Message from the CEO

Glancing back at 2014, I want you to feel encouraged. At no time in the history of mitochondrial disease research has there been as much interest and progress in finding treatments. Pharmaceutical companies and academic research institutes are taking notice of the years of research supported by UMDF through your efforts. This is leading to unprecedented clinical trial activity and the ongoing need for our Patient Registry – which will help identify patients who could benefit from proposed treatments – directly benefitting you or your loved one. If you or your loved one hasn’t signed on to the registry yet, I can’t emphasize enough how important your participation is. Pharmaceutical companies will only design trials if there are enough people to populate them.

With representation in every state and 152 countries we will not rest on our successes but constantly strive to serve our members and supporters better every day. We continue to hone our messaging and focus to better meet mission success; “Promoting research and education for the diagnosis, treatment and cure of mitochondrial disorders and providing support to affected individuals and families.” Our momentum has led us to this point, but it is not time to rest. Our job is to move the science forward as quickly as possible. To do that, we are focusing on “Coordination, Communication and Collaboration.”

The French philosopher Auguste Comte had cures in mind when he said, “Every science consists in the coordination of facts; if the different observations were entirely isolated, there would be no science.” Supporting and empowering you is our main focus as we continue to “coordinate” patients, physicians and researchers, allied health, pharmaceutical, diagnostic and philanthropic communities, identifying and connecting needs with abilities and opportunities. How?

- Coordinating initiatives and efforts with “like” patient groups and organizations
- Coordinating existing research with hospitals, universities and the National Institutes of Health.
- Coordinating similar interests of the pharmaceutical industry.
- Coordinating and aligning UMDF’s efforts and resources to better meet the needs of our patients.
- Coordinating efforts and expertise to develop and implement the Mitochondrial Disease Community Registry (MDCR).

Sydney Harris said, “The two words ‘information’ and ‘communication’ are often used interchangeably, but they signify quite different things. Information is giving out; communication is getting through.” UMDF is committed to “getting through.” UMDF “communicates” its mission with the medical and pharmaceutical communities providing encouragement and resources addressing your needs. How?

- Communicating the needs of our patients to those with the resources to address them.
- Communicating the needs and accomplishments of the research community to our diagnostic and pharmaceutical partners.
- Communicating need, value and opportunity to the philanthropic community.
- Communicating the importance of member involvement in the legislative process.
- Communicating the value of participation in the Mitochondrial Disease Community Registry (MDCR).

Mattie Stepanek who lost his battle with mitochondrial myopathy at the young age of thirteen said, “Unity is strength... when there is teamwork and collaboration, wonderful things can be achieved.” The result of coordination and communication is collaboration and
Mattie was correct, “wonderful things can be achieved.” UMDF is collaborating with many entities to meet our mission. How?

- **Collaborative** relationships are being established with our academic, research and industry partners.
- **Collaborative** efforts with our global partners have resulted in co-funding important research toward treatments and possible cures. Continuing a global approach to mission success, we are enhancing relationships with our partners from Canada, Australia, Germany, Belgium, The Netherlands, France, Spain, United Kingdom, Italy and Japan. We believe this collaboration will result in enhanced efforts toward treatments and cures for the mitochondrial community.
- **Collaboration** on a global basis with Euromit. The Euromit Conference is the largest European based scientific conference in the world dedicated to understanding how mitochondria are involved in disease. By working in concert with Euromit, we break down the “silos” and make sure important information is shared between countries – serving to speed up the process of identifying treatments.
- **Collaboration** with other mitochondrial groups by supporting webinars and symposium platforms with tremendous educational value.
- **Collaboration** with, and making available to, all individuals, patient foundations and academic institutions participation in the Mitochondrial Disease Community Registry (MDCR).
- **Collaboration** with the North American Mitochondrial Disease Consortium (NAMDC), serving at the committee level and supporting the NAMDC Scientific Registry. The NAMDC registry will also grow and support opportunities for more clinical trials and ultimately treatments.
- **Collaborating** with over 100 international mitochondrial disease experts, we are creating the Mitochondrial Sequence Data Resource (MSeqDR). A genomic data resource that will help diagnose primary mitochondrial diseases (bringing together genomic data already being collected in clinics and labs around the world), increasing the potential for accurate diagnosis and new treatments targeted to precise disorders.
- **Collaborating** with all our mitochondrial partners to maintain the success of the UMDF Annual Symposium and regional conferences providing you with the most current materials.
- **Collaborating** with the NIH by co-sponsoring with the Office of Dietary Supplements (ODS) a workshop on Nutritional Interventions in Primary Mitochondrial Disease.
- **Collaborating** with our supporters bringing them opportunities that will make a difference in the lives of many.

**Coordination, Communication and Collaboration: three C’s** that will help us achieve the fourth and most important C: **CURE!**

We firmly believe that with your continued help and support of the UMDF Mission we will be successful in bringing beneficial results to the mitochondrial community.

Yours toward a cure,

![Signature]

Charles A Mohan Jr.
UMDF CEO

“To follow, without halt, one aim: There’s the secret of success.”

Anna Pavlova
Energy for Action

Education

Family Meetings

From San Marcos to Phoenix, Albuquerque to Chicago, UMDF bring world renowned medical experts to patients and families. In this past fiscal year, the UMDF traveled to 10 different cities providing expert information and resources to more than 2,000 patients and their families. Mitochondrial medicine experts such Bruce Cohen, MD., Richard Boles, MD., Dimitry Niyazov, MD., present the latest information in the proper treatment and care for patients and advancements that are being made on the medical front. Patients and families are able to participate in a question and answer session with physicians about their own issues and concerns. UMDF is happy to provide these educational outreach programs for affected individual and their families.

