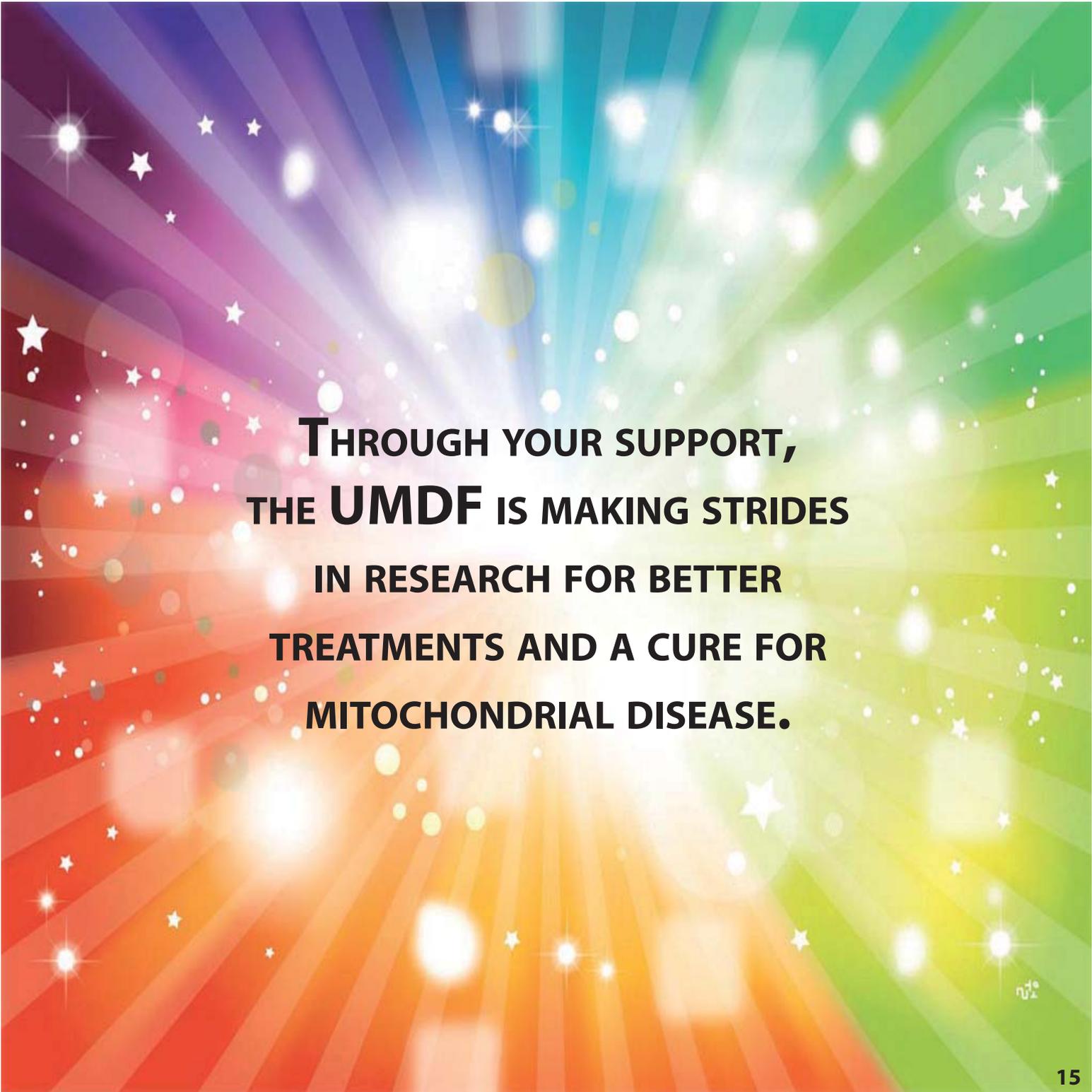
There were ten Energy for Life Walkathons held in the winter and spring of 2012 in these cities: Ann Arbor, MI; Atlanta, GA; Binghamton, NY; Cedar Falls, IA; Evansville, IN; Houston, TX; Indianapolis, IN; Nashville, TN; Pittsburgh, PA; San Francisco, CA, and St. Louis, MO. These ten walks raised about \$1,627,000.



*Dick Sperling, who has mitochondrial disease,
Sharon Zysman, and Dick's wife, Patti at the
walk in Williamsville, NY.*



*UMDF staff and volunteers pose for a photo at the Energy for Life
Walkathon training held in Pittsburgh, PA, in the spring of 2012.*



**THROUGH YOUR SUPPORT,
THE **UMDF** IS MAKING STRIDES
IN RESEARCH FOR BETTER
TREATMENTS AND A CURE FOR
MITOCHONDRIAL DISEASE.**

UMDF FUNDED NEARLY \$11 MILLION IN PROVIDING SUPPORT, EDUCATION, AND RESEARCH TOWARDS A CURE

In June of 2012, the UMDF awarded \$531,000 to six researchers whose projects may lead to a cure for mitochondrial disease or better treatments for those who battle it. The research grant awards were presented at the UMDF's annual symposium, "Mitochondrial Medicine 2012: Capitol Hill," which was held at the Bethesda North Marriott Hotel and Conference Center in Bethesda, MD, June 13 - 16, 2012. This year's awards bring the total amount of UMDF funded research to nearly \$11 million since 1996. The UMDF is the largest, non-governmental contributor of grants focused on mitochondrial disease research. Charles A. Mohan, Jr., UMDF CEO/Executive Director said, "We are pleased that we can provide this much money towards research that will hopefully lead to a cure for mitochondrial disease. It is truly our mission to support those affected by this devastating disease and find a cure for it."

