

UMDF

Lighting
the Way . . .

In the
Search to
Fund a Cure!



United Mitochondrial Disease Foundation

2003-2004

Annual Report

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.



Charles Mohan, Jr.
Chairman, UMDF

UMDF Mission

The mission of the United Mitochondrial Disease Foundation has been updated:

To promote research and education for the diagnosis, treatment and cure of mitochondrial disorders and to provide support to affected individuals and families.

The words education and diagnosis have been added to better identify UMDF's focus.

We are not rich by what we possess but rather by what we can do without.
-Immanuel Kant

Grants

In 2003-2004, UMDF continues to expand its grant program by again doubling our award to \$1,000,000. This grant award attracted over 83 Letters of Intent with 45 full grant proposals being reviewed and 9 being selected for funding.

Symposia

This year's symposium, *Streams of Energy*, the 6th annual symposium on Mitochondrial Diseases co-sponsored by the Mitochondria Research Society, the Mitochondrial Medicine Society, the Pittsburgh Mercy Health System and UMDF, received more positive comments this year than ever before. UMDF Symposia is becoming the recognized symposium on mitochondrial disorders in the world.

Strategic Planning

UMDF has completed and is in the process of implementing its 3rd strategic plan. The planning session was highly interactive and provided a forum for spirited debate with regard to the UMDF and its future. The planning participants made a number of informed decisions with regard to the foundation's chosen future and how it will operate in the future. Implementation has begun enhancing UMDF's effectiveness by developing its structure, staff and infrastructure for 2005.

Chapters, Groups and Members

Chapters, Support Groups and the general membership are energized and committed to the UMDF Mission. The Atlanta Area is our newest chapter with many other support groups working toward chapter status as well as members desiring to establish support groups. The strategic plan reiterated what we have always realized; chapters and support groups are the future of UMDF. We are addressing this need by hiring a full time Director of Membership Services to enhance and build upon the services already provided.

Development

From Auctions to Brew at the Zoo, fundraising events are occurring all over the USA. Successful fundraising events have been standardized and in packet format and are now available to everyone interested in taking a pro-active stance against mitochondrial disease.

Post-doctoral fellowships, initially funded with a three year grant from the Sage Foundation, have resulted in five new fellows entering the field of mitochondrial research.

UMDF Office

Continuing to fulfill the direction of the new strategic plan, UMDF has brought on board a full time certified financial officer. UMDF's new CFO, Mark Campbell, is busy evaluating and establishing proper financial procedures effectuating more timely and accurate financial information. This will be a major advantage to the national office as well as the chapters and general membership.

UMDF is continuing to build the IT infrastructure by entering into a contractual arrangement with our consultants, The Stadler Group. A complete renovation and transition of the database and web site is underway and should be completed in the coming months.

The UMDF continues to receive an increasing number of phone calls, e-mail, checks, and good ideas that we need to pursue. UMDF continues to stay on the move-thanks to the efforts of its members and supporters.

Yours Toward a cure,

Charles A. Mohan, Jr.
Chairman, UMDF

About the United Mitochondrial Disease Foundation

The United Mitochondrial Disease Foundation promotes research and education for the diagnosis, treatment, and cure of mitochondrial disorders and provides support to affected individuals and families.

UMDF continues to validate its mission through grants awarded annually dedicated to the research of mitochondrial mechanisms and diseases. UMDF developed a grants award process based upon the funding awards process used by the National Institutes of Health. A tremendous amount of basic science continues to be done, with the hopes that unlocking the secrets of the mitochondria will lead to treatments and a cure of mitochondrial diseases.

UMDF established a Scientific Advisory Board which includes 27 researchers, scientists, and doctors—all leaders in their respective fields—to evaluate and choose the recipients for each year's awards. UMDF first awarded \$30,000 in 1997. Since then, UMDF has awarded more than \$1.6 million towards research with \$715,000 going to nine researchers in 2004.

Programs for People

The second part of UMDF's mission is realized through outreach to those touched in some way by the disease. The UMDF provides support and information to thousands of patients, family members, donors, researchers, doctors and other allied health professionals. UMDF continues to educate the general public, and the medical and the scientific communities about mitochondrial diseases as another component of its outreach programming. Public awareness and outreach fulfill a significant obligation that UMDF has to its mission.