Nine-year-old Makenzie Lawrey is a big sister on a mission to save her little brother, Gavin, and others that suffer from Mitochondrial Disease. She’s a little girl with big dreams. She wants the whole world to know what Mito is and believes that one day there will be a cure. She wants people to know the kinds of incredible superheroes kids with Mito Disease are. She wrote and published a book “Mighty Mito Superhero” in honor of her brother’s life long journey with an ultimate goal to raise $1 million for UMDF. Join Makenzie, Gavin and their family to spread the word and the awareness. To read more about Makenzie’s mission, visit her website http://www.hope4mito.com/

Grand Rounds

The only way doctors will be able to better understand and accurately diagnose patients with mitochondrial disease is to educate them. That is why UMDF travels the nation with our Grand Rounds Program. Grand Rounds are held in major hospitals and medical facilities. Renowned mitochondrial medical experts present information to physicians about mitochondrial disease, its presentation in patients, its diagnosis and treatments and therapies. To date, more than 4,000 physicians have been educated through the UMDF Grand Rounds Program. Here are the Hospitals and Medical Facilities at which Grand Rounds occurred in 2013-2014:

- Cardinal Glennon Children’s Medical Center – St. Louis, MO
- Washington University School of Medicine – St. Louis, MO
- Phoenix Children’s Hospital – Phoenix, AZ
- Nemours Children’s Hospital – Orlando, FL
- Mayo Clinic Children’s Center- Rochester, MN
- Gillette Children’s Hospital - St. Paul, MN
- Saint Mary’s Hospital - Rochester, MN
- Lurie Children’s Hospital- Chicago, IL
- Embassy Suites Conference Center -San Marcos, TX
- Dell Children’s Hospital –Austin, TX
- Tulane University - New Orleans, LA
Support

Support Meetings

Several times a month, patients and families gather across the country. They meet in church basements, community centers, or any place that is willing to provide them space. UMDF Support Meetings have taken place in communities both large and small. In the past year, more than 60 of these meetings have taken place providing information and answers to more than 1500 affected individuals in their families. These UMDF sponsored meetings vary in topic but are aligned with our mission to provide support to affected individuals and their families. Some meetings provide expert speakers who discuss topics like therapies, potential treatments, palliative care, and grief. For many, this is a meeting where they can find support and know that they are not alone in their journey.

S.P.A. Weekend

UMDF sponsored a pilot program called Mito S.P.A. (Support. Play. Acknowledge.) as a way of recognizing the needs of this deserving group. The Mito S.P.A. weekend was the brainchild of Missy Knight and Joy Roeh, two Houston, TX UMDF volunteers. The weekend consisted of engaging activities that addressed the needs, hopes, and challenges of caregivers and affected adults. Time was also allowed for participants to network, share ideas, and just take a break from their very busy lives. Thirty people attended the free weekend program which was held all day Saturday, September 14, 2013, until noon on Sunday, September 15, 2013, in the Houston Embassy Suites.

Connect

Can you help me find a physician in my area?” or “What information do you have on MELAS?” These are just some of the thousands of questions that come into the UMDF National Office on a daily basis. UMDF Staff fielded 6,000 phone calls in the last fiscal year. It is our mission to connect affected individuals and their families to medical experts, information about their condition, treatment and therapy resources, or to direct them to sources for other information.

The UMDF Website is a vast resource for information about mitochondrial disease, its treatment, patient tools and clinician tools. In the last fiscal year, the UMDF website was visited by 1.4 million people in more than 160 countries. The UMDF has a very strong social media presence. More than 8,000 people ‘Liked’ and followed the UMDF in the past fiscal year. UMDF has a very strong presence from both the patient and scientific side on Twitter and Google+.

In an effort to allow affected individuals and families to better connect and interact, UMDF launched its very own online “Inspire” page. Inspire builds online health and wellness communities for patients and caregivers, in partnership with national patient advocacy organizations, and helps life science organizations connect with these highly engaged populations. More than 160 people signed up to interact on the UMDF Inspire page in the last fiscal year.
Energy for Action

Awareness Week

UMDF's volunteers made a tremendous impact across the globe during this year's Mitochondrial Disease Awareness Week, September 15-21, 2013. The UMDF was able to support its volunteers by sending out free educational materials to raise awareness. The staff sent out nearly 70,000 pieces of collateral. Materials were requested for awareness activities that were held in the United States, Canada, and Ireland. These activities raised awareness in schools, churches, medical communities, places of employment, and to the general public as volunteers either distributed educational materials at awareness and fundraising events or to individuals, such as physicians. Volunteers also created awareness on social media sites, television news reports, and newspaper articles.

Path to a Cure

The United Mitochondrial Disease Foundation (UMDF) created “UMDF’s Path to A Cure”. The UMDF’s Path to A Cure is a virtual online brick path designed to pave the way for funding real cures for mitochondrial disease. Affected individuals, family members, friends, and coworkers can participate simply by purchasing a brick and placing it on UMDF’s Path to A Cure. All purchased bricks stay on the path forever. You can visit the path at www.umdfpathtoacure.org

Above: The Terminal Tower in Cleveland, OH alight in green for Awareness Week. Left: Niagara Falls
Marriott Grant

The UMDF was excited and incredibly grateful to be the recipient of a five-year $975,000 grant awarded by the J. Willard and Alice S. Marriott Foundation.

This grant was awarded to the UMDF because the Marriott Foundation wants to support UMDF’s current and future efforts for treatments and cures for mitochondrial disease. This is a significant investment that will help us move forward at an even greater pace than we have been able to achieve in the past several years. UMDF was delighted to demonstrate the great strides made in enhancing existing collaborations and promoting the sharing of information between the academic, research and clinical communities, Congress and governmental agencies, and pharmaceutical innovators.

This improved communication and collaboration will further enhance the development of treatment and cures for mitochondrial disease.

Advocacy

With representation from a dozen congressional offices, the Congressional Mitochondrial Disease Caucus held a Capitol Hill briefing entitled “Mitochondrial Drug Development and a Primer on the FDA Drug Approval Process.” The meeting, convened at the request of Rep. Anna Eshoo (D-CA-19) and Rep. Tim Murphy (R-PA-18), enabled the UMDF to educate congress on the exciting developments with EPI-743 and on the Food and Drug Administration (FDA) approval process for similar drugs.

Speaking at the March 13, 2014, briefing was Guy Miller, MD, PhD, CEO of Edison Pharmaceuticals of Mountain View, CA. Dr. Miller briefed those in attendance about the process involved in developing EPI-743, current clinical trials and the pathway his company traveled through the FDA.

Also speaking at the briefing was Michael Werner, J.D. Werner, who was recently named “Top 50 Global Stem Cell Influencers,” educated attendees about the process of developing and bringing new drugs to market. This information is critical for healthcare staffers to understand as more drugs are being approved, playing a vital role in healthcare and rare diseases.