At the symposium, UMDF announced that Lisa Emrick, M.D., of the Baylor College of Medicine in Houston, TX, was the winner of the 2012 Clinical Fellowship Training Award. The clinical fellowship training award is designed to support the training of physician scientists who plan to practice clinical management of patients with mitochondrial disorders and to conduct patient-oriented research in the field of Mitochondrial Medicine. Lisa will receive \$60,000 over one year for the clinical fellowship and will focus on "Characterization of Neurologic Deficits and Response to Treatment in Patients with MELAS and other Mitochondrial Disorders."



Valerio Carelli, Ph.D. (left) accepted the Chairman's Award on behalf of Carla Giordano, M.D., Ph.D. Dan Wright, UMDF Board Chair and Lissa Poincenot, UMDF member presented the award.



Dan Wright, UMDF Chairman of the Board of Trustees and Jean Bassett, UMDF Research Grants Coordinator presented Lisa Emrick, M.D. (center), with the Clinical Fellowship Training Award at Mitochondrial Medicine 2012: Capitol Hill.



Dan Wright, UMDF Board Chair and Kristi Cole, UMDF member presented a grant award to Mariana G. Rosca, M.D. (center)

2012 UMDF GRANT RECIPIENTS

Chairman's Award Recipient - \$108,000 over 2 yrs.

Carla Giordano, M.D., Ph.D., University of Rome, Rome, Italy

"Estrogen Mediated Regulation of Mitochondrial Biogenesis and Functions: Possible Therapeutic Implications for Leber's Hereditary Optic Neuropathy."

She will use phytoestrogens, plant compounds with estrogenic properties, to enhance mitochondrial energy metabolism. This research could result in effective treatments for a progressive mitochondrial disease that severely impairs vision.

\$100,000 over 2 yrs.

William James Craigen, M.D., Ph.D., Baylor College of Medicine, Houston, Texas

"Testing Gene Therapy in an Animal Model of Mitochondrial Respiratory Chain Disorders."

His lab is developing procedures using viruses to deliver the correct genetic information to mice that have defective mitochondria, in an attempt to greatly improve their energy metabolism. This could lead to the development of an effective gene therapy for young mitochondrial disease patients.

\$100,000 over 2 yrs.

Mariana G. Rosca, M.D., Case Western Reserve University, Cleveland, Ohio

"Rescuing Complex I Defective Mitochondria and Target Organs with Methylene Blue."

She is developing a treatment that could bypass a defective mitochondrial enzyme, enhancing energy metabolism. Improving the performance of mitochondria in this way could address a defect that is responsible for a third of all mitochondrial disease cases.

\$93,000 over 2 yrs.

Javier Torres-Torronteras, Ph.D., Vall d'Hebron Research Institute, Barcelona, Spain

"Preclinical Studies for the Gene Therapy of Mitochondrial Neurogastrointestinal Encephalomyopathy (MNGIE). Longterm Follow-up and Use of Adeno-associated Viral Vectors."

He will investigate the effectiveness of a gene therapy that he developed for use in mice with mitochondrial disease. This research will aid in determining the best approaches for treating human mitochondrial disease with gene therapy.

\$80,000 over 2 yrs.

David A. Sinclair, Ph.D., Harvard Medical School, Boston, Massachusetts

"Ultra-high-throughput Screening for Mitochondrial Enhancers as Novel Targets for Treating Mitochondrial Diseases."

