News

Roadmap to a Cure
In FY 2016-17, UMDF began the development of the framework to optimize clinical care. Collaborations continued with partner organizations within the community and with the Mitochondrial Medicine Society (MMS).

MDCR
The Mitochondrial Disease Community Registry is a patient populated registry. In this fiscal year, UMDF saw registration numbers increase by 40% to over 2,000 registrants. MDCR is the best chance we have to collect information that will facilitate the diagnosis and treatment of mitochondrial disease, as well as to discover ways to manage the symptoms and improve the quality of life of those individuals who are already affected by it.

UMDF Leadership Transition Announced
After serving the mitochondrial disease community for more than two decades, United Mitochondrial Disease Foundation (UMDF) Chief Executive Officer and Executive Director, Charles A. Mohan, Jr., has announced that he will transition from his role as CEO/Executive Director at the end of 2018. Mohan made the announcement to the UMDF Board of Trustees and to foundation staff.

Mohan began the UMDF in the basement of his house, and for more then 23 years, Mohan has been a volunteer, a member of the Board of Trustees, and served as CEO since 2006.

“What Chuck has accomplished at UMDF is nothing short of astounding,” said Brent Fields, Chairman of the UMDF’s Board of Trustees and CEO of Big Brothers and Big Sisters of Austin, TX. “When he was starting out in the 90’s and talking about the disease, people would ask ‘mito what’?”

Under Mohan’s leadership, Fields says UMDF is funding scientists and researchers who are creating clinical trials and potential treatments for the disease. Patient voices are being heard at the NIH and in Congress.

“This is only possible because Chuck said yes two decades ago to creating, building and nurturing the success of the UMDF,” Fields added.

Current Honorary Board Member, John DiCecco, has known Mohan and his family years before the UMDF’s founding. “I believe Chuck to be a pioneer,” DiCecco said. “Chuck’s vision to create an organization that provides help, hope, answers, and research where there was none is such a powerful legacy for the entire community.” DiCecco said.
Advocacy

Research

Through successful advocacy, UMDF added mitochondrial disease to the list of research projects funded by the Department of Defense under the Congressionally Directed Medical Research Fund for 2017. UMDF has been part of the CMDRP since 2015. We have provided both consumer and scientific reviewers for proposed research projects that have applied for funding. This effort resulted in $7 million funding mitochondrial disease specific projects in FY 2016. This is an ongoing effort to have mitochondrial disease included in this appropriation.

Congressional Caucus

Our best avenue to bring awareness to mandate diagnostic changes may come from our advocacy efforts. We are utilizing our Congressional Mitochondrial Disease Caucus briefings to raise awareness of the diagnostic odyssey and challenges patients and families face in effort to educate federal officials and to effect change. In FY 2016-17 we had 32 bi-partisan members of this caucus.

Day on the Hill

Our mitochondrial disease community participated in the fourth “Day on the Hill” on June 29, 2017. More than 200 participants travel to Capitol Hill to advocate for the issues that impact our entire community.
In 2016-2017 our dedicated volunteers and Regional Coordinators planned and hosted 24 Energy for Life Walkathons across the United States. Our Energy for Life Walkathons are in their 7th year of raising funds, spreading awareness and creating a community for those affected by mitochondrial disease.

Teams and individuals fundraised through a variety of ways, including social media, personal asks, letter and/or email campaigns or hosting wrap-around fundraising events. With their effort, we were able to raise over $1,000,000.

The following cities were host to an Energy for Life Walkathon in 2016-2017:

- Akron
- Atlanta
- Central Texas
- Charlotte
- Chicago
- Cincinnati
- Dallas-Fort Worth
- Delaware Valley
- Detroit
- Houston
- Indianapolis
- Kansas City
- Minnesota
- Nashville
- Omaha
- Pittsburgh
- San Francisco Bay Area
- Seattle
- Southern Wisconsin
- Southwest Florida
- St. Louis
- Tampa Bay
- Western New York

To see a list of Energy for Life Walkathons in your area, visit [www.energyforlifewalk.org](http://www.energyforlifewalk.org)
Fundraising Events

In addition to our Energy for Life Walkathons, volunteers around the country helped to fundraise through various special events. These volunteers worked hard to raise a grand total of over $500,000 in 2016-2017!

Some classic fundraisers, such as our Coins for a Cure, Lightbulb Campaign and Activate Your Mitochondria were a hit this year. Other events included Golf Outings, Galas, Lemonade Stands, Walk/Run events, Give Back Nights and a variety of other events!