Regional Symposia

In this fiscal year, the UMDF piloted a new program featuring a scaled down symposium meeting set in regions across the nation. Our first UMDF Regional Symposium was held in Indianapolis, Indiana. UMDF offered clinicians, scientists, allied health and patients and families, an abbreviated symposium format. Medical and scientific meetings were held on one day and patient and family meetings the following day. Several hundred attended this meeting. They found this format and the information presented exceptional. For many, this was their first exposure to a UMDF Symposium. For others unable to travel to the UMDF National Symposium, this was a convenient way to be updated on the latest information.
Symposium

Raise your hand if this is your first UMDF Symposium,” UMDF CEO/Executive Director Charles A. Mohan asked patients and families gathered for the opening meeting of Mitochondrial Medicine 2014: Pittsburgh. As attendees across the crowded ballroom started to put their hands into the air, it was apparent that the majority of those present were attending this annual meeting for the first time. They came from as nearby as the Pittsburgh suburbs to as far away as western Canada. All of them were eager to learn more about their disease, network with each other, and meet with the physicians who were there to help.

“This symposium is unique because you have the opportunity to become empowered by sharing your experiences and having the opportunity to meet some of the top clinical mitochondrial specialists from around the world,” Mohan told those gathered. For those who are new to the meeting, the UMDF offers patients and families sessions dealing with mitochondrial disease. Patients were also presented important information about the new mitochondrial disease patient registry, an update on clinical trials, and information on transitioning from child to adult care.

Each year, the UMDF presents the Vanguard Award to an individual recognized as being in the forefront of medical or scientific contributions in the field of mitochondrial medicine or research for many years.

The 2014 recipient of the UMDF Vanguard Award was Charles Hoppel, MD. Dr. Hoppel demonstrates a lifetime commitment of progress towards a cure, whether through research or medical treatment. He diligently served the UMDF on both the Board of Trustees and the Scientific and Medical Advisory Board. He also provided inspiration to others in an effort to bring new scientific or medical experts into the field of mitochondrial medicine and research.

Dr. Hoppel is Chief of the Division of Clinical Pharmacology at Case Western Reserve University and Associate Director of Research at the Louis Stokes Veteran Affairs Medical Center in Cleveland. His lab does extensive research in mitochondrial disease. Dr. Hoppel has a grandson affected by mitochondrial disease.
2014 Grant Award Winners

In 2014, the UMDF funded nearly a half million dollars in research projects. Six projects presented to the Grants Review Board were funded. Two of the projects focus on potential therapies, three focus on treatments and one examines causes of mitochondrial disease. The UMDF remains the largest non-governmental funder of research into mitochondrial disease and dysfunction. Since 1996, UMDF has funded nearly $13 Million in research focused on potential treatments and cures for mitochondrial disease.

Hubert Smeets, PhD
Department of Genetics and Cell Biology
Maastricht University, The Netherlands
Chairman's Award - $25,000

“Development of an autologous myogenic stem cell therapy for carriers of a heteroplasmic mtDNA mutation, a proof of principle study.”
Dr. Smeets has developed a process using transplantation of a patient's own muscle stem cells that have been freed of mitochondrial DNA mutations. The resulting formation of normal muscle fibers promises to set the stage for significant new therapies for mitochondrial disease.

Francisca Diaz, PhD
Department of Neurology
University of Miami Miller School of Medicine
$80,000

“Modulation of GSK3 activity to maintain neuronal survival in complex IV deficient mouse.”
Dr. Diaz is using a much studied mouse model in which a mitochondrial respiratory enzyme has been deactivated in nerve cells. She will study the effectiveness of modulating glucose metabolism as a treatment for these mice, with the potential for extending this therapy to human mitochondrial disease patients.

Carlos Moraes, PhD
Department of Neurology
University of Miami Miller School of Medicine
$120,000

“Developing specific mitochondrial nucleases to eliminate mutant mtDNA.”
Dr. Moraes has developed a process for removing disease-causing mitochondrial DNA mutations from affected mitochondria. Extension of this research seems likely to lead to the development of gene therapies for human mitochondrial disease.

Scot Leary, PhD
Department of Biochemistry
University of Saskatchewan
$120,000

“Targeted delivery of copper to mitochondria: investigating its therapeutic potential for the effective treatment of patients with mutations in SCO1 and SCO2.”
Dr. Leary is investigating therapies for copper delivery to mitochondria in patients with impaired ability to synthesize a vital mitochondrial respiratory enzyme that requires copper as a building block. This research could lead to the development of early intervention therapies for mitochondrial disease.

Michael James Bell, MD
University of Pittsburgh,
Pittsburgh, PA
$25,000

“Improving CNS delivery of brain antioxidants after acute metabolic decompensation in mitochondrial disease.”
Dr. Bell will investigate a combination of two FDA-approved drugs for their effectiveness in treating children and young adults with Leigh's Syndrome. This work has the potential to improve brain function in patients with a mitochondrial disease for which there are currently no proven treatments.

Erin Seifert, PhD
Department of Pathology
Thomas Jefferson University
$120,000

“Pathogenesis of myopathies caused by mitochondrial phosphate carrier mutations.”
Dr. Seifert is studying mutations that severely affect the delivery of phosphate for ATP synthesis in the mitochondria of skeletal muscle and the heart. This foundational research will provide new insights into important mechanisms responsible for mitochondrial disease.
Science
UMDF Launches Patient Registry

The creation and launch of the Mitochondrial Disease Community Registry (MDCR) marks a significant milestone for those affected by mitochondrial disease. For the first time in the brief known history of mitochondrial disease, our community will be collecting and sharing data in a manner that will positively impact the development of treatments and cures. The registry is meant to be a community asset that all parties interested in improving the lives of patients affected by mitochondrial disease can rally around. The UMDF is committed to long-term financial sponsorship, serving as the guardian of the data, and to overall coordination of the project. We selected the Genetic Alliance as a partner for this initiative because of their patient-focused philosophy. We share a vision with the Genetic Alliance that registry data belongs to no one other than the person who provided that data, and that a disease advocacy organization such as the UMDF is the ideal steward of such data. Whereas large academic, health and drug development organizations certainly possess at least partially altruistic motivations in addressing mitochondrial disease, a disease advocacy organization is singularly interested in facilitating the most rapid possible development of effective treatments and cures for those affected by mitochondrial disease.

The MDCR collects patient-centric health data that will be utilized to develop treatments, identify new symptoms (leading to better diagnoses) and provide information to researchers that seek to study mitochondrial disease. The MDCR will also identify new patients in need of support from our community. Our goal is to identify and characterize every person affected by mitochondrial disease, no matter where they are located, living or deceased. Caregivers and family members of those affected, whether themselves affected or not, are also encouraged to register and contribute to the community.

This is our disease, your information, our best hope for treatments and cures.

Corynna Strawser didn’t let Mitochondrial Disease define her. She chose to live her life to the fullest, deciding to spread awareness and educate others about mitochondrial disease.