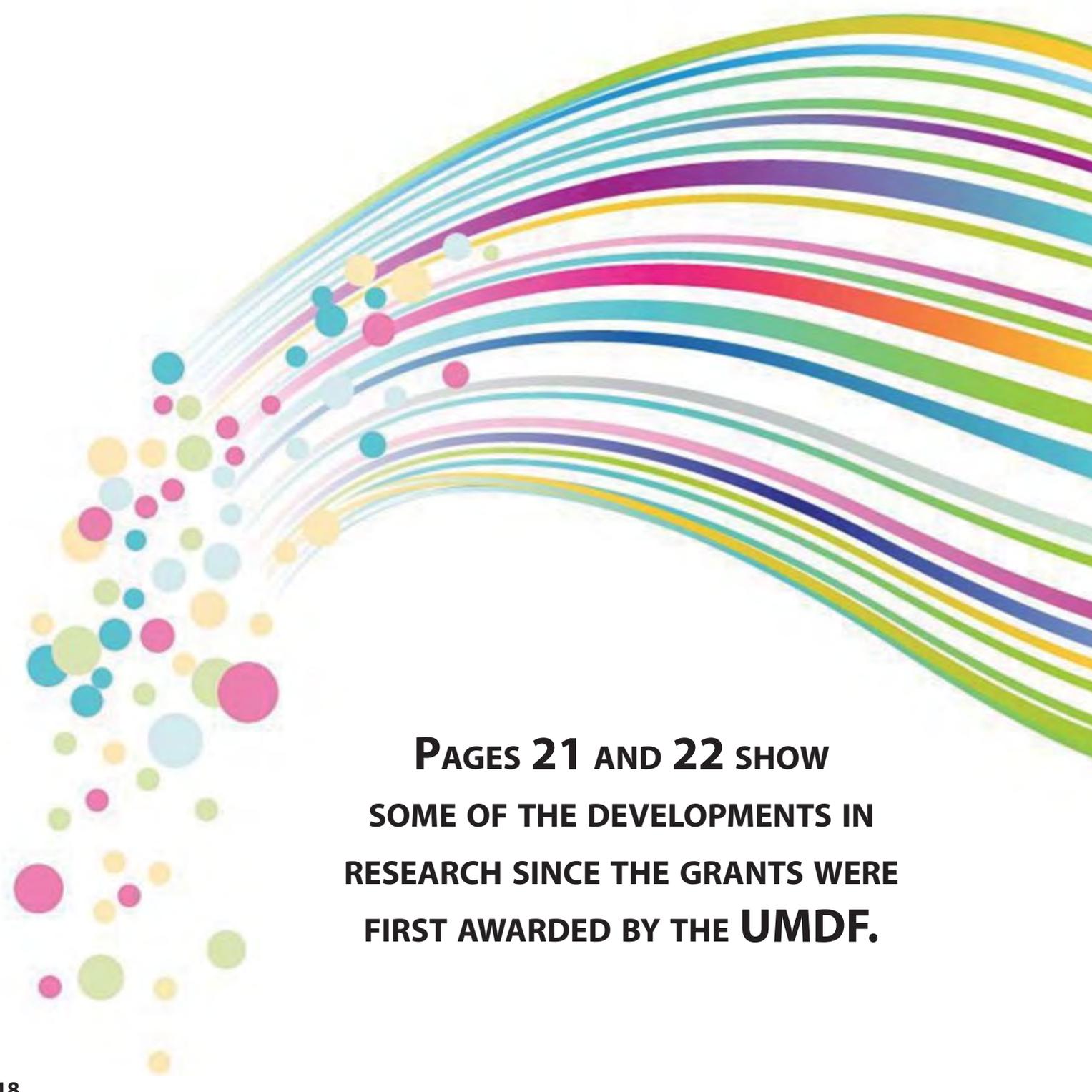
He will screen a large number of genes for their ability to enhance mitochondrial energy metabolism. Applying his findings to cell culture models of various mitochondrial diseases could lead to the discovery of new treatments.

\$50,000 over 1 yr.

Nuno Raimundo, Ph.D., Yale University School of Medicine, New Haven, Connecticut

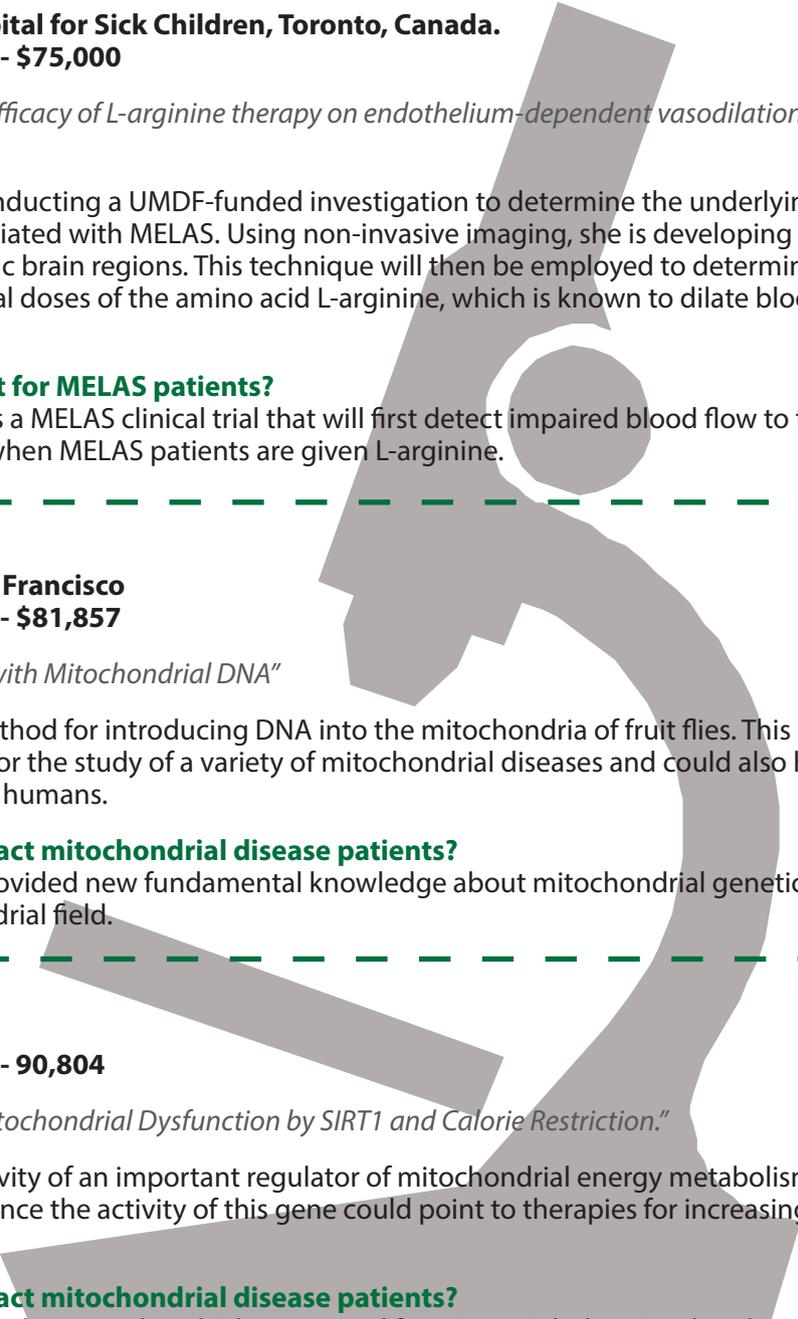
"Mechanisms and Treatment of Mitochondrial Deafness."