UMDF continues to serve patients and families with a myriad of programs which include: newsletters and mailings, support groups and chapters, a member service phone line for information and referrals, networking opportunities, access to a reference library with up-to-date information on mitochondrial diseases, a website, and an annual symposium focused on mitochondrial diseases where members have the opportunity to meet clinicians and other members faced with battling the effects of the same disease.

UMDF chapters and groups provide members with opportunities for mutual support and productive action. Some groups form around the need to talk with others faced with the same concerns. Other groups form to raise funds for research or to raise awareness and educate physicians. UMDF provides groups and chapters with guidance on operations, assistance in communicating with local members, materials for public awareness and physician education, and advice on fundraising. Fundraising events continue to be a major source of funds for the foundation, as well as an excellent way to raise awareness about the disease. UMDF fundraising events run the gamut from golf outings and 5K walks and runs to elegant wine tasting receptions and dinner dances.

Events Promote Support



Fundraisers Promote Awareness



Symposia Promote Education





UMDF has experienced growth and change in many chapters and groups across the United States.

As new groups start to form in Western Michigan and in Alabama, several groups continue to move toward chapterhood!

The status of the chapters, groups and leaders listed to the right depicts groups/chapters in 2003-2004. Some changes occurred after June 30, 2004 and will be noted in the next annual report.



ARIZONA

★Arizona Chapter

Phoenix, AZ

Interim Leaders: Sharon Shaw, Thom Montgomery and Jane Shumaker
Members: 100+

CALIFORNIA

★Southern California Chapter

Los Angeles, CA

Vice President: Kathy Fares
Members: 350+

FLORIDA

Florida Rays of Hope Support Group
Melbourne, FL

Contacts: Christine Golden
Carrie Waters

Members: 50+

GEORGIA

Atlanta Area Support Group

Atlanta, GA

Contact: Holly Capp
Members: 125+

INDIANA

★Indiana Chapter

Indianapolis, IN

President: Sue Ann Bube
Members: 80+

ILLINOIS

Chicago Area Support Group

Chicago, IL

Contacts: Gail Wehling and Karen Lewis
Members: 105+

St. Louis Area Group

Contact: Marsha Hohe

Members: 40+

MARYLAND

Tri State Area (DC) Support Group

Contact: Andrea Gropman, M.D.

Members: 30+

MASSACHUSETTS

★New England Chapter

Boston, MA

President: Bridget Willis

Members: 150+

MICHIGAN

Detroit, MI

Contact: Ann Clark

Members: 150+

MISSOURI/KANSAS

★Kansas City Chapter

Kansas City, MO

President: Heidi Harmon

Members: 45+

NEW YORK

★New York Metro Chapter

Long Island, NY

President: Tom Shubeck

Members: 325+

New Paltz Group

Contact: Beth and James DeArce

OHIO

★Ohio Chapter

Cleveland, OH

President: Jennifer Lyman

Members: 300+

Columbus Support Group

Contact: Shawna Steele

Members: 50+

Cincinnati Support Group

Contact: Jennifer Neal (Cooper)

Members: 45+

OREGON

Pacific Northwest Support Group

Contacts: Cathy Akins and Cori Feist

Members: 80+

PENNSYLVANIA

★Delaware Valley Chapter

Philadelphia, PA

President: Maripat Shelly

Members: 250+

Western PA Support Group

Contact: Karen Wilson

Members: 150+

SOUTH CAROLINA

Columbia, SC

Contact: Karis Mott

Members: 50+

TEXAS

Dallas Area Support Group

Dallas, TX

Contact: Tova Sido

Members: 75+

VIRGINIA

Virginia Support Group

Williamsburg, VA

Contact: Shelby Hawthorne

Members: 50+

OUTSIDE OF THE

UNITED STATES

AUSTRALIA

Queensland, Australia

Contact: Tara Collyer

Members: 30+

CANADA/ONTARIO

Contact: Valerie McGarry

Members: 20+

Research Grant Projects Funded in 2004

David Chan, MD, PhD, California Institute of Technology, Pasadena, CA
Award Amount: \$128,000

Project Title: Understanding the role of mitochondrial fusion in mitochondrial myopathies

Summary: This project will produce lab mice that have undergone tissue-specific deactivation of factors needed for mitochondrial fusion and will study the effects that this has on skeletal and cardiac myopathies.

