United Mitochondrial Disease Foundation

2015-2016 Annual Report

UNITED MITOCHONDRIAL DISEASE FOUNDATION®

Welcome

Message from the CEO

Peter Ferdinand Drucker (1909 – 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. His quote, *"Efficiency is doing things right; effectiveness is doing the right things,"* is the quintessential reason UMDF has developed a "Roadmap to a Cure."

Increased focus on our mission of *"Promoting research and education for the diagnosis, treatment and cure of mitochondrial disorders and providing support to affected individuals and families,"* forces us to become more "effective" by identifying and doing the "right things." The "right things" are the three pillars of our "Roadmap to a Cure:"

1. Diagnostic development
2. Coordinated Patient Care
3. Therapeutic Development.

We realize the challenges before us demands increased coordination; we need to identify and align available assets. We need increased communication; we must make our needs known, and it is imperative that we increase and enhance collaboration; we must unite, engage and partner with the global mitochondrial community to bring treatments and cures to our patients. We also realize that we need to marshal the resources to support these very important roadmap components.

Twenty years ago we identified the need for a unified effort resulting in the collaboration of other mito groups forming one "United" foundation. This "United" approach has helped increase interest in mitochondrial disease resulting in clinical trials that many of us thought we would not see in our lifetime. Today there are great levels of interest from academia, researchers and industry in mitochondrial function and the impact it has on many disorders. This success and increased potential demands that we continue to coordinate, communicate and collaborate.

We have created a UMDF Scientific Portfolio. This portfolio is the umbrella under which all the necessary components will reside to develop accurate and non-invasive diagnostics, standardized and coordinated patient care leading to safe and effective treatments and ultimately cures.

We are capitalizing on the opportunities that exist and the potential they present, and to that end have formed the UMDF Industry Advisory Council (IAC). The IAC is charged with supporting the mission of the UMDF and will be an action-oriented platform to facilitate cross-sector collaboration that can help prioritize and provide focus to UMDF mission-appropriate initiatives, consistent with a shared responsibility to patients with mitochondrial disease.

The IAC will provide a platform from which a diverse group of stakeholders, representing multiple disciplines and with varied expertise, can provide input for addressing key priorities within the Mitochondrial Disease Roadmap.

The IAC membership is representative of the broad stakeholder community within the Mitochondrial Disease field, including pharmaceutical & biotechnology companies, lab and diagnostics companies, nutraceutical companies, health care providers, and payers. In addition, the IAC will include membership from the UMDF Scientific and Medical Advisory Board (SMAB), and will incorporate representation from the patient and caregiver community, as appropriate. UMDF will also seek to engage key government officials (e.g. from FDA, CMS etc.) in IAC activities, as appropriate.

We realize we cannot follow this roadmap alone, we need all the mitochondrial leaders involved to help develop, expand and support the roadmap components. Realizing the need for collaboration we have reached out globally to all mitochondrial leaders inviting them to discuss the formation of a global mitochondrial summit. We firmly believe that "Uniting" the global community is necessary to bridge the existing gaps between diagnosis and treatments and effective coordinated patient care. The first roundtable discussion will be take place July 1, 2017 at the UMDF International Symposium.

I was asked what I thought the financial commitment would be to move these initiatives forward. I immediately said, "$50 million would be a good start." UMDF has committed $1 million of our next year's budget to support our scientific portfolio; we have a long ways to go.

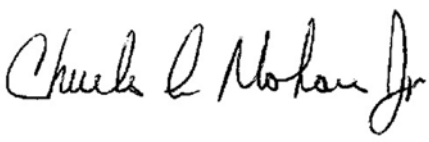
Because of your continued help and support, UMDF is truly a global voice and advocate accelerating and engaging a global focus on diagnostic development, patient care and therapeutic development.

Our future is bright but we need your continued support to capitalize on the opportunities before us to bring 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."*

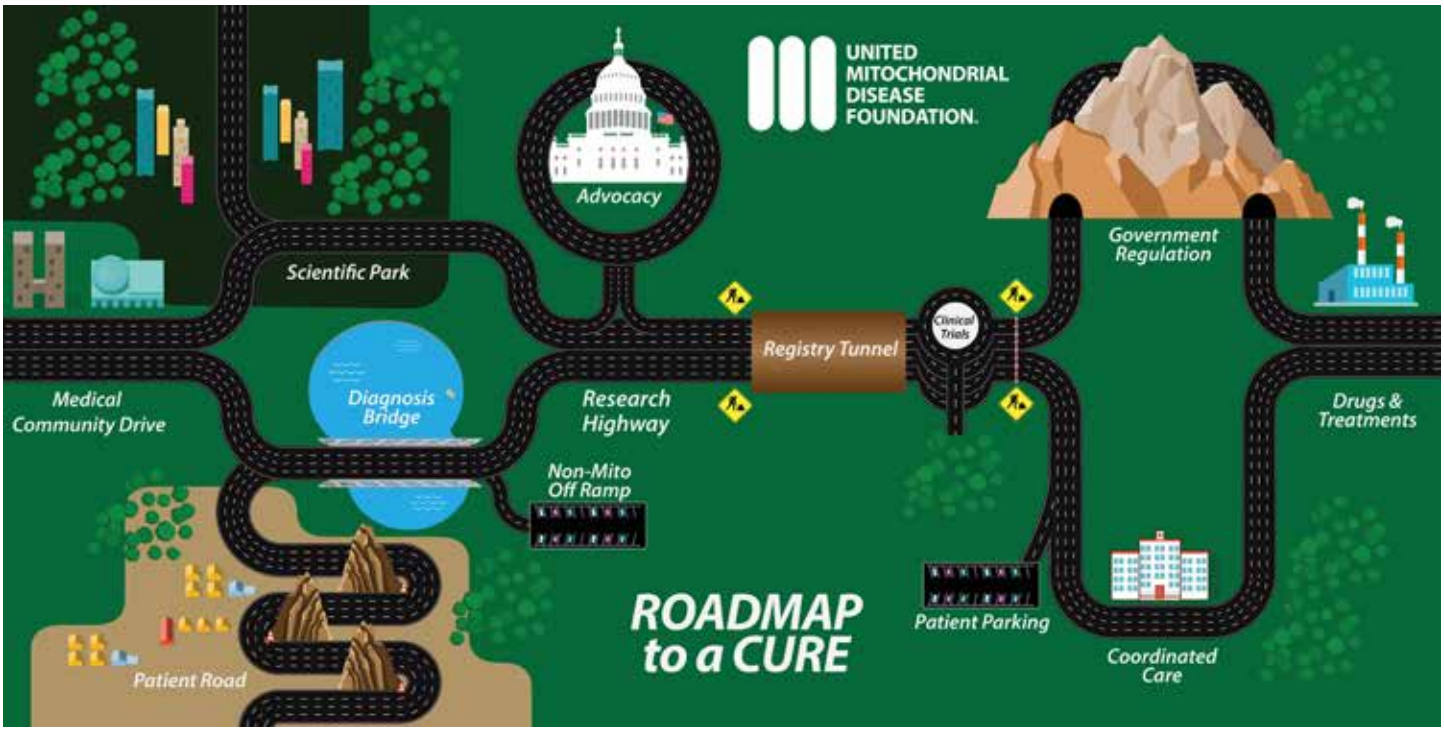
Support of the Roadmap with its three pillars of diagnostic development, patient care and therapeutic development, will produce the results that are in the best interest of the communities we serve.