Corynna and her parents, Kristi and Sean, created a Facebook page in August 2013 to update her followers about her journey until Corynna’s passing in December of 2013. Courage from Corynna now has over 7,000 followers. $5,400 was raised solely from selling T-shirts.

The fundraiser inspired Greenville, OH, and Evansville, IN, community members to organize the declaration of “Mitochondrial Disease Awareness Day,” on November 25th.

The Strawser family also established a research fund through the UMDF. Kristi explained that starting a research fund allowed Corynna to see the impact she made and to see how her legacy would live on. Her research fund currently has over $20,000 in donations. To check out her research fund, please visit www.umdf.org/corynnastrawser.
Medical Child Abuse Dominates the News

It can be a parent’s worst nightmare. An accusation can be made in a number of ways that parents and caregivers are not acting in the best medical interest of your child. The formal name is Medical Child Abuse. When the case of Justina Pelletier played out through various media outlets, UMDF had quietly and proactively helped many parents diffuse these situations before they became public. We worked with hospitals, educators, and lawyers in providing important information about the unique and often misunderstood and complex medical needs required for the patient’s care. We immediately briefed our families and provided information through our website and webinars. Many affected individuals wonder why mitochondrial disease and other patients with complex metabolic issues seem to be at a higher risk for being suspected of medical child abuse.

Treatments

The Food and Drug Administration is being asked to allow clinical trials for a new technique that replaces the mitochondria of a mother with the mitochondria of a donor. Researchers are hoping that this ‘mitochondrial replacement therapy’ (MRT) will prevent a variety of diseases caused by mutations in the mitochondrial DNA. Far from creating a “designer baby,” these are breakthroughs that can majorly and joyfully change the quality of life and longevity for a child or adult, much like stem cell and bone marrow transplants have done for those suffering with blood cancers. MRT technology will be beneficial to those who might carry disease, but even more exciting, understanding mitochondrial dysfunction and diseases has the potential to transform medicine and have a much broader impact on human health.

In this fiscal year, the UMDF developed a position on the issue of MRT. The United Mitochondrial Disease Foundation (UMDF) maintains that every individual has the right to safe and effective health care as well as access to all current therapeutic innovations for the alleviation and prevention of mitochondrial diseases. We strongly support further scientific investigation of oocyte MRT as well as constructive debate towards the clinical approval of this therapy in women with mtDNA-related diseases. If demonstrated to be safe and efficacious, this technique should be made available as an option to families who carry mtDNA defects.
Family Research Funds

UMDF Family Research Funds are established by families as a way to honor or memorialize a loved one affected by mitochondrial disease. Donations to one of the funds listed below ensures that the world’s top mitochondrial scientists are receiving the support they need to perform breakthrough research. Research Funds from July 1, 2013 to June 30, 2014:

- The Anthony Demarko Maccarelli Research Fund
- The Ainsley Paige Higgins Research Fund
- The Andrew Radney Research Fund
- The Angelray Research Fund
- The Ayden & Faith Hingsbergen Research Fund
- The Bishop/Lauer Family Research Fund
- The Brady Sterchi Family Research Fund
- The Brandon David Harris Research Fund
- The Brandon Heschel Leach Research Fund
- The Breylon Senn Research Fund
- The Brittany Wilkinson Research Fund
- The Caleb Jacobs Research Fund
- The Carter Buffum Research Fund
- The Carter Lackey Research Fund
- The Champions for Chad Research Fund
- The Christopher Schindler Research Fund
- The Connor McArthur Research Fund: Kids Like Connor
- The Cooper & Isla Watson Research Fund
- The Corynna Strawser Research Fund
- The Dawnta & Levi Kendall Family Research Fund
- The Elena’s Hope Research Fund
- The Elizabeth Piro Research Fund
- The Emily Steadman Research Fund
- The Emma Frances Dalton Research Fund
- The Hunt Michael Hollis Research Fund
- The Isabella Magee Research Fund
- The Isabella Lin Ramirez Research Fund
- The Isabelle Sherman Research Fund
- The Jack Edwards Research Fund
- The Jackson Rothschild Research Fund
- The Jaethan Myers Research Fund
- The Jaxon Sharma Research Fund
- The John Geraci Research Fund
- The Jonath Ritterbush Research Fund
- The Jude Manley Research Fund
- The Kaden Jarret Huddleston Fund
- The Kaidon Andrew Stamper Research Fund
- The Katherine Dickens Research Fund
- The Kristen Charleston Research Fund
- The Lauren Benney Research Fund
- The Leslie Whitt-Williams Research Fund
- The Lex Santo Research Fund
- Lincoln’s Hope Research Fund
- The Lindsey Norris Research Fund
- The Logan Sloane Aronson Research Fund in Honor of Sydney Breslow
- The Michael Angelo LoPresti Research Fund
- The Nicholas James Torpey Research Fund
- The Unstoppable Nina Hall Research Fund
- The Oliver Scheier Research Fund
- The Olivia Paige Goldberg Research Fund
- The Rachael Albertson Research Fund
- The Samuel Cutliff Research Fund
- The Spry Research Fund
- The T.J. Amber Research Fund
- The Taryn Fogel Research Fund
- The Will Martin Family Research Fund
- The Will Woleben Family Research Fund

United Mitochondrial Disease Foundation
Energy for Life Walkathons

In 2013-2014, UMDF hosted our Energy for Life Walkathon (EFL) in 22 cities across the United States, organized by Regional Coordinators and volunteer walk committees. The 7,612 participants formed 461 teams who were active in fundraising a total of $951,094.

The Energy for Life Walkathons rely on teams to fundraise through various means including; email campaigns, social media, Coins for a Cure, Lightbulb Point of Sale campaigns, wrap-around events, letter-writing campaigns and good old grassroots fundraising!

Our 2013-2014 Energy for Life Walkathon Locations included: Minnesota, Chicago, Columbus GA, Delaware Valley, Kansas City, Detroit, Western New York, Charlotte, Central Texas, Milwaukee, Akron, Houston, St. Louis, Nashville, San Francisco, Pittsburgh, Atlanta, Evansville, Binghamton, Dallas, Tampa & Iowa. To see if we have a walk in your city, visit www.energyforlifewalk.org!

Activate Your Mitochondria

In January of 2014, Activate Your Mitochondria made its debut as UMDF’s newest fundraising initiative. Activate Your Mitochondria is designed to provide a fundraising platform for those who want to participate in a marathon, triathlon, bikeathon or even a bowling tournament while raising funds for UMDF’s mission.