Miriam Meisler, PhD, University of Michigan

Award Amount: \$108,305

Project Title: The nuclear-encoded gene OMI and Mitochondrial Disease

Summary: Their experience with a mouse model possessing a mutation that causes abnormal mitochondrial function leading to neuromuscular disease has led them to design a study in which they will screen 300 mitochondrial disease patients for the same mutation.

Volkmar Weissig, PhD, Sc, Northeastern University, Boston, MA

Award Amount: \$99,360

Project Title: Development of a method for transforming mitochondria in living mammalian cells with exogenous DNA

Summary: They plan to develop and perfect a mechanism for transporting exogenous plasmid DNA through the interior of cells to the mitochondria, with subsequent mitochondrial uptake of the DNA.

Vamsi Mootha, MD, Massachusetts Institute of Technology

Award Amount: \$90,200

Project Title: Genomic Approaches to Human Cytochrome c Oxidase Deficiency

Summary: They will use a comprehensive computational strategy to identify genes that code for assembly factors responsible for cytochrome c oxidase; candidate sequences will be validated through the use of RNA interference in cultured cells with subsequent biochemical assay of potential changes in respiratory function.

Joseph Garcia, MD, PhD, University of Texas SW Medical Center

Award Amount: \$88,852

Project Title: The hypoxia sensing transcription factor EPAS1/HIF-2a is a novel mitochondrial disease candidate in mice and man

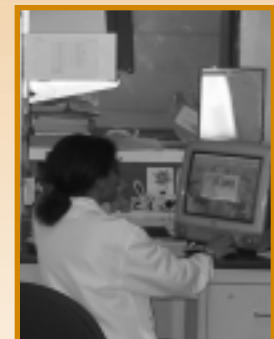
Summary: They will screen cell lines that have been collected from 200 pediatric mitochondrial disease patients for the presence of a mutated protein that normally stimulates the production of anti-oxidant enzymes and will express the coding errors in cultured cells to examine the specific dysfunction associated with the protein.

Stefan Strack, PhD, University of Iowa, Iowa City

Award Amount: \$88,000

Project Title: Protein phosphatase 2A in mitochondrial function and disease

Summary: Methods will be developed to block the activity of a mitochondrial regulatory protein that normally renders brain cells vulnerable to toxin-induced degeneration, with the goal of rescuing the cells from the effects of the toxins.



Grant Checks Presented During Mitochondrial Medicine 2004

"I am writing in order to say thanks to you for organizing such a great meeting. For me, it was the first time that I actually got in touch with parents of children affected by mitochondrial diseases -- this made a lasting impression on me. As a basic scientist working only at the bench, I do know that my research eventually will benefit patients, but putting names and above all faces to it, is different.

I was and I still am emotionally touched, and this adds a lot of additional motivation to do hard bench work, which unfortunately is too often not as successful as one wishes and therefore always comes with a great deal of frustration.

Attending this meeting was a unique and very valuable experience for me and I am looking forward to St. Louis."

*With best regards,
Volkmar Weissig, PhD, ScD*



Brian Robinson, PhD, Hospital for Sick Children, Toronto, Canada
Award Amount: \$44,000

Project Title: Drug development for the regulation of respiratory chain components in mitochondria

Summary: They will screen a large number of chemicals from a family of heterocyclic compounds that show promise for stimulating the production of mitochondrial respiratory proteins.