With your help we will make safe and effective treatments and cures the reality and not the dream.



Charles A Mohan Jr.
UMDF CEO

Roadmap to a Cure



For many years there has been interest within the Board of Trustees of the UMDF to develop a Roadmap to a Cure for mitochondrial diseases. From 2014-2015, a strategic planning process was carried out that led to a deep discussion at the UMDF Trustee Meeting in January 2016 about a framework as well as specific milestones for creating a first version of a Mitochondrial Disease Roadmap. Three pillars of investigation were identified:

Pillar #1: DIAGNOSIS

Gap: The current landscape of the diagnosis pillar is challenging due to the extreme complexity of mitochondrial disease. There is a broad need to better identify and characterize patients; improved diagnostic methods; consensus indices to measure mitochondrial health and increased patient access to genetic testing.

Goal: Create the infrastructure to support research data using the patient registry, "Mitochondrial Disease Community Registry" (MDCR) and improved patient bio banking to steward bio samples in collaboration with the NAMDC and the Mayo Clinic.

Pillar #2: THERAPEUTIC DEVELOPMENT

Gap: There are no licensed therapies for mitochondrial disease in the United States. There is a notable absence of well-controlled studies within the field. Industry sponsored clinical trials are rapidly increasing in number.

Goal: Coordinate stakeholders in academia, government and the drug development industry to address important topics such as validated outcome measures, patient-report outcomes and regulatory guidance. These steps are necessary in gaining treatments and cures for mitochondrial disease more efficiently and quickly.

Pillar #3: PATIENT CARE

Gap: Mitochondrial disease patients receive care from a relatively small number of knowledgeable specialists. The many different types of mitochondrial disease and the many symptoms associated with each challenge even the most knowledgeable of doctors. The result is clinical care that is often inconsistent.

Goal: Take advantage of a national focus on personalized medicine, affording an opportunity for the mitochondrial disease community to help develop the programs and tools that will advance patient care in the 21st century. To that end, we are committed to collaborating with the Mitochondrial Medicine Society to establish standards of care and to create validation, standardization, support and oversight of Care Networks and Centers of Excellence models.

Energy for Action

Advocacy

Historic FDA Meeting

On October 19, 2015, our disease community had a landmark meeting with the FDA that began the process of defining a mitochondrial disease therapeutic regulatory strategy. Participants in the Critical Path Innovation Meeting (CPIM) included patients, caregivers, researchers, clinicians and industry - all active and engaged in the mitochondrial disease community. Including others that participated remotely, the total involvement of nearly 90 individuals represented the largest group the FDA had ever hosted for such a meeting. Philp Yeske, Ph.D, UMDF's Science and Alliance Officer presented in person on the challenges of therapeutic research in mitochondrial disease to the dozen or so FDA personnel that also participated. More importantly, he was able to convey the importance of hearing the "patient voice" in the therapeutic development process. During the CPIM, information was exchanged between these stakeholders and the FDA personnel, mainly focused on the topics of clinical trial design, selecting outcome measures for those trials, and biomarker selection. The single clearest message from the FDA to the audience of this newsletter was "help us understand what feel, function and survive means for your disease community."

DoD Funding Secured

The United Mitochondrial Disease Foundation is pleased to announce that mitochondrial disease have been listed again in the Department of Defense Peer Reviewed Medical Research Program. Thanks to everyone who advocated for this critical inclusion during UMDF's 2015 Day on the Hill or by contacting Congress. Mitochondrial disease is listed along with more than 40 other diseases and illnesses eligible for research funding. This is the second year in a row that UMDF has been able to help the entire community by having mitochondrial disease included.

In addition to the inclusion, UMDF worked with the Congressional Directed Medical Research Program (CDMRP) to identify affected individuals, family members, and care givers who would consider participating on a review panel for research projects. While participation is anonymous, we know that dozens of members from our community applied for the program and many were selected. UMDF also helped CDMRP recruit researchers to sit on the scientific review panel.

CDMRP Awards Researchers

In 2015-16, UMDF learned that researchers were awarded more than $11 million in funding under the DoD's CDMRP. After years of advocacy aimed at creating this program, efforts paid off as research is being funded to benefit the military families and all who suffer from mitochondrial disease.

Energy for Action

Jack Black Dances for UMDF

It is not unusual for longtime UMDF supporter Jack Black to make a splash and raise awareness for mitochondrial disease and donations for UMDF. On Wednesday, January 27, 2016, Jack appeared on The Ellen DeGeneres Show to promote his upcoming film, *Kung Fu Panda 3*. During the course of the interview, Ellen told Jack he could raise up to $10,000 for a charity of his choice. Jack was instructed by Ellen that he would have to perform a dance based on the card that she held up. Jack chose the United Mitochondrial Disease Foundation as his charity of choice and did some really creative dancing to earn the money.