In the first six months, runners, swimmers, bikers and walkers who chose to ‘Activate’ their mitochondria and utilized the fundraising website were able to raise over $45,000.

If you have a passion for an active lifestyle or want to start, join us to Activate Your Mitochondria at www.umdf.org/activate.
INDEPENDENT AUDITOR’S REPORT

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

We have audited the accompanying financial statements of the United Mitochondrial Disease Foundation, Inc. (the “Foundation”) (a nonprofit organization), which comprise the statements of financial position as of June 30, 2014 and 2013, and the related statements of activities, functional expenses and cash flows for the years then ended, and the related notes to the financial statements.

Management’s Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditor’s Responsibility

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 from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor’s judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity’s preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity’s internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

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, 2014 and 2013, 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
McMurray, Pennsylvania
February 6, 2015
UNITED MITOCHONDRIAL DISEASE FOUNDATION, INC.

STATEMENTS OF FINANCIAL POSITION
JUNE 30, 2014 AND 2013

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<td><strong>Total net assets</strong></td>
<td>1,437,273</td>
<td>1,037,113</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TOTAL LIABILITIES AND NET ASSETS</strong></td>
<td>$2,951,845</td>
<td>$2,576,141</td>
</tr>
</tbody>
</table>

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

United Mitochondrial Disease Foundation

Form 990 (2013)

Part V

Statements Regarding Other IRS Filings and Tax Compliance

Check if Schedule O contains a response or note to any line in this Part V

1a Enter the number reported in Box 3 of Form 1099. Enter 0 if not applicable

1b Enter the number of Forms W-2G included in line 1a. Enter 0 if not applicable

1c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?

2a Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return

2b If at least one is reported on line 2a, did the organization file all required federal employment tax returns?

Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)

3a Did the organization have unrelated business gross income of $1,000 or more during the year?

3b If "Yes," has it filed a Form 990-T for this year? If "No," to line 3b, provide an explanation in Schedule O

3c At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?

3d If "Yes," enter the name of the foreign country


4a Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?

4b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?

4c If "Yes," to line 4a or 4b, did the organization file Form 8886-T?

4d Does the organization have annual gross receipts that are normally greater than $100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?

4e If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?

5a Organizations that may receive deductible contributions under section 170(c).

5b Did the organization receive a payment in excess of $75 made partly as a contribution and partly for goods and services provided to the payor?

5c Did the organization notify the donor of the value of the goods or services provided?

5d If "Yes," indicate the number of Forms 8282 filed during the year

5e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?

5f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?

5g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?

5h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?

6a Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?

7 Section 501(c)(7) organizations. Enter:

7a Did the organization receive a payment in excess of $25 made partly as a contribution and partly for goods and services provided to the payor?

7b Did the organization notify the donor of the value of the goods or services provided?

7c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?

7d If "Yes," indicate the number of Forms 8282 filed during the year

8 Sponsoring organizations maintaining donor advised funds.

9a Did the organization make a distribution to a donor, donor advisor, or related person?

9b Did the organization make a distribution to a donor, donor advisor, or related person?

10 Section 501(c)(12) organizations. Enter:

10a Initiation fees and capital contributions included on Part V, line 12

10b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities

11 Section 501(c)(12) organizations. Enter:

11a Gross income from members or shareholders

11b Gross income from other sources. Do not net amounts due or paid to other sources against amounts due or received from them.

12a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?

12b If "Yes," enter the amount of tax-exempt interest received or accrued during the year

13a Is the organization licensed to issue qualified health plans in more than one state?

13b Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans

13c Enter the amount of reserves on hand

14a Did the organization receive any payments for indoor tanning services during the tax year?

14b If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O

Form 990 (2013)
## UNITED MITOCHONDRIAL DISEASE FOUNDATION, INC.  
### STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS  
FOR THE YEARS ENDED JUNE 30, 2014 AND 2013  

### Financials

#### PUBLIC SUPPORT AND REVENUE

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Total</th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Support:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fundraising</td>
<td>$1,303,047</td>
<td>$113,940</td>
<td>$1,416,987</td>
<td>$1,396,670</td>
<td>$3,384</td>
<td>$1,460,054</td>
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<tr>
<td>Contributions</td>
<td>791,694</td>
<td>1,150</td>
<td>792,844</td>
<td>826,897</td>
<td>3,465</td>
<td>830,362</td>
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<tr>
<td>In honor of</td>
<td>131,227</td>
<td>0</td>
<td>131,227</td>
<td>113,312</td>
<td>0</td>
<td>113,312</td>
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<tr>
<td>In memory of</td>
<td>75,781</td>
<td>0</td>
<td>75,781</td>
<td>70,240</td>
<td>0</td>
<td>70,240</td>
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<tr>
<td>In kind</td>
<td>8,540</td>
<td>0</td>
<td>8,540</td>
<td>63,247</td>
<td>0</td>
<td>63,247</td>
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<tr>
<td>Grants</td>
<td>223,570</td>
<td>138,503</td>
<td>362,073</td>
<td>117,135</td>
<td>114,588</td>
<td>231,723</td>
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<tr>
<td>Cancellation of grants payable</td>
<td>338</td>
<td>0</td>
<td>338</td>
<td>23,893</td>
<td>0</td>
<td>23,893</td>
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<tr>
<td><strong>Total Support</strong></td>
<td>2,534,197</td>
<td>253,993</td>
<td>2,787,790</td>
<td>2,611,394</td>
<td>181,437</td>
<td>2,792,831</td>
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<tr>
<td><strong>Revenue:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symposium and seminars</td>
<td>284,706</td>
<td>0</td>
<td>284,706</td>
<td>274,764</td>
<td>2,000</td>
<td>276,764</td>
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<tr>
<td>Sales</td>
<td>12,727</td>
<td>0</td>
<td>12,727</td>
<td>7,055</td>
<td>0</td>
<td>7,055</td>
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<tr>
<td>Miscellaneous</td>
<td>983</td>
<td>0</td>
<td>983</td>
<td>1,157</td>
<td>0</td>
<td>1,157</td>
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<tr>
<td><strong>Total Revenue</strong></td>
<td>298,416</td>
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<td>298,416</td>
<td>282,976</td>
<td>2,000</td>
<td>284,976</td>
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<tr>
<td>Investment income</td>
<td>58,689</td>
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<td>58,689</td>
<td>52,745</td>
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<td>52,745</td>
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<tr>
<td>Net unrealized gain on investments</td>
<td>123,039</td>
<td>0</td>
<td>123,039</td>
<td>135,637</td>
<td>0</td>
<td>135,637</td>
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<tr>
<td>Net realized gain on investments</td>
<td>98,010</td>
<td>0</td>
<td>98,010</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Gain on disposal of fixed assets</td>
<td>568</td>
<td>0</td>
<td>568</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Net assets released from program restrictions</td>
<td>296,983</td>
<td>(296,983)</td>
<td>0</td>
<td>202,700</td>
<td>(202,700)</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total Support and Revenue</strong></td>
<td>3,409,902</td>
<td>(43,390)</td>
<td>3,366,512</td>
<td>3,285,452</td>
<td>(19,263)</td>
<td>3,266,189</td>
</tr>
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</table>