If you are interested in helping be part of the cure by hosting a special event, contact us at events@umdf.org!

Symposium

Nearly 350 patients and families joined approximately 270 scientists and clinicians in the Washington, DC area for the UMDF’s Mitochondrial Medicine International Symposium. The symposia was held from June 28 – July 1, 2017.

Patients from as far as Hawaii to as nearby as Virginia participated in the two day patient and family meeting at the Hilton Alexandria Mark Center Hotel in Alexandria Virginia.

In addition to the patient and family platform, members of the LHON community held its annual meeting in conjunction with the symposia.

A number of topics were presented including those on exercise, nutrition, and palliative care.

Teen sessions, underwritten by the Edith L. Trees Charitable Trust, provided activities and a prom.
Science

2017 Grant Award Winners

In 2017, through the generous support of donors, the UMDF provided over a half million dollars in research grants and clinical study awards. Since 1996, UMDF has provided more than $11 million, making it the leader in non-governmental funding for research aimed at discovering a faster diagnosis and effective treatments and potential cures for mitochondrial disease.

2017 Funded Projects

Chairman’s Award
Prashant Mishra, MD, PhD
University of Texas Southwestern Medical Center
Children’s Research Institute
$100,000
“Identification of SLC Family Members as Predictive Biomarkers for Mitochondrial Disease”
The development and validation of blood based biomarkers for mitochondrial disease remains a top priority in the research community. This project investigates the potential use of specific solute carrier (SLC) family members in blood serum as novel predictive biomarkers of mitochondrial disease. Preliminary data generated in Dr. Mishra’s lab indicates that SLC family members are not only altered in the disease setting, but could also serve as therapeutic development targets.

New and Early Principal Investigator Award
Rustum Karanjia, MD, PhD
Doheny Eye Center
UCLA
University of Ottawa
$100,000
“Photopic Negative Response as an Objective Biomarker in Mitochondrial Disease”
Many forms of mitochondrial disease have eye-related symptoms, including LHON, DOA, Leigh Syndrome and MELAS. There is a significant and need for better measurements of eye function as it relates to disease progression. Dr. Karanjia intends to measure eye cell electrical activity over 18 months in affected individuals utilizing Photopic Negative Response (PhNR). This data will help to validate PhNR as a potential biomarker for optic nerve function in mitochondrial disease patients.

Postdoctoral Fellowship Award
Melissa Anne Walker, MD, PhD
Massachusetts General Hospital
$100,000
“A Single Blood Draw Test of Mitochondrial Disease”
here are currently no consensus biomedical tests for mitochondrial disease due to its complex and diverse nature, a situation which makes effective diagnosis and treatment extremely challenging. The goal of Dr. Walker, working in the lab of Dr. Vamsi Mootha, is to develop a rapid, facile blood test for mitochondrial activity based on a single blood draw. Preliminary data points to a simple, inexpensive test that could be applied in any standard clinical laboratory. The funds provided by the UMDF will allow for continued development and validation of this assay in both healthy controls as well as affected individuals with a genetically confirmed diagnosis of mitochondrial disease.
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, 2017 and 2015, 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, 2017 and 2016, 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
May 11, 2018

STELMACK DOBRANSKY & EANNACE, LLC
McMurray, Pennsylvania
May 11, 2018
### UNITED MITOCHONDRIAL DISEASE FOUNDATION, INC.

#### STATEMENTS OF FINANCIAL POSITION
**JUNE 30, 2017 AND 2016**

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2016</th>
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</thead>
<tbody>
<tr>
<td><strong>ASSETS</strong></td>
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<tr>
<td>Cash and cash equivalents</td>
<td>$1,084,565</td>
<td>$1,238,892</td>
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<td>Accounts receivable</td>
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<td>32,208</td>
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<td>Grants receivable (Note 3)</td>
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<td>Pledges receivable (Note 4)</td>
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<td>Inventories</td>
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<td>Investments (Note 5)</td>
<td>2,165,734</td>
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<td>Prepaid expenses</td>
<td>50,307</td>
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<td>Fixed assets - net (Note 6)</td>
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<td>40,454</td>
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<tr>
<td><strong>TOTAL ASSETS</strong></td>
<td>$3,610,335</td>
<td>$3,505,827</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>LIABILITIES AND NET ASSETS</strong></th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>LIABILITIES</strong></td>
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</tr>
<tr>
<td>Accounts payable</td>
<td>$395,730</td>
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<tr>
<td>Accrued liabilities</td>
<td>73,254</td>
<td>89,471</td>
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<td>Grants payable (Note 7)</td>
<td>1,412,873</td>
<td>1,543,810</td>
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<td>Deferred revenue</td>
<td>83,014</td>
<td>79,645</td>
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<td><strong>Total liabilities</strong></td>
<td>1,964,871</td>
<td>2,049,863</td>
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</tbody>
</table>

| **NET ASSETS**                |          |            |
| Unrestricted                  | 992,009  | 1,002,435  |
| Temporarily restricted (Note 9)| 653,455  | 453,529    |
| **Total net assets**          | 1,645,464| 1,455,964  |