The donation was made by Chideo, through their partnership with The Ellen DeGeneres Show. Chideo is a content-driven fundraising platform that offers exclusive and original videos across a broad spectrum of entertainment, sports, business, music, fashion, food, design and culture in an effort to modernize our approach to charitable giving. Chideo's primary goal is to give celebrities, non-profits and brands an easy way to quickly drive awareness and raise funds for important causes through the creation of unique and entertaining content. On behalf of all patients and families, UMDF extends our sincere thanks Jack Black, Ellen DeGeneres and Chideo.

Clincal Trail Results Presented at Symposium

Stealth BioTherapeutics (Stealth), a clinical-stage biopharmaceutical company developing investigational drugs to treat mitochondrial dysfunction, announced the presentation of positive results from MMPOWER, a Phase 2 trial evaluating the systemic delivery of elamipretide for the treatment of primary mitochondrial myopathy, or muscle weakness, in patients with a genetically confirmed mitochondrial disease.

Stealth BIOTHERAPEUTICS

The findings demonstrated statistically significant improvements with elamipretide in distance walked in six minutes, the study's primary efficacy endpoint and an accepted measurement of functional exercise capacity.

The results were presented at Mitochondrial Medicine 2016, the United Mitochondrial Disease Foundation (UMDF) symposium, in Seattle.

"We are thrilled with the encouraging results from the MMPOWER trial presented at this year's symposium," said UMDF Executive Director and CEO Charles A. Mohan, Jr. "The UMDF and the broader advocacy community look forward to fully supporting the upcoming Phase 3 trial."

Energy for Action

Education & Support

Grand Rounds

The United Mitochondrial Disease Foundation has made it a priority to provide physician education about mitochondrial disease with our Grand Rounds Program. The program introduces and/or broadens the knowledge base on mitochondrial diseases. The primary purpose of the Grand Rounds 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. In FY 2015-2016, more than 550 clinicians, nurses, therapists, educators, and other medical professionals were reached through UMDF Grand Rounds.

Maine Medical Center
Portland, ME

University of Nebraska
Omaha, NE

St. Luke's and St. Alphonsus
Boise, ID

Cook Children's Hospital
Fort Worth, TX

UT Southwestern Medical Center
Dallas, TX

Doernbecher Children's Hospital
Portland, OR

Levine Children's Hospital
Charlotte, NC

Children's Hospital of Orange County
Orange CA

University of Louisville School of Nursing
Louisville, KY

University of Kansas Medical Center
Kansas City, KS

Mayo Clinic
Jacksonville, FL

Regional Symposia

The UMDF is proud to enhance our educational programming through regional symposia at key locations across the United States. The program offers a full day CME activity on Friday and a half day of sessions for patients/families on the following Saturday. Both groups will come together for a Friday night reception to encourage networking and exchange of information. The UMDF hopes to see this program build in the coming years – not only through our efforts but also by collaborating with other organizations to reach as many clinicians and allied health as possible. Following is the list of regional symposium locations in this fiscal year:

February 2016
Central Regional Symposium
UT Health/Children's Memorial Hermann Hospital, Houston, TX

February 2016
Southeast Regional Symposium
Duke University School of Medicine, Durham, NC

May 2016
Great Lakes Regional Symposium
Mayo Clinic, Rochester, MN

Symposium

Mitochondrial Medicine 2016: Seattle was infused with a distinctly positive atmosphere. Words heard commonly throughout the research presentations were “enthusiastic,” “optimistic,” “progressive,” and “exciting,” among others.

Even if one didn’t understand the technological terminology, it was easy to become excited because many of the scientists were obviously excited. It was mentioned several times that the number of research grants, or projects, has increased dramatically in the past year, and probably will continue to do so in the future.

No one expects anyone to suddenly find a single cure for mitochondrial disease, because it is a range of genetic mutations which singly or in combination can cause many different symptoms. Many people have varying combinations of mutations or defects which have never been diagnosed. The nature of this progress is extremely diverse, but commonly describes new tools that are being discovered and developed which facilitate investigation of genetic and biochemical processes which were considered mysterious or impossible to pursue last year.

During the four days of the scientific assembly, about forty formal presentations were delivered. The speakers were universally awesome. They came perfectly prepared with detailed audiovisuals, and spoke rapidly for approximately 25 minutes, invariably ending right on time. Then, instead of the resounding silence which typically follows such a heavy flow of complex information (“drinking water from a fire hose”), there were usually several people waiting in line to ask questions.

In addition to the half-hour presentations, there were many fifteen minute abstract presentations, with the presenters equally skilled, and there were many poster presentations available for all attendees to view and discuss.

The delivery of this amount of information in such a limited period of time is rare, requiring a great deal of organizational and speaking talent. This bodes well for the future of the path to a cure.

Science

2016 Grant Award Winners

In 2016, 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.

Brendan J. Battersby, Ph.D., Research Director
Biomedicum Helsinki, Research Programs Unit-Molecular Neurology
University of Helsinki (Finland)
Principal Investigator Award – 2 years/$70,000
Investigating the Pathogenesis of C12orf65 Deficiency in Mitochondrial Translation and Mitochondrial Disease
The goal of this research project led by Dr. Battersby is to address a significant gap in mechanistic knowledge within the mitochondrial field-ribosome function and translation. The outcome of this work could provide unique insights into the broad range of mitochondrial disease symptoms that result from mutations in the C12orf65 gene.

Alessandro Bitto, Ph.D.,
Department of Pathology, University of Washington Medical Center (USA)
Postdoctoral Fellowship Award – 2 years/$70,000
Molecular Mechanisms for Suppression of Mitochondrial Disease by Acarbose,
Dr. Bitto, under the mentorship of Dr. Matt Kaeberlein, will evaluate an FDA-approved drug called acarbose for efficacy in a translational mouse model of Leigh Syndrome. The drug impacts mTOR signaling, an important mitochondrial function pathway whose understanding could open up a broad therapeutic strategy for mitochondrial disease.

CHAIRMAN'S AWARD
Nicola Brunetti-Pierri, MD, FACMG
Associate Investigator, Telethon Institute of Genetics and Medicine (Italy)
Small Clinical Study Award – 1 year/$25,000
Phenylbutyrate Therapy for Pyruvate Dehydrogenase Deficiency

This grant, winner of the 2016 Chairman's Award for highest rated research proposal after peer review, is a clinical study of a new potential therapy for pyruvate dehydrogenase complex (PDHC) deficiency by lowering lactate levels. This project comes 5 years after Dr. Brunetti-Pierri received a UMDF grant to first test phenylbutarate on patient cells. Subsequent animal model studies confirmed the promising in vitro data that resulted from the first grant, and now a pilot clinical trial will be carried out across multiple centers in Italy. Positive results from the pilot study would lead to a larger study directed toward PDHC deficiency patients.