He has developed an animal model for the study of hearing loss due to a mutation in mitochondrial DNA. The insights gained from this research could lead to the prevention and treatment of a type of deafness that is linked to mitochondrial malfunction.



**PAGES 21 AND 22 SHOW
SOME OF THE DEVELOPMENTS IN
RESEARCH SINCE THE GRANTS WERE
FIRST AWARDED BY THE **UMDF.****

RECENT PROMISING DEVELOPMENTS IN RESEARCH



Ingrid Tein, M.D.

Division of Neurology, Hospital for Sick Children, Toronto, Canada.

2010 UMDF Funded Project - \$75,000

"Pilot study to investigate the efficacy of L-arginine therapy on endothelium-dependent vasodilation & mitochondrial metabolism in MELAS syndrome."

Dr. Tein and associates are conducting a UMDF-funded investigation to determine the underlying vascular pathology of the stroke-like episodes associated with MELAS. Using non-invasive imaging, she is developing a procedure for detecting impaired blood flow to specific brain regions. This technique will then be employed to determine whether brain circulation improves in patients given oral doses of the amino acid L-arginine, which is known to dilate blood vessels, increasing blood flow to the brain.

What is the potential impact for MELAS patients?

This exciting current project is a MELAS clinical trial that will first detect impaired blood flow to the brain, and then determine if brain circulation improves when MELAS patients are given L-arginine.

Patrick H. O'Farrell, P.h.D.

University of California-San Francisco

2009 UMDF Funded Project - \$81,857

"Selecting for Transformation with Mitochondrial DNA"

Dr. O'Farrell will develop a method for introducing DNA into the mitochondria of fruit flies. This important research will produce reliable animal models for the study of a variety of mitochondrial diseases and could also help guide attempts to repair the mitochondrial genome in humans.

How does this research impact mitochondrial disease patients?

This significant project has provided new fundamental knowledge about mitochondrial genetics, and brought a seasoned researcher into the mitochondrial field.

Sarika Srivastava

Harvard Medical School

2009 UMDF Funded Project - 90,804

"Investigating the Rescue of Mitochondrial Dysfunction by SIRT1 and Calorie Restriction."

Dr. Srivastava studied the activity of an important regulator of mitochondrial energy metabolism in mice. This was significant because finding ways to enhance the activity of this gene could point to therapies for increasing energy production by mitochondria.

How does this research impact mitochondrial disease patients?

This study sheds light on ways that mitochondrial energy and function might be stimulated in diseased patients, which may open new avenues for mito therapies.

Bridget Elizabeth Bax, M.D.
St. George's University of London
2008 UMDF Funded Project - \$116,428

"Evaluation of the efficacy and safety of erythrocyte encapsulated thymidine phosphorylase therapy in two patients with mitochondrial neurogastrointestinal encephalomyopathy."

Dr. Bridgett Bax and her colleagues at St. George's University of London are conducting clinical research funded by the UMDF to investigate potential therapies for MNGIE. They are specifically interested in developing a form of enzyme replacement therapy for these patients. Using a novel approach called erythrocyte encapsulation they are supplying the missing enzyme to patients through use of their own treated red blood cells. This is significant because there is currently no means of ridding patients of the toxic compounds that accumulate because of the absence of thymidine phosphorylase.

How does this research impact patients with MNGIE?

Supporting data from this MNGIE study will significantly contribute to their request for approval in the United Kingdom for a MNGIE clinical trial. Orphan Medicinal Product Designation has already been granted by the U.S. Food and Drug Administration (FDA) and the European Medicines Agency.

Rebeca Acin-Perez, Ph.D.
Weill Medical College, Cornell University
2008 UMDF Funded Project - \$99,990

"OXPHOS modulation by mitochondrial protein phosphorylation in mtDNA mutant cells."

Cells with mutated mitochondrial DNA have a diminished ability to produce ATP. Her research project investigated how these mutations affect the proteins that regulate ATP synthesis. This is significant because it may lead to new drug therapies.

How does this research impact mitochondrial disease patients?

They have determined that two interconnected processes that control metabolism allow the cell to conserve energy. They believe these observations may result in promising therapies to reduce the effects of mitochondrial disease.