#### FUNCTIONAL EXPENSES

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Total</th>
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<th>Total</th>
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<tr>
<td><strong>Program services:</strong></td>
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<tr>
<td>Research</td>
<td>927,552</td>
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<td>927,552</td>
<td>987,583</td>
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<td>987,583</td>
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<tr>
<td>Public awareness</td>
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<td>293,552</td>
<td>357,829</td>
<td>0</td>
<td>357,829</td>
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<tr>
<td>Education/member support</td>
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<td>1,004,196</td>
<td>998,610</td>
<td>0</td>
<td>998,610</td>
</tr>
<tr>
<td><strong>Total program services</strong></td>
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<td>0</td>
<td>2,225,300</td>
<td>2,344,022</td>
<td>0</td>
<td>2,344,022</td>
</tr>
<tr>
<td><strong>Supporting services:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Administrative and general</td>
<td>146,464</td>
<td>0</td>
<td>146,464</td>
<td>134,178</td>
<td>0</td>
<td>134,178</td>
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<tr>
<td>Fundraising</td>
<td>594,588</td>
<td>0</td>
<td>594,588</td>
<td>666,294</td>
<td>0</td>
<td>666,294</td>
</tr>
<tr>
<td><strong>Total supporting services</strong></td>
<td>741,052</td>
<td>0</td>
<td>741,052</td>
<td>800,472</td>
<td>0</td>
<td>800,472</td>
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<tr>
<td><strong>Total expenses</strong></td>
<td>2,966,352</td>
<td>0</td>
<td>2,966,352</td>
<td>3,144,494</td>
<td>0</td>
<td>3,144,494</td>
</tr>
</tbody>
</table>

#### CHANGES IN NET ASSETS

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Total</th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Net Assets - Beginning of year</strong></td>
<td>644,700</td>
<td>392,413</td>
<td>1,037,113</td>
<td>503,742</td>
<td>411,676</td>
<td>915,418</td>
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<tr>
<td><strong>Net Assets - End of year</strong></td>
<td>$1,088,250</td>
<td>$349,023</td>
<td>$1,437,273</td>
<td>$644,700</td>
<td>$392,413</td>
<td>$1,037,113</td>
</tr>
</tbody>
</table>

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

July 1, 2013 through June 30, 2014

Life Investors - $50,000 and up

Edith L Trees Charitable Trust
The J. Willard & Alice S. Marriott Foundation
Patrick J. Kelley

Transgenomic, Inc
W. Dan and Pat Wright
William Wright Family Foundation

Energy Investors - $10,000 - $49,999

Courtagen Life Sciences, Inc.
Cresa Cares, Inc.
The DiCecco Family Charitable Foundation
Grantham, Mayo, Van Otterloo
Tom and Elizabeth Hefferon
William S. Kallaos Family Foundation
Peter Kelley
Sebastiano J. Lopresti
Mary Auth Manning

Niehs
Raptor Pharmaceuticals
Sage Foundation
Spike TV - Viacom International
Stealth BioTherapeutics
The Spartanburg County Foundation
The TJX Foundation Inc.
Tishcon
William E. Wright

Hope Investors - $5,000 - $9,999

Murat Askin
Baxter International Foundation
Baylor Miraca Genetics Laboratories
Steve and Deborah Buenaga
Canadian Pacific
Cavalier Clothing
Charlotte Pipe & Foundry Company
ClubCorp Charities, Inc.
Bruce H. and Anna Cohen
Carl R. and Noreen Daniels
Edison Pharmaceuticals Inc.
Emerson Process Management
Peter and Connie Geisler
Hinrichs Financial Corporate Benefits LLC
Johnson & Johnson Family of Companies

Josie Mazzo Children’s Charites
Laurie S. Kaguni
Gordon and Shirley Kidd
John and Andrea L. Kieffer
David H. and Theresa Langer
Lumber Liquidators, Inc.
March of Dimes
Donna M. Mohan
Rachael's Gift Inc.
Robert Snell
Solace Nutrition
Staples Oil, Inc.
VOYA Foundation
L. Shaun and Joanna P. Williams
Donors

July 1, 2013 through June 30, 2014

Friends - $1,000 - $4,999

A Tow Atlanta, Inc.  Wendy L. Campbell  Tom C. and Melinda Edwards
Abcam Inc. - Eugene  Carmax Foundation  Electrical Associates
Akron Children’s Hospital  Cayman Chemical Company  Tom and Maria Ellis
Allegis Group Foundation  R. S. and Melissa Cederburg  Enterprise Holdings Foundation
America’s Compounding Center  Marcy Chapman  Joseph and Elizabeth Ernst
Amvets Riders Chapter 88  David Charney  John and Diane Evans
Anthony Baldi & Associates  Shirley Chen  Extended Ag Services Inc.
John B. and Hannah Appel  Ronald and Janet Christenson  Scott and Marni J. Falk
Applied Materials  Christus St. Catherine Colleagues  FiftyTwo4Mom
Assurant Foundation  Mike and Lynn Clark  Flat Earth Wrestling Club
Stephen and Rosalind Atkins  James L. S. Collins  Diane M. Fluty
Aurora City Schools  Colorado Center for Reproductive Medicine  Freno Family
Joseph A. Auth  Columbus Bank and Trust  Michael S. and Rhonda Friedberg
B & V’s Snack Bar LLC  Columbus Regional Healthcare System, Inc.  Donald and Nancy Garrison
Babiarz Law Firm P.A.  Concord Properties  GeneDx
Tommy and Cheryl Baker  Bob and Linda Cooper  John and Claire Gilbert
Paula M. Barnard  Kathryn Crawford  Mary E. Gilmer
Baxter Pharmaceutical Solutions LLC  Crooksville Village School District  Give With Liberty
Michael and Susan Beaudoin  Cross Goldsmith Memorial Fund  Ralph O. Glendinning
Jay and Risa Bender  Crowe Horwath LLP  Gloria & Frank Pipp Family Foundation
Best Deal Auto Sales, Inc.  Carole Davis  Erich Gnaiger
Richard Biscardi  Deaconess Hospital Inc.  Lance Goff
Jeff Black  Delta Gamma Foundation  Goodrich Petroleum
Blackwell Realty  Alice Deng  Patricia Gordon and Alan Koreneff
Oscar and Debra Schindler Boultinghouse  Francisca Diaz  David and Phyllis Gray
Thomas and Julie Brackmann  John A. and Julie DiCecco  Michael Greash
Bradley Arant Boulten Cummings  Domtar Paper Company  Greater Kansas City Community Foundation
Robert Bromm  Kathleen L. Doreau  Green Oaks Hospital
Alex and Benita Burcham  Dr. Pepper Snapple Group  Laura Griffin
Burmans Pharmacy  Evelyn Downey  Christine Grizzard
Kurt Byth  Christine Drusch  Tiffany Grove
C & V Schrey Trust  Chris Edwards