Adam Hughes, Ph.D.
Assistant Professor of Biochemistry, University of Utah School of Medicine (USA)
Principal Investigator Award – 2 years/$100,000

Quality Control of Unimported Mitochondrial Precursor Proteins
Utilizing yeast models, Dr. Hughes intends to explore the link between loss of mitochondrial membrane potential and mis-targeted mitochondrial proteins. That the accumulation of such proteins and their associated "waste disposal" is a source of mitochondrial pathology is a novel and intriguing premise that could open up many new avenues in future research.

Leo Nijtmans, Ph.D.
Radboud University Medical Centre, Nijmegen (Netherlands)
Principal Investigator Award – 1 year/$40,000
Mitochondrial Complexome Profiling Provides a Novel Tool to Diagnose and Understand Complex I Deficiency
Complex I disorders are some of the most common types of mitochondrial disease. Dr. Nijtmans will utilize a profiling technique to study protein interactions within Complex I using patient cell lines. The results will provide insight into Complex I assembly and function, and could ultimately lead to new therapeutic targets for investigation.

George A. Porter, Jr., MD, Ph.D.
Assistant Professor, Department of Pediatrics, Division of Cardiology, University of Rochester Medical Center (USA)
Principal Investigator Award – 2 years/$100,000
Manipulating the Permeability Transition Pore to Ameliorate Neonatal Heart Failure
Many types of mitochondrial disease have associated cardiomyopathies. In this translational research project Dr. Porter will test potential therapies for cardiomyopathies in a mouse model. Success in this project would initially open the possibility for treating neonates with bioenergetics disorders, and eventually have potential for more broadly treating mitochondrial disease patients with Complex I disorders.

Eric A. Shoubridge, Ph.D.
Professor and Chair, Department of Human Genetics, Montreal Neurological Institute, McGill University (Canada)
Principal Investigator Award- 2 years/$75,000
Interrogating the Mitochondrial Interactome Using BioID

Dr. Shoubridge's project will identify functional networks within the mitochondria based on the analysis of protein-protein interactions. In addition to the potential for revealing new insights into mitochondrial disease, the availability of a mitochondrial protein interactome will be a generally useful resource for addressing basic questions regarding mitochondrial structure and function in both a normal and diseased state.

Zarazuela Zolkipli Cunningham, MBChB MRCP

Division of Neurology, The Children's Hospital of Philadelphia (USA)
Small Clinical Study Award – 1 year/$25,000

Development and Validation of a New Outcome Measure in Mitochondrial Disease

Dr. Zolkipli Cunningham and collaborators aim to develop a new outcome measure for mitochondrial myopathy that is specifically designed for use in Phase II/III clinical trials. The patient perspective will be critical to the project, helping to ensure that meaningful measures are developed over the full range of disease state- from early ambulatory to late non-ambulatory. Recognizing the urgent need for improved clinical trial endpoints, the development of this scale will build upon existing scales and tools.

Financials

SD&E | STELMACK DOBRANSKY & EANNACE LLC

Certified Public Accountants and Business Consultants

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

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

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, 2016 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, 2016 and 2015, 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 14, 2017

Financials

UNITED MITOCHONDRIAL DISEASE FOUNDATION, INC.

STATEMENTS OF FINANCIAL POSITION
JUNE 30, 2016 AND 2015

	2016	2015
ASSETS		
Cash and cash equivalents	$ 1,238,892	$ 895,942
Accounts receivable	32,208	43,295
Grants receivable (Note 3)	198,625	107,575
Pledges receivable (Note 4)	20,000	40,000
Inventories	33,095	38,690
Investments (Note 5)	1,885,570	1,867,114
Prepaid expenses	56,983	52,311
Fixed assets - net (Note 6)	40,454	85,948
TOTAL ASSETS	$ 3,505,827	$ 3,130,875
LIABILITIES AND NET ASSETS		
LIABILITIES		
Accounts payable	$ 336,937	$ 318,974
Accrued liabilities	89,471	71,292
Grants payable (Note 7)	1,543,810	1,185,577
Deferred revenue	79,645	44,750
Total liabilities	2,049,863	1,620,593
NET ASSETS		
Unrestricted	1,002,435	998,874
Temporarily restricted (Note 9)	453,529	511,408
Total net assets	1,455,964	1,510,282
TOTAL LIABILITIES AND NET ASSETS	$ 3,505,827	$ 3,130,875

UNITED MITOCHONDRIAL DISEASE FOUNDATION, INC.

STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS
FOR THE YEARS ENDED JUNE 30, 2016 AND 2015

	2016			2015		
	Unrestricted	Temporarily Restricted	Total	Unrestricted	Temporarily Restricted	Total
PUBLIC SUPPORT AND REVENUE						
Support:						
Fundraising	$1,350,746	$ 198,279	$ 1,549,025	$ 1,321,336	$ 221,561	$ 1,542,897
Contributions	703,183	1,076	704,259	680,051	150	680,201
In honor of	136,471	0	136,471	96,876	0	96,876
In memory of	78,578	0	78,578	102,195	0	102,195
In kind	53,667	0	53,667	37,117	0	27,117
Grants	264,340	137,184	401,524	277,222	223,000	500,222
Cancellation of grants payable	3,789	0	3,789	21,840	0	21,840
Total support	2,590,774	336,539	2,927,313	2,526,637	444,711	2,971,348
Revenue:						
Symposium and seminars	522,243	500	522,743	363,505	3,100	366,605
Sales	6,963	0	6,963	10,838	0	10,838
Miscellaneous	371	0	371	1,666	0	1,666
Total revenue	529,577	500	530,077	376,009	3,100	379,109
Investment income	87,046	0	87,046	71,306	0	71,306
Net unrealized gain (loss) on investments	(85,423)	0	(85,423)	(23,183)	0	(23,183)
Net realized gain (loss) on investments	3,503	0	3,503	(3,954)	0	(3,954)
Gain (loss) on disposal of fixed assets	(385)	0	(385)	0	0	0
Net assets released from program restrictions	394,918	(394,918)	0	285,426	(285,426)	0
Total support and revenue	3,520,010	(57,879)	3,462,131	3,232,241	162,385	3,394,626
FUNCTIONAL EXPENSES						
Program services:						
Research	1,039,648	0	1,039,648	1,014,232	0	1,014,232
Public awareness	331,860	0	331,860	345,902	0	345,902
Education/member support	1,126,709	0	1,126,709	1,082,250	0	1,082,250
Total program services	2,498,217	0	2,498,217	2,442,384	0	2,442,384
Supporting services:						
Administrative and general	244,965	0	244,965	172,813	0	172,813
Fundraising	773,267	0	773,267	706,420	0	706,420
Total supporting services	1,018,232	0	1,018,232	879,233	0	879,233
Total expenses	3,516,449	0	3,516,449	3,321,617	0	3,321,617
CHANGES IN NET ASSETS	3,561	(57,879)	(54,318)	(89,376)	162,385	73,009
NET ASSETS - Beginning of year	998,874	511,408	1,510,282	1,088,250	349,023	1,437,273
NET ASSETS - End of year	$1,002,435	$ 453,529	$ 1,455,964	$ 998,874	$ 511,408	$ 1,510,282