<table>
<thead>
<tr>
<th><strong>TOTAL LIABILITIES AND NET ASSETS</strong></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$3,610,335</td>
<td>$3,505,827</td>
</tr>
</tbody>
</table>
## UNITED MITOCHONDRIAL DISEASE FOUNDATION, INC.

### STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS

FOR THE YEARS ENDED JUNE 30, 2017 AND 2016

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2016</th>
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<tbody>
<tr>
<td></td>
<td>Unrestricted</td>
<td>Temporarily</td>
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<tr>
<td><strong>PUBLIC SUPPORT AND REVENUE</strong></td>
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<td>Support:</td>
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<td>Contributions</td>
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<td>In honor of</td>
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<tr>
<td>In memory of</td>
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<tr>
<td>In kind</td>
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<td>Grants</td>
<td>241,850</td>
<td>199,814</td>
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<td>Cancellation of grants payable</td>
<td>113,785</td>
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<td>Total support</td>
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<td><strong>FUNCTIONAL EXPENSES</strong></td>
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<td>Program services:</td>
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<td>Research</td>
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<td>Public awareness</td>
<td>394,889</td>
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<td>Education/member support</td>
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<td>Total program services</td>
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<td>Supporting services:</td>
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<td>Administrative and general</td>
<td>269,713</td>
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<tr>
<td>Fundraising</td>
<td>857,841</td>
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<tr>
<td>Total supporting services</td>
<td>1,127,554</td>
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<tr>
<td>Total expenses</td>
<td>3,616,572</td>
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<tr>
<td><strong>CHANGES IN NET ASSETS</strong></td>
<td>(10,426)</td>
<td>199,926</td>
</tr>
<tr>
<td><strong>NET ASSETS</strong></td>
<td>$ 992,009</td>
<td>$ 653,455</td>
</tr>
</tbody>
</table>

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

July 1, 2016 through June 30, 2017

Power Investors - $100,000 and above
The J. Willard & Alice S. Marriott Foundation
William Wright Family Foundation

Life Investors - $50,000 and $99,999
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July 1, 2016 through June 30, 2017

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United Mitochondrial Disease Foundation
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July 1, 2016 through June 30, 2017

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Mr. and Mrs. James McMaster
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Mr. and Mrs. Anthony Nicolas
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July 1, 2016 through June 30, 2017

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Mr. Stephan Sandman
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Mr. Nick Schneider
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Mr. James Seitz
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Mr. Matthew Smith
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Mr. and Ms. Jacob Spigelman
Ms. Patty Stageman
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Mr. Peter Stathakis
Mr. and Mrs. Terry Steele
Mr. and Mrs. Stephen Sterchi
Mr. Robert K. Stevick
Sun National Bank
Mr. Martin Sutker
Mr. and Mrs. Christopher Swinn
Mr. and Mrs. Douglas Szopo
TJ Maxx - District 4101
The TJX Companies, Inc.
Mr. Neil Tarnpool
TEAM Logistics Systems Inc.
Texas Chili Company
Mr. and Mrs. Jarred Thomas
The Thomas Family
Ms. Carolyn Thompson
Dr. John Thompson
Mr. and Mrs. Mark Thornsberry
Time Disposal Trash
Mr. Robert Tranbaugh
Transwestern
Mr. and Mrs. Robert Tuccillo
Dr. Jennifer Turner
United Heritage Charity Foundation
United Incentives Incorporated
UPMC
Usher Oil Company
Dr. Samantha Vergano
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Mr. James Volker
The Vranos Family Foundation
Mrs. Janeen Waddell
Mr. and Mrs. Li Wang
Mr. Brent Warner
The Joshua & Luke Welch Charitable Fund
Mr. and Mrs. Phil Whatley
Mr. and Mrs. Robert Whitehouse
Mr. Jerry Woodruff
Ying Family Foundation
Dr. Terry Yochum
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