Brendan James Battersby, Ph.D.
University of Helsinki
2008 UMDF Funded Project - \$150,000

"Identifying genetic modifiers of tissue-specific mitochondrial DNA segregation."

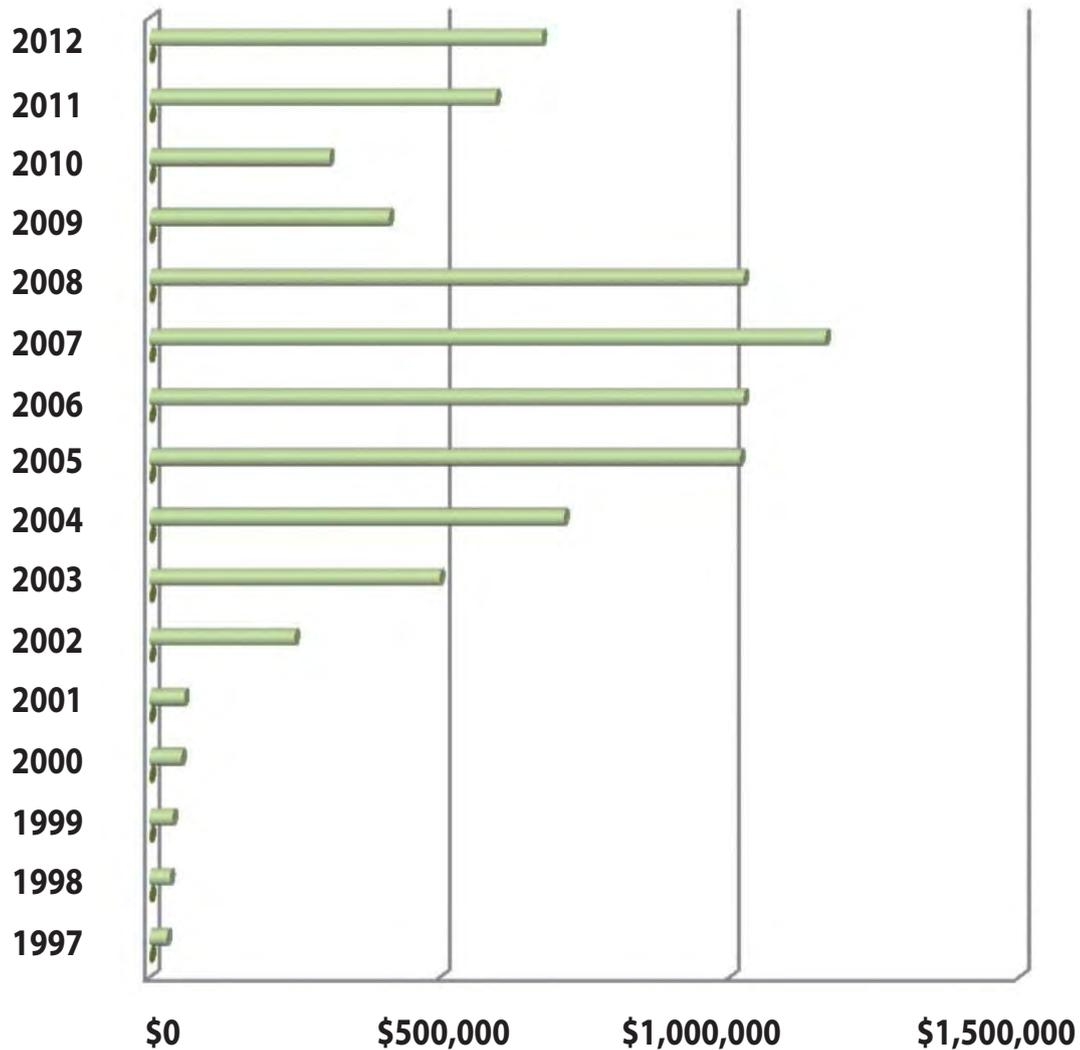
Their goal is to identify genes in mice that control a cell's ability to recognize mitochondria that contain abnormal DNA and thus have an impaired ability to produce ATP. If a therapy could be developed that encouraged cells to selectively retain mitochondria with normal DNA while eliminating abnormal mitochondria, it would be of great benefit to mitochondrial disease patients.

How does this research impact mitochondrial disease patients?

Their important research resulted in the first gene discovered that regulates mitochondrial DNA selection. They will explore this in greater detail and the results may help determine the onset and severity of mitochondrial DNA mutations.