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

Donors

July 1, 2015 through June 30, 2016

Power Investors - $100,000 and above

The J. Willard & Alice S. Marriott Foundation

William Wright Family Foundation

Life Investors - $50,000 and $99,999

Edith L Trees Charitable Trust

Mr. Patrick Kelley

Reata Pharmaceuticals, Inc.

Stealth BioTherapeutics

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

Burmans Community Pharmacy (2)
Butterflies of Hope (5)
Charlotte Pipe & Foundry Company (5)
FedEx (5)
Ms. Angelina Foglia (2)
Global Genes
Mr. and Mrs. Hooper Hardison (7)
Mr. and Ms. Thomas Hefferon (18)
Mr. David Heikkinen and Dr. Ann Heikkinen (2)
Mr. Peter Kelley (10)
Kelley Management Consulting (7)
Mr. and Mrs. John Kieffer (3)
Mr. Sebastiano Lopresti & Family (4)
Mr. Herbert J. Markley (9)
MetlLife Center For Special Needs Planning (1)
RA Kirby Foundation (1)
Robert J. Bauer Family Foundation (2)
Sage Foundation (14)
Seattle Childrens Research Institute (8)
Mr. Richard Smith (1)
The Ellen DeGeneres Show
The George W. Bauer Family Foundation (1)
The Spartanburg County Foundation (10)
Tishcon Corp (8)
VOYA (2)
William Roney & Joanne Kelley Family Foundation
William S. Kallaos Family Foundation (2)
Dr. and Mrs. L. Shaun Williams MD (5)

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

Akron Children's Hospital (4)
Mr. and Mrs. Josh Albertson (6)
Mr. Joseph Auth (13)
Baylor Miraca Genetics Laboratories (8)
Blue Spark Technologies
Mr. and Mrs. Rob Bosak (11)
Ms. Annette Braverman (2)
Cincinnati Children's Hospital (12)
Dr. and Mrs. Bruce Cohen MD (16)
The Congero-Andersen Family (7)
Courtagen Life Sciences, Inc. (4)
Mr. and Mrs. Michael Foglia (2)
Mr. and Mrs. Peter Geisler (3)
GeneDx (5)
Mrs. Maha Giavis (3)
Horizon Pharma (1)
JDM Fund (7)
Kendra Scott Design (1)
Mr. and Mrs. Gordon Kidd (15)
Mr. and Mrs. Nicholas Koch (1)
Mr. and Mrs. David Langer (18)
Maple and Motor (2)
March of Dimes (11)
Mitochondrial Research Guild
Nikos S. Kefalidis Foundation, Inc. (10)
Santhera Pharmaceuticals (2)
Dr. Annette St. Pierre-MacKoul (2)
Ms. Bethany Stamper (3)
Mr. and Mrs. Brent Staples (6)
Mr. Eric Stein and Dr. Maxine Eichner (4)
Sure Logistics, Llc (2)
The DiCecco Family Charitable Foundation (3)
The Slow Bone (2)
The Vranos Family Foundation (7)
Dr. and Mrs. Harry Weinrauch (10)
Mr. and Mrs. John Whitehead (1)
Mr. Robert Whitehead (1)
Mr. and Mrs. W Dan Wright (19)
Zippo Manufacturing Co. (3)