United Mitochondrial Disease Foundation
Donors

July 1, 2013 through June 30, 2014

Guardian
HF Financial
Anne M. Hall
Brock and Becky Hamre
Barre K. Hansen and Family
Ann Hardison
Edward and Ellen Hardison
Hooper Hardison
Sara Hayes
Michael and Leslie Heilman
Todd K. and Linda Hickerson
Jim and Marilyn Hill
Ivan Hinrichs
Tom and Ruth Hodge
Siegfried and Hannelore Hoppe
Houghton Mifflin Harcourt
Larry J. Howe
Khurram and Sameera Hussain
Liang - Bin Hsueh
Hyperion Therapeutics
IBM Corporation
Illinois Tool Works Foundation (ITW)
JH Audio
Michael Judd
KC Royals Alumni Foundation
KC Running Company
Bill and Bonnie Kallaos
William and Connie Kallaos
Ernst-Bernhard Kayser
Joanne Kelley
Otto and Anna Kemp
Keykert USA, Inc.
David & Paula Kirsch Family Fund
Tim and Laura Knapp
Kobelco Stewart Bolling, Inc.
Kohl’s Cares Program
Bob and Lynda Kukla
Christopher and Kathleen LaCroix
John M. Land
James F. and Cheryl Landes
Brandi M. Lawrey
Michelle Leach
Pat and Michele Levy
Mark Lilliedahl
Al Lindseth
Lockridge Grindal Nauen P.L.L.P.
Melissa Looney
Rachyl Madigan
Bryan P. and Julie Manley
Maple and Motor
Martin Marietta Materials
Shari H. Mason
Massive Black Inc.
MassMutual
Scott McCleary
McCown Gordon Construction
Chris and Karen McKulka
Melissa L. McRaven
Mechanical, Inc.
Megan Meese
Memorial Hermann Health System
Mercer University College of Pharmacy
Meta Bank
Methodist Health Foundation/Indiana Un
Health Meth. Hospital
Meyer Companies, Inc.
MFS Investment Management
Minnechaug Regional High School
Mitobridge
MitoMedical
Gary and Karen Moberly
Mohan's Restaurant
Charles A. and Adrienne Mohan
Mike Monroe
James W. Monteverde
Pamela K. Moore
Ben and Katie Morrow
Alan W. Mortensen
Motive Medical Intelligence
Jim and Patricia A. Mowrer
Francis and Barbara Mroz
Steve Mueller
Prabir Mukherjee
Carrie Mullin
Debora Naegeli
Jill C. Nasso
Emily Neenan
M. Elaine Neenan
David Neill
Neotech Products Inc.
Jennifer T. Norman
Billy and Brenda L. Norris
Raymond O’Hara
Oroboros Instruments
Rhonda Orpin
Cindy Owens
Tim and Arnita Ozgener
William T. Oxenham Foundation, Inc.
Martin Packouz
Donors

July 1, 2013 through June 30, 2014

Palm Valley Lutheran Church
Neal and LuAnn Palmer
Benny and Valorie Perez
Michael and Kimberly Perez
Deane and Glenda Peters
Denise L. Peterson
Pine Pharmacy
Michelle Snyderman Platt
David K. and Cheryl Porter
PP Systems Inc
Precision Heating Cooling & Refrigeration
PreGel America
Pricewaterhouse Coopers
PSA Healthcare
Puget Sound Kidney Centers
Stanley Quanbeck
Becky R. Raiber
Jose Ramirez
Andrew and Kristin Reardon
Tyler E. and Terisa Reimschisel
Restat
Reytec Construction Resources, Inc.
Joseph and Pat Rice
Riggins Marketing Inc.
Mark and Dana Ritterbush
Rodgers Builders, Inc.
William C. Roney III
Roofing Consultants Ltd
Rotary Club of Monroeville
Rothstein Kass Foundation, Inc.
Kyle Rowse
S&T Bank Charitable Foundation
Santhera Pharmaceuticals
Brett G. Scanlan
Scharff Charitable Foundation
Mark E. Schneider
Brett and Jeannine Schoenecker
Bradley Schumacher
Schuster Enterprises, Inc.
H. Scott and Kimberly Connell
Senis of Middletown Inc.
John and Christy Shea
Pat and Jane Shelley
Cynthia Sickler
Siemens Caring Hands Foundation
Michael and Dawn Simmons
Catherine Sims
Jack Sommers
Southern Ohio Bikers, Inc.
R. D. and Pam Sprinkle
St. Mary’s Health System
Annette M. St. Pierre-Mackoul
Patty Stageman
Peter and Cindy Statthakis
Bill and Beth Steadman
David L. and Nancy Stelmaszek
Michael and Kristin Stelmaszek
Gregory Stromberg
Stromquist & Co. Inc.
Sure Logistics
Swift Energy Operating, LLC
Symantec Corporation
Synovus
Tavares Elementary School
Steven and Jami Teske
The Allstate Foundation
The Hunt Michael Hollis Fund
The Monteverde Group, LLC
The Peachtree Club
The Pittsburgh Foundation
The Precision Divisions, Inc.
The Seaway Project
The Slow Bone BBQ
The Zachary L. Friedberg Foundation
Bruce Tomlin
Total System Services, Inc.
Mary Beth Trapp
William B. Turner
John and Amy Underwood
Bob Van Valkenburg
Thomas E. and Mary J. Vasilich
ViaSource
Michael and Diane Vincent
Paul Vincent
James J. Volker
Walmart
Charles and Cynthia Walsh
Li Kan Wang and Ivy Li
Henry Waters
Shawn and Renee Welch
Mary Ann West
Phil and Susan Whatley
Whiting Oil & Gas Corp.
Bryan Williams
Lisa A. Wilson
Stephen Wilson
John C. Zetterower
Zippo Manufacturing Co.
Administration

New Board Members

The UMDF welcomed new trustees to the Board of Directors.