UMDF FUNDED RESEARCH SINCE 1997

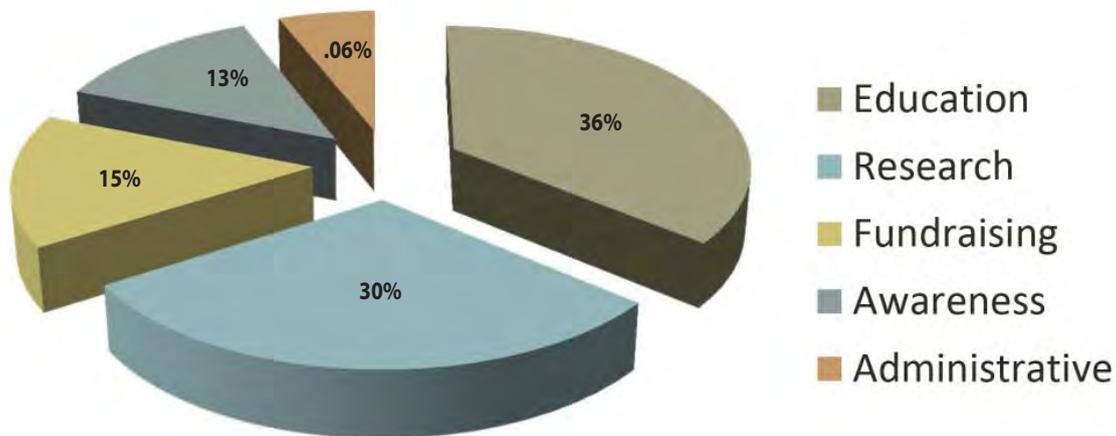
RESEARCH DOLLARS PROVIDED



Since 1996, the UMDf has funded nearly \$11 million in research projects, clinical fellowships, and scientific and family educational meetings all aimed at providing patients with a faster diagnosis and better treatment options. Our ultimate objective is to find a cure for mitochondrial disease.



UMDF MAXIMIZES THE POWER OF EVERY DOLLAR DONATED



For every dollar donated to the UMDF over the last five years,
\$.79 was allocated to research, education, and awareness;
\$.15 was allocated to fundraising and
\$.06 was allocated to administrative expenses.

This chart shows the allocation of funds for every dollar donated to the UMDF over the last five years.

Research - .30 cents from every dollar donated was used for the UMDF Research Grant Program to fund the most promising research.

Education - .36 cents from every dollar donated was used for programs that benefit patients, families, and the medical community. These programs include our annual symposium, the UMDF Grand Rounds and Family Meeting Programs, our educational materials (Mito 101 and the MitoFirst Handbook) and our support of newly diagnosed and current patients.

Awareness/Advocacy - .13 cents of every dollar was used to promote awareness of mitochondrial disease as well as support our advocacy efforts that are designed to secure additional funding for primary mitochondrial disease research.

Fundraising - .15 cents of every dollar was allocated towards fundraising.

Administrative - .06 cents of every dollar was allocated to rent, utilities, UMDF operational costs.



3328 Washington Road
McMurray, PA 15317-3005
Tel (724) 260-0900
Fax (724) 260-5210

Certified Public Accountants and Business Consultants

Joseph S. Stelmack, CPA
Joseph T. Dobransky, CPA
Vincent M. Eannace, CPA

INDEPENDENT AUDITOR'S REPORT

To the Board of Trustees of the
United Mitochondrial Disease Foundation, Inc.

We have audited the accompanying statements of financial position of the United Mitochondrial Disease Foundation, Inc. ("the Foundation") as of June 30, 2012 and 2011, and the related statements of activities, functional expenses and cash flows for the years then ended. These financial statements are the responsibility of the Foundation's management. Our responsibility is to express an opinion on these financial statements based on our audits.

We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audits provide a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of the United Mitochondrial Disease Foundation, Inc. as of June 30, 2012 and 2011, and the changes in its net assets and its cash flows for the years then ended in conformity with accounting principles generally accepted in the United States of America.

Stelmack Dobransky & Eannace, LLC

STELMACK DOBRANSKY & EANNACE, LLC
McMurray, Pennsylvania

February 6, 2013

**UNITED MITOCHONDRIAL
DISEASE FOUNDATION, INC.**

**STATEMENTS OF FINANCIAL POSITION
JUNE 30, 2012 AND 2011**

	2012	2011
ASSETS		
Cash and cash equivalents	\$ 667,724	\$ 564,165
Accounts receivable	73,801	16,900
Inventories	29,595	25,811
Investments (Note 3)	1,396,035	1,386,772
Prepaid expenses	24,573	15,773
Fixed assets - net (Note 4)	48,648	40,132
TOTAL ASSETS	<u>\$ 2,240,376</u>	<u>\$ 2,049,553</u>
<u>LIABILITIES AND NET ASSETS</u>		
LIABILITIES		
Accounts payable	\$ 283,750	\$ 207,854
Accrued liabilities	45,628	37,539
Grants payable (Note 5)	989,484	849,469
Deferred revenue	6,096	38,765
Total liabilities	<u>1,324,958</u>	<u>1,133,627</u>
NET ASSETS		
Unrestricted	503,742	593,399
Temporarily restricted (Note 7)	411,676	322,527
Total net assets	<u>915,418</u>	<u>915,926</u>
TOTAL LIABILITIES AND NET ASSETS	<u>\$ 2,240,376</u>	<u>\$ 2,049,553</u>