Donors

July 1, 2015 through June 30, 2016

Friends - $1,000 - $4,999

3M Foundation (1)
84 Lumber Company (7)
A Tow Atlanta, Inc. (4)
Advanced Physical Therapy (1)
Aetna
Alex Crisp Foundation (4)
Mr. Greg Alexander (1)
Allegis Group Foundation (3)
Mr. Daniel Allen (6)
Applied Medical Technology, Inc. (1)
Arena Sports, Inc. (1)
Assurant Foundation (4)
Drs. Stephen and Rosalind Atkins (15)
AXA Foundation (16)
Mr. and Mrs. Tim Babiarz (2)
Babiarz Law Firm P.A. (9)
Mrs. Vicki Bain (2)
Mr. and Mrs. Michael Baker (15)
Mr. and Mrs. Tommy Baker (10)
Mr. Anthony Baldi (5)
Ball Corporation (6)
Ms. Paula Barnard (6)
Barrett Johnston Martin & Garrison LLC (1)
Ms. Rosemarie Bastone (1)
Ms. Dawn Batchelder (3)
Baxter International Foundation (3)
Baxter Pharmaceutical Solutions LLC (3)
Mr. John Belk (5)
Dr. and Mrs. Jay Bender MD (19)
Bertram Pharmacy (2)
BioRx, LLC (5)
Ms. Valerie Biscardi and Ms. Monica Cammarata (6)
Biscardi Visions, PC (1)
Mr. and Mrs. Bill Blank (4)
Mr. and Mrs. Brandt Blanken (11)
Mr. and Mrs. Joshua Block (9)
Mr. Thomas Blue
Dr. and Mrs. James Bolton DDS (14)
Mr. and Ms. Lane Booker (1)
Mr. Tim Boyle (1)
Mr. and Mrs. Jeff Bradshaw (6)
Mr. Mark Braverman (3)
Mr. and Mrs. George Breslow (12)
Mr. Robert Bromm (13)
Mr. and Mrs. Rich Brotherton (4)
Mr. and Mrs. Chuck Brown (4)
Mr. Christopher Burkhardt
Mr. and Mrs. Kurt Byth (3)
Car Sales Express
Mr. and Mrs. Brian Carter (1)
Dr. and Mrs. Art Caylor MD (15)
Mr. and Mrs. R. Scott Cederburg (9)
Dr. David Charney (8)
Chernega Construction LLC (1)
Children of Light (5)
Ms. Honey Chipman (2)
Mr. and Mrs. Ronald Christenson (5)
Ms. Lynn Clark (6)
Coconut Point Ford (1)
Mr. and Mrs. David Codier (11)
Mr. James L. S. Collins (5)
Ms. Dawn Conrad
Corporate Office Properties Trust (1)
Miss Emma Costick (3)
Mr. Patrick Crutcher (1)
Mr. and Mrs. John Culbertson (1)
Dr. and Mrs. John Curran (4)
Mr. and Mrs. Bill Daniel (1)
Mr. William Daniel (19)
Mrs. Gladys Dano (2)
David & Paula Kirsch Family Fund (4)
Mr and Mrs. Glenn Davis (2)
Dawda, Mann, Mulcahy & Sadler
Delta Gamma Foundation (3)
Detail Design Inc.
Detroit Medical Center
Mr. and Mrs. William Diaz (1)
Dig Pink Volleyball Tournament (1)
Rep. Gene DiGirolamo (2)
Mr. and Mrs. Dave Dobke (16)
Mr. Eric Dobke (8)
Dole Packaged Foods (6)
Mr. Michael Donahue (1)
Donald J. & Callista F. Milroy Charitable Fund (2)
Mr. Jim Dooley (2)
Dr. Cynthia Dorroh and Mr. Craig Topham (2)
Duane Morris LLP (1)
Duke Energy Foundation (6)
The Dunleavey Family (1)
Mr. and Mrs. Justin Ebert (2)
Edison Pharmaceuticals Inc. (3)
Electrical Associates (3)
Enterprise Holdings Foundation (4)
Eugene M. Lang Foundation (1)
Exerkine (1)
Extended Ag Services Inc. (4)

Donors

July 1, 2015 through June 30, 2016

Mr. and Mrs. Brent Fields (7)
Mr. and Mrs. Milton Forman (10)
Four Seasons Wealth Management (1)
Fraternal Order of Eagles #1488
Fraternal Order of Eagles #606 (1)
Mr. and Mrs. David Garrison (6)
Judge and Mrs. Donald Garrison (20)
GDR Marketing
Mrs. Lora Geer (1)
Genetic Metabolic Center for Education
Dr. and Mrs. Michael Geraci (3)
Mrs. Norma Gibson (20)
Gillette Children's Specialty Healthcare (3)
Girlfriend's Journey To A Cure (2)
Gloria & Frank Pipp Family Foundation (14)
Go Daddy (1)
Mr. Jim Goldberg
Carole Goldin (7)
Mr. and Mrs. Sheldon Goldstein (7)
Mr. and Mrs. Joe Goodman (1)
Grace Community Church-Memphis, TN (6)
GraceWorks Unlimited (1)
Mr. and Mrs. Kevin Graessle
Mr. and Mrs. Stephen Graham (1)
Mr. and Mrs. David Gray (13)
Mr. and Mrs. Michael Grealish (2)
Mrs. Tiffany Grove (3)
Gulf Elementary School-Cape Coral, FL (1)
Gulf Middle School-Cape Coral, FL (1)
Mr. and Mrs. Michael Hall (3)
Mrs. Anne Hall (3)
Ms. Edie Hanna (2)
Mr. and Mrs. Edward Hardison (6)
Mr. and Mrs. Clayton Hardon (10)
Hellenic Spirit Foundation
Ms. Alexandra Hesse (4)
Hewlett Packard Foundation (6)
Prof. W. Highsmith Jr. (5)
Mr. Ivan Hinrichs (5)
Mr. and Ms. Tom Hodge (4)
Hoffman, Bricker & Adams, PC (2)
Miss Cindy Holt (5)
HomeBank Texas
Mr. Gary Huselton (6)
Mrs. Marian Iak (2)
IBM Corporation (4)
Illinois Tool Works Foundation (10)
J.T. & T. Inc. (1)
James Street Tavern, Inc. (2)
Mr. and Mrs. David Janes (14)
Jasculca Terman Strategic Communications (1)
Mrs. Andrea Jones (4)
Josie Mazzo Children's Charities (9)
Dr. and Mrs. Glenn Kalick DVM (15)
Mr. and Mrs. Billy Kallaos Jr. (2)
Ms. Joanne Kelley and Mr. William Roney (10)
Mrs. Alice Kellington (16)
Carolyn Kenny (1)
Kiekert USA, Inc. (14)
Mr. and Ms. Christopher Kindbom (17)
Knoxville Disc Golf Association (1)
Mr. and Ms. Alan Koreneff (5)
Mr. and Mrs. Bob Kukla (7)
Mr. Carl Lampart
Mr. and Mrs. Jeffrey Lawrey (4)
Mr. and Mrs. Brian LeBlanc
Mr. and Mrs. Gard Leeper (1)
Mr. and Mrs. Edgar Levy (6)
Mr. Tom Lewis (1)
Ms. Nancy Loberg (10)
Mr. James Loomer (1)
Mr. Paul Lovullo (3)
Mr. Don Lundy (1)
Mr. and Mrs. Jim Malecha (1)
Mr. and Mrs. Bryan Manley (10)
Mr. and Mrs. Mark Marchese (3)
Mrs. Victoria Marcinkevich (1)
Mr and Mrs. Martin Mathews (6)
Mr. Jeff McAffer and Ms. Sydney McAffer
Mrs. Cat McDonald (4)
Mr. Michael McElroy
Medomics (7)
Mr. and Mrs. Jeff Mee (15)
Mrs. Megan Meese (2)
Meuse Family Foundation (6)
Mrs. Teresa R. Meyers (1)
Mr. Stephen Miller (7)
Mitobridge (2)
Mr. and Mrs. Gary Moberly (8)
Mr. and Mrs. Charles A. Mohan Jr. (20)
Mohan's Restaurant (20)
Ms. Danielle Molder (1)
Mr. and Mrs. Ben Morrow (6)
The Mouk Family (4)
Mr. and Mrs. Brad Mountz (4)
Mr. and Mrs. Jim Mowrer (10)
Mr. and Mrs. Francis Mroz (5)
Mr. Steve Mueller (2)
The Mullin Family (4)
Mr. Neil Mussett (1)
Mr. David Neill (5)
Northeast Elementary School-Brentwood, NY
Oakland High School-Murfreesboro, TN
Mr. and Mrs. Frank O'Connor (11)
OHL Foundation (1)