**Brent Fields**, from Central Texas, is serving his first term. Brent is CEO of Big Brothers Big Sisters, a nonprofit mentoring organization that serves over 1,000 youth. Prior to his current role, he was an Administrator in the healthcare arena and then a Vice President with the American Heart Association. He has over 25 years of executive leadership experience in various industries ranging from education and counseling to healthcare and nonprofit services. His educational background includes a Bachelors Degree in Communications, a Masters Degree in Education, a Clinical Residency, and a Certification in Health Promotion Management. He and his wife, Suzette, have actively supported local UMDF efforts in the greater Austin area the past couple of years, including their involvement in the local Energy For Life Walk. They have three children, and their youngest, Chloe, has a mitochondrial disease.

**John Kieffer** was nominated and appointed to the board. John is a sales and business executive with the 3M Company and has held numerous leadership roles in the US, Asia, and Europe throughout his 30-year career at 3M. Recently, John has been leading 3M’s customer-facing “Business Transformation” program, which is a global project to move all of 3M’s customers and employees to a unified set of customer engagement and order management business processes/systems. John and his wife Andrea have two grown children, Matt and Melissa, both in their 20’s. Melissa has been recently diagnosed with a mitochondrial disease (MELAS). John, Andrea, and Melissa have been active in the Minnesota Chapter of the UMDF. They recently relocated from St. Paul, Minnesota to Austin, Texas.

**Patrick Kelley**, who has been a UMDF Board Member since 2011, began his service as Chairman of the Board in May, 2014. He is the founder and President of Kelley Management Consulting (KMC), Inc., a general management consulting firm headquartered in Evanston, IL. KMC partners with business leaders to develop and implement strategies to grow the long-term strategic and economic value of their business. Prior to forming KMC in 2001, Patrick spent over 15 years in management and technology consulting working across a wide variety of industries and with businesses of all sizes.

A notable focus area for Patrick in recent years has been in spearheading KMC’s efforts to develop strategies that combine and leverage both quantitative and qualitative customer information to drive improved decision-making, improve the customer experience, and increase process efficiency of clients, their customers and suppliers.

Prior to his consulting career, Patrick worked in the financial services industry in New York City and holds a B.A. in Economics from the University of Michigan and an M.B.A. in Operations Planning and Marketing from the University of Chicago, Graduate School of Business.

Patrick lives in the Chicago area. He is the father of 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. Patrick has a son, Patrick, who was born in 1998 and has a mitochondrial disease.
Administration

Scientific & Medical Advisory Board

Marni Falk, MD - Chair  
The Children's Hospital of Philadelphia  
Philadelphia, PA

Laurence Bindoff, MD  
Haukeland University Hospital  
Bergen, Norway

William C. Copeland, PhD  
National Institute of Environmental Health Sciences  
Research Triangle Park, NC

Andrea L. Gropman, MD, FAAP, FACMG  
Children's National Medical Center  
Washington, D.C.

Richard H. Haas, MB, BChir  
UCSD Medical Center  
San Diego, CA

Marcia Haigis, PhD  
Harvard Medical School  
Boston, MA

Michio Hirano, MD  
Columbia University Medical Center  
New York, NY

Carla Koehler, PhD  
University of California, Los Angeles  
Los Angeles, CA

Mark Korson, MD  
Tufts Medical Center  
Boston, MA

Giovanni Manfredi, MD, PhD  
Weill Medical College of Cornell University  
New York, NY

Edward E. McKee, PhD  
Indiana University School of Medicine  
South Bend, IN

Sumit Parikh, MD  
Cleveland Clinic  
Cleveland, OH

Russell P. Saneto, DO, PhD  
Seattle Children’s Hospital  
Seattle, WA

Fernando Scaglia, MD  
Baylor College of Medicine  
Houston, TX

Mark Tarnopolsky, MD, PhD, FRCP (C)  
McMaster University  
Hamilton, Ontario

Gerard Vockley, MD, PhD  
University of Pittsburgh Medical Center  
Pittsburgh, PA

Staff Additions

Science and Alliance Officer

The United Mitochondrial Disease Foundation has announced that Phil Yeske has been hired as the organization’s Science and Alliance Officer. Dr. Yeske’s new role in the foundation is to convey the importance of science and business relationships in the development and treatment of mitochondrial diseases.

“It is now widely accepted that patient groups like the UMDF are ideally positioned to facilitate this complex process,” Yeske said. “UMDF is already actively engaged in many of the most important components. A few of these components include funding basic and clinical research, creating patient registries as well as a clinical research network, and working to ensure a consistent, global collection of patient data,” he added.

He pointed out that there is already a powerful mix of science, advocacy, and business brewing that he believes will lead to exciting new treatments and cures in the coming years for those affected by mitochondrial disease.

Regional Coordinator

As part of our strategic initiatives, UMDF added a new Regional Coordinator. Representing the Northeast Region is Nicole Shanter.

Nicole has been a longtime UMDF employee working in fundraising and member services. Nicole will oversee activities in the states of New York, Pennsylvania, New Jersey, Delaware, Maryland, West Virginia, and Virginia.

- Charles A. Mohan Jr.  
  CEO/Executive Director
- Mark Campbell  
  Chief Financial Officer
- Phil Yeske, PhD  
  Science and Alliance Officer
- Kara Strittmatter  
  Director of Member Services
- Clifford Gorski  
  Director of Communications
- Tania Hanscom  
  Special Events Coordinator
- Leslie Heilman, JD  
  Associate Director of Development
- Donna Nameth  
  Data Entry Manager
- Melinda O'Toole  
  Member Services Associate
- Liz Weiss  
  Special Events & Member Services Associate
- Nicole Shanter  
  Special Events & Development Associate
- Barbara Podowski  
  Administrative Assistant
- Janet Owens  
  Executive Administrative Assistant
- Jeff Gamza  
  Multimedia Coordinator
- Cassie Franklin  
  Gift Officer
- Anne Simonsen  
  Regional Coordinator - Great Lakes
- Margaret Moore  
  Regional Coordinator - Southeast