See Independent Auditor's Report and Notes to the Financial Statements

**UNITED MITOCHONDRIAL
DISEASE FOUNDATION, INC.**

**STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS
FOR THE YEARS ENDED JUNE 30, 2012 AND 2011**

	-----2012-----			-----2011-----		
	Unrestricted	Temporarily Restricted	Total	Unrestricted	Temporarily Restricted	Total
PUBLIC SUPPORT AND REVENUE						
Support:						
Fundraising	\$1,425,637	\$ 102,611	\$ 1,528,248	\$1,469,512	\$ 144,870	\$1,614,382
Contributions	342,683	8,000	350,683	199,680	172,057	371,737
In honor of	113,592	0	113,592	127,879	0	127,879
In memory of	86,230	0	86,230	83,623	0	83,623
In kind	37,733	0	37,733	33,605	0	33,605
Grants	107,158	98,226	205,384	57,214	178,167	235,381
Cancellation of grants payable	135,000	0	135,000	43,501	0	43,501
Total support	2,248,033	208,837	2,456,870	2,015,014	495,094	2,510,108
Revenue:						
Symposium and seminars	263,315	0	263,315	219,625	2,000	221,625
Membership	17,330	0	17,330	21,161	0	21,161
Sales	15,475	0	15,475	11,214	0	11,214
Miscellaneous	0	0	0	0	0	0
Total revenue	296,120	0	296,120	252,000	2,000	254,000
Investment income	43,702	0	43,702	38,760	0	38,760
Net unrealized gain (loss) on investments	(33,701)	0	(33,701)	204,017	0	204,017
Net realized (loss) on investments	0	0	0	(120)	0	(120)
Net assets released from program restrictions.....	119,688	(119,688)	0	442,176	(442,176)	0
Total support and revenue	2,673,842	89,149	2,762,991	2,951,847	54,918	3,006,765
FUNCTIONAL EXPENSES						
Program services:						
Research	785,012	0	785,012	748,459	0	748,459
Public awareness	288,946	0	288,946	242,315	0	242,315
Education/member support	870,703	0	870,703	830,930	0	830,930
Total program services	1,944,661	0	1,944,661	1,821,704	0	1,821,704
Supporting services:						
Administrative and general	126,403	0	126,403	130,923	0	130,923
Fundraising	692,435	0	692,435	609,997	0	609,997
Total supporting services	818,838	0	818,838	740,920	0	740,920
Total expenses	2,763,499	0	2,763,499	2,562,624	0	2,562,624
CHANGES IN NET ASSETS	(89,657)	89,149	(508)	389,223	54,918	444,141
NET ASSETS - Beginning of year	593,399	322,527	915,926	204,176	267,609	471,785
NET ASSETS - End of year	\$ 503,742	\$ 411,676	\$ 915,418	\$ 593,399	\$ 322,527	\$ 915,926

See Independent Auditor's Report and
Notes to the Financial Statements

UMDF BOARD OF TRUSTEES - FY 2011 - 2012



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Houston, TX



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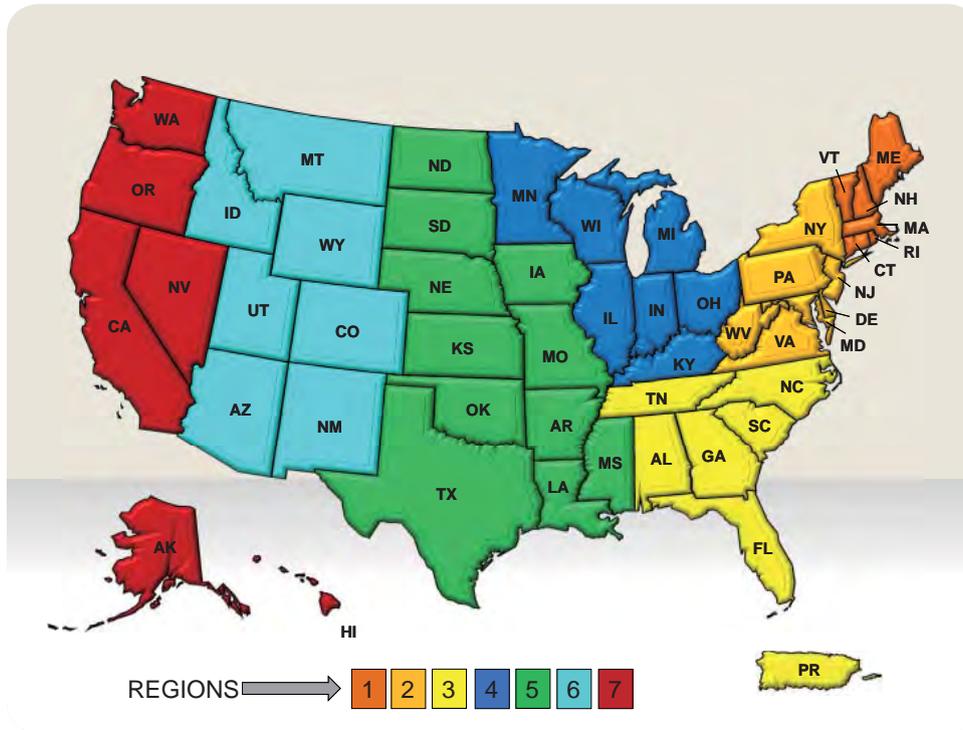
**Mark Tarnopolsky,
M.D., Ph.D., FRCP(C)**
McMaster Univ., Hamilton,
Ontario, Canada

UMDF connect

Resources for help & support.



In addition to the support staff at the UMDf National Office, help is available to you across the United States and around the world. To reach a state contact for support and/or if your state is not listed and you would still like to connect, simply e-mail to: connect@umdf.org. When sending the e-mail, please include the leader's name or city/state in the subject line for us to better serve your needs. Interested in getting involved? Visit: www.umdf.org/volunteerops or call: 1-888-317-8633!