Donors

July 1, 2015 through June 30, 2016

Oroboros Instruments (9)
Mr. Martin Packouz (13)
Mr. and Mrs. Neal Palmer (15)
Partners Financial Charitable Foundation (2)
Mr. Andy Pashby
Mr. Douglass Passon Jr (1)
Mr. Scott Pedersen
Mr. and Mrs. Michael Perez (2)
Dr. Michelle Snyderman Platt (10)
Pledgeling Foundation
Mr. and Mrs. Mark Podolsky
Ms. Sarah Poplack (1)
Ms. Page Porter (3)
Mr. and Mrs. Bobbie Porter (6)
PriceWaterhouse Coopers (2)
Puget Sound Kidney Centers (3)
Rachael's Gift Inc. (5)
Mr. and Mrs. Andrew Reardon (2)
Drs. Fred and JoAnn Reckling (2)
Mr. Edward Reeves
Mr. and Mrs. Leroy Reifsteck (2)
Dr. and Mrs. Tyler Reimschisel (7)
Revenue Optimization Solutions LLC (2)
Mr. and Mrs. Joseph Rice (19)
Mr. and Mrs. Matthew Richardson (4)
Mr. and Mrs. William Riley (2)
Ms. Megan Ritchey
Mrs. Joscelyn Rivers (1)
Roberts-Winegardner Funeral Home (1)
Dr. Sheryll Rockway (2)
Mr. John Romeo (2)
Roofing Consultants Ltd (11)
Mr. and Mrs. Billy Rosenthal
Mr. Rory Roth
Miss Cristina Rue (1)
Ruhana & Ruhana Enterprises Llc (3)
Ruth Camp Campbell Foundation (1)
Mr. and Mrs. Don Ryan (4)
S&T Bank Charitable Foundation (12)
Dr. Russell Saneto DO, PhD (15)
Mr. and Mrs. Brett Schoenecker (13)
Ms. Denise Schumacher (10)
Mr. Lyle Schutte (17)
Scott & Tricia Russell Family Fund (2)
Send & Save Office LLC
Drs. John and Amanda Sharma (2)
Showalter Construction Co (5)
Mr. and Mrs. Jerry Shuck (15)
Ms. Cynthia Sickler (4)
Mr. David Sills (1)
Ms. Catherine Sims (3)
Southern Ohio Bikers, Inc. (6)
Springleaf Foundation Inc. (1)
St. Bernadette Catholic School-Monroeville, PA (14)
St. John Lutheran Church-Boiling Springs, PA (1)
Stage Stores (1)
Ms. Patty Stageman (5)
Star Fuel Centers, Inc. (12)
Mr. and Mrs. Peter Stathakis (3)
Mr. Timothy Steward (2)
Mr. and Mrs. Neil Strosnider (1)
Ms. Jamie Taylor
Texas Chili Company (2)
The Allstate Foundation (3)
The Gallery of Fine Art (1)
The Peachtree Club (8)
The Pittsburgh Foundation (6)
Thomas Worthington High School-Worthington, OH
Frances Thompson (4)
Mr. and Mrs. Mark Thornsberry (7)
TJ Maxx - District 4101 (1)
Mrs. Jana Twigg (4)
Mr. Steven Umhoefer (8)
Mr. and Ms. John Underwood (9)
University of Pittsburgh Medical Center
Usher Oil Company (3)
Vanguard Charitable
Villa Annette (1)
Mr. James Volker (2)
Mr. Weston Wadsworth (1)
Mr. Joe Waller (12)
Mrs. Joann Walsh (1)
Mr. and Mrs. Li Kan Wang (13)
Waterford Property Company Foundation (4)
Mr. and Mrs. Shawn Welch (13)
Mr. and Mrs. David Wells (17)
Mr. Andrew Wert (1)
Mr. Vince Wesolowski (1)
West Genesee School District-Cammillus, NY (1)
Mr. and Mrs. Phil Whatley (6)
The Whitehouse Family (1)
Mrs. Sylvia Wilhelm (2)
Wilkins Lodge #577 BPO Elks
Ms. Susan Winokur HCS-D (2)
The Wolf Family (1)
Dr. Philip Yeske PhD (7)
Mr. John Zetterower (6)

Events

Energy for Life Walkathons

In fiscal year 2015-2016, our dedicated volunteer planning committees hosted 28 Energy for Life Walkathons in cities across the United States. In small towns and big cities alike, these walks created a buzz of awareness for mitochondrial disease through fundraising.

If you participated in an EFL Walkathon, you were one of 515 teams who worked so hard to fundraise over $1,183,401 to support the mission of the UMDF. Our walk teams and individual fundraisers were able to reach this goal by fundraising through various means which include personal asks, social media, letter-writing campaigns, wrap-around fundraisers, corporate partnerships and of course the support of their family and friends.

The following cities and regions were host to an Energy for Life Walkathon in 2015-2016:

Akron	Detroit	Omaha
Atlanta	Evansville	Pittsburgh
Birmingham	Ft. Myers	San Francisco Bay Area
Central Texas	Houston	Seattle
Charlotte	Indianapolis	Southern Wisconsin
Chicago	Kansas City	St. Louis
Cincinnati	Minnesota	Tampa Bay
Columbus, GA	Nashville	Western New York
Dallas	New England	
Delaware Valley	New Orleans	

To see a list of Energy for Life Walkathons in your area, visit www.energyforlifewalk.org

Fundraising Events

There are millions of fundraising events happening each year and our mito community is deep in the heart of these events raising money for the UMDF. These dedicated volunteers are parents, caretakers, siblings, grand-parents, extended family members or dear friends of someone who is fighting mitochondrial disease. They work hard in their 'spare' time to organize, plan, promote and execute third party and sanctioned fundraising events that together raised over $362,125 for the UMDF in 2015-2016!