★ Stars Denote Chapter and/or Chapter Leadership in that State

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VERMONT

MaryBeth LeFevre

CONNECTICUT, MASSACHUSETTS, NEW HAMPSHIRE, RHODE ISLAND

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★ DC – See Virginia

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★ Dawn Murphy, DC/Baltimore/Northern Virginia Chapter

NEW JERSEY

★ Laurel Smith, Delaware Valley Chapter

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Jennifer Schwartzoff, Buffalo, Western NY Mito Group

Erica Beyea, Buffalo, Western NY Parents Mito Group

Sandy Sallaj, Buffalo, Western NY Parents Mito Group

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Lori Piccirilli, Binghamton

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Jessica Myers, Erie Mito Group

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Judi Bartle, Central Virginia Mito Group
Sharon Hoffert, Central Virginia Mito Group
Molly McCaffrey Adams, Richmond

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★Anne Tuccillo, DC/Baltimore/Northern Virginia Chapter

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Garry Krueger, North Central Florida
Joan Morris, Titusville, FL
Denise Richardson, Fort Lauderdale
Holly Schneider, Coconut Creek
Jennifer Slauter, Orlando, Central FL Mito Group
Sophie Szilagy, North East Florida

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Sebastien Cotte, Atlanta
Gail LaFramboise, West Central Georgia
Shelly Lorenzen, Sugar Hill
Marybeth Morris, Atlanta area
Cheryl Porter, Atlanta
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Nancy Garrison, Nashville
Brandalyn Henderson, Nashville
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Patti Bauer, Springfield
Victoria Helms, St. Louis Area Mito Group
Hope Grover, St. Louis Area Mito Group

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Missy Leone, Eastern Michigan Mito Group
Suzanne Arends, Western Michigan Mito Group
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Holly Worden, Lakeview

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★Anne Simonson, Minneapolis/St. Paul Chapter

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Jody Thompson, Central Ohio
Amanda & Jason Salensky, Cincinnati Mito Group
Chris & Alisa Rawski, Toledo

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Karen Loftus, Milwaukee
Terilyn Musser, LaCrosse/Eau Claire
Mindy Welhouse, Kimberly

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Krystena Richards, Mt. Sterling

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IOWA

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Darla Klein, Des Moines, Iowa Mito Group
Kim Novy, Des Moines, Iowa Mito Group

KANSAS (see Missouri)

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Mandy Poche, Baton Rouge
Anna Stewart, Bossier City
Chantel Wooley, Corington

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Marty Campbell, Beach, ND
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Jennifer Pfefferle, Boise, Idaho Mito Group

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UTAH

Laura McCluskey, Orem

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Kimberli Freiling, Monmouth

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Tyler Liebegott, Pennsylvania
Colleen Powell, Pennsylvania
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Executive Administrative
Assistant



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Chief Financial Officer



Donna Nameth
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Communications



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Leslie Heilman, J.D.
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Don Gielas
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Tania Hanscom
Special Events
Coordinator



Rachel Mazur
Special Events
Associate



Nicole Shanter
Special Events
Associate

THE BENEFITS OF BEING A UMDF MEMBER

UMDF brings mitochondrial disease experts to your community. Patients can get answers to their questions about mitochondrial disease and treatment options without spending thousands of dollars traveling to other centers.

Through Grand Rounds, UMDF sends mitochondrial medicine experts to medical facilities around the nation who teach other physicians how to recognize the signs and symptoms of mitochondrial disease so that patients won't need to wait years for a diagnosis.

UMDF has funded millions of dollars in research that jump-starts clinical trials leading to potential treatments.

More than 72,000 inquiries for support, education and information have poured into UMDF over the years. UMDF is there for you!

UMDF funds Research Fellows whose sole career focus is on learning how to diagnose and treat mitochondrial disease – adding to the cadre of specialist available to you.

UMDF provides patients with lifesaving resources, such as our Emergency Room Letter, which was recently used to educate an emergency medical team saving the life of a mitochondrial disease patient.

UMDF's "Ask the Mito Doc" answers your questions utilizing a panel of medical experts.

You can have access to a support group through UMDF's national network of affected individuals and their families giving you the ability to connect and share with each other in your own community.

In order to establish a base of patients with mitochondrial disease and link them to clinical trials and potential treatments, UMDF partially funds the North American Mitochondrial Disease Consortium (NAMDC) which operates research sites across the United States and Canada.

UMDF hosts the largest scientific and family symposium for mitochondrial medicine in the world. Scientists and clinicians provide the latest information in the diagnosis and treatment of mitochondrial disease. Patients and their families have the opportunity to learn and discuss these developments in person with the experts.

Responding to the needs of the patient community, UMDF created MITO 101, which is an introduction to mitochondrial disease for newly diagnosed and current patients. MITO 101 outlines common issues and problems you might experience associated with mitochondrial disease.

To raise awareness, volunteers from across the nation participate in Energy for Life Walkathons. More than 25 are held annually with over 10,000 participants. UMDF's goal is to have Energy for Life Walkathon in each state.

UMDF empowers affected individuals and their families by serving as their voice on Capitol Hill, result in the passage of legislation designed to increase funding for mitochondrial medicine research at the federal level.