There are SOOOO many fundraising options that you can do, a few of them are a lemonade stand on your sidewalk, a 5K run, golf outing or a wine tasting auction – the sky is really the limit (ask our volunteer who did a 'Skydiving for a Cure' fundraiser!) when it comes to events.

Our UMDF Staff has the tools that YOU need to bring the FUN to FUNdraising – give us a call or email events@umdf.org

Activate Your Mitochondria

Athletes and individuals around the country are continuing to activate their mitochondria and raising funds through **Activate Your Mitochondria**. If you are running marathons, biking, swimming, hiking or lifting, this is a great way to do the things you love AND raise funds for the UMDF!

Between July 1, 2015 and June 30, 2016, our athletes raised over $57,716 utilizing **Activate your Mitochondria**. These athletes were running multiple marathons, hiking the AT, and working their mitochondria.

If you are interested in becoming an athlete with our Activate Your Mitochondria, visit *www.umdf.org/activemito* today!

Unstoppable Nina Hall

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, 2015 to June 30, 2016:

The Rachael Albertson Research Fund

The T.J. Amber Research Fund

The Angelray Research Fund

The Logan Sloane Aronson Research Fund in Honor of Sydney Breslow

The Lauren Benney Research Fund

The Carter Buffum Research Fund

The Samuel Cutliff Research Fund

The Emma Frances Dalton Research Fund

The Katherine Dickens Research Fund

The Jack Edwards Research Fund

Elena's Hope Research Fund

The John Garrett Evans Research Fund

The Luca Florio Research Fund

The John Geraci Research Fund

The Olivia Paige Goldberg Research Fund

The Unstoppable Nina Hall Research Fund

The Brandon David Harris Research Fund

The Olivia Skye Hesse Research Fund

The Ayden and Faith Hingsbergen Research Fund

The Hunt Michael Hollis Research Fund

The Kaden Jarret Huddleston Fund

The Caleb Jacobs Research Fund

The Dawnta and Levi Kendall Family Research Fund

The Kids Like Connor Research Fund

The Melissa Kieffer Research Fund

The Carter Lackey Research Fund

The Lincoln Huff Research Fund

The Brandon Heschel Leach Research Fund

The Aiden Lee Research Fund

The Hayley Leib Research Fund

The Michael Angelo LoPresti Research Fund

The Anthony Demarko Maccarelli Research Fund

The Amy Macris Research Fund

The Isabella Magee Research Fund

The Jude Manley Research Fund

The Will Martin Family Research Fund

The Grant McElveen Family Research Fund

The Gabriella Menotti Family Research Fund

The Jaethan Myers Research Fund

The Lindsey Norris Research Fund

The Andrew Radney Research Fund

The Jonah Ritterbush Research Fund

The Jackson Rothschild Research Fund

The Lex Santo Research Fund

The Alex Schumacher Research Fund

The Breylon Senn Research Fund

The Jaxon Sharma Research Fund

The Isabelle Sherman Research Fund

The Noah Shulman Research Fund

The Kaidon Andrew Stamper Fund

The Emily Steadman Research Fund

The Brady Sterchi Family Research Fund

The Corynna Strawser Research Fund

The Carter Stride Research Fund

The Nicholas James Torpey Research Fund

The Wappner-Craig Family Research Fund

The Cooper & Isla Watson Research Fund

The Leslie Whitt-Williams Research Fund

The Brittany Wilkinson Research Fund

The Will Woleben Family Research Fund

National

Scientific & Medical Advisory Board

Sumit Parikh, MD, Chair

William Craigen, MD, PhD

Marni Falk, MD

Amy Goldstein, MD

Andrea L. Gropman, MD, FAAP, FACMG

Richard H. Haas, MB, BChir

Marcia Haigis, PhD

Carla Koehler, PhD

Dwight Koerbel, MD, PhD

Mark Korson, MD

Giovanni Manfredi, MD, PhD

Robert McFarland, MBBS, PhD

Gerard Vockley, MD, PhD

Kendall Wallace, PhD

Richard Youle, PhD

Board of Trustees

Patrick Kelley, Chair

W. Dan Wright, Vice Chair

John A. DiCecco, Treasurer

Brent Fields, Secretary

John Kieffer, Trustee-at-Large

Bruce H. Cohen, MD

Sumit Parikh, MD, SMAB Chair

Hooper Hardison

Richard Leach

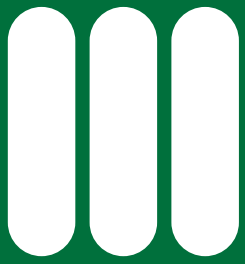
Sharon Shaw Reeder

Tyler Reimschisel, MD

Charles A. Mohan, Jr., Chair Emeritus

Staff

- **Charles A. Mohan Jr.**
  CEO/Executive Director
- **Mark Campbell**
  Chief Financial Officer
- **Philip Yeske, PhD**
  Science and Alliance Officer
- **Kara Strittmatter**
  Meeting Event Director
- **Clifford Gorski**
  Director of Communications
- **Tania Hanscom**
  National Walk Manager
- **Beth Whitehouse**
  Director of Development
- **Donna Nameth**
  Data Entry Manager
- **Barbara Cullaj**
  Administrative Assistant
- **Janet Owens**
  Executive Administrative Assistant
- **Jeff Gamza**
  Multimedia Coordinator
- **Cassie Franklin**
  Gift Officer
- **Julie Hughes**
  Development Associate
- **Tara Maziarz**
  Special Events Associate
- **Anne Simonsen**
  Regional Coordinator - Great Lakes
- **Margaret Moore**
  Regional Coordinator - Southeast
- **Nicole McCaslin**
  Regional Coordinator - Northeast
- **Jessica Rios**
  Regional Coordinator - Central



UNITED
MITOCHONDRIAL
DISEASE
FOUNDATION®