Gregory Enns, MB, ChB, Stanford University, CA
Award Amount: \$34,179

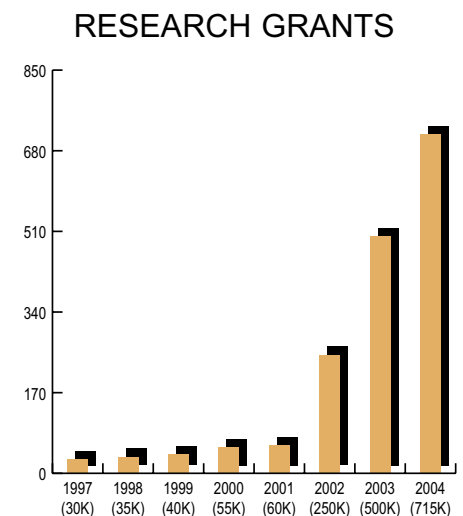
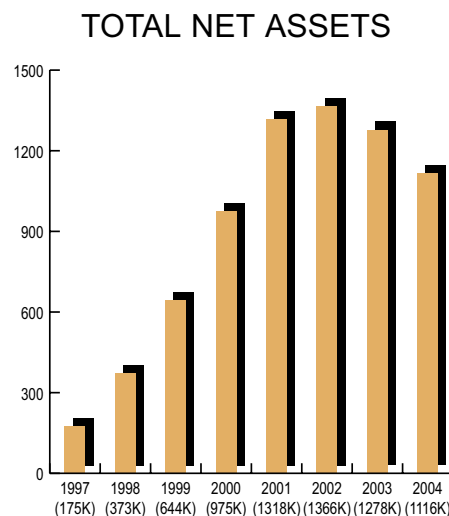
Project Title: GSH levels, reactive oxygen species production, lipid peroxidation, products and mitochondrial membrane potential in patients with mitochondrial disease

Summary: They will look for correlations between the relative health status of mitochondrial disease patients and various factors associated with oxidative stress in the patients' cells.

Ramon Marti, PhD, Fundacio Institut Hospital, Barcelona, Spain
Award Amount: \$33,776

Project Title: Restoration of thymidine phosphorylase activity in MNGIE patients through platelets infusion

Summary: Patients with the rare mitochondrial disease MNGIE will be infused with platelets that contain the enzyme they are missing, with the goal of decreasing plasma levels of toxic nucleosides that usually accumulate and damage the patients' mitochondria.



INDEPENDENT AUDITOR'S REPORT

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

We have audited the accompanying statement of financial position of the United Mitochondrial Disease Foundation, Inc. ("the Foundation") as of June 30, 2004 and 2003, and the related statements of activities and cash flows for the years then ended. These financial statements are the responsibility of the Foundation's management. Our responsibility is to express an opinion on these financial statements based on our audits.

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

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of the United Mitochondrial Disease Foundation, Inc. as of June 30, 2004 and 2003, 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
Pittsburgh, Pennsylvania

September 21, 2004

STATEMENTS OF FINANCIAL POSITION JUNE 30, 2004 AND 2003

	2004	2003
ASSETS		
Cash and cash equivalents	\$ 1,345,192	\$ 973,683
Contributions receivable (Note 2)	50,000	99,020
Interest receivable	4,951	702
Investments (Note 3)	734,068	642,050
Prepaid expenses	45,530	7,445
Fixed assets - net (Note 4)	42,199	56,735
TOTAL ASSETS	\$ 2,221,940	\$ 1,779,635
LIABILITIES		
Accounts payable	\$ 36,152	\$ 47,769
Grants payable (Note 5)	986,087	382,599
Deferred revenue	83,419	71,204
Total liabilities	1,105,658	501,572
NET ASSETS		
Unrestricted	958,488	1,102,269
Temporarily restricted (Note 6)	157,794	175,794
Total net assets	1,116,282	1,278,063
TOTAL LIABILITIES AND NET ASSETS	\$ 2,221,940	\$ 1,779,635



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

**STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS
FOR THE YEARS ENDED JUNE 30, 2004 AND 2003**

	2004			2003
	Temporarily Unrestricted	Temporarily Restricted	Total	Total
SUPPORT AND REVENUE				
Support:				
Fundraising	\$ 835,699	\$ 34,225	\$ 869,924	\$ 589,699
Contributions	55,667	45,000	100,667	37,381
In honor of	156,545	0	156,545	114,335
In kind	19,490	0	19,490	17,262
In memory of	127,634	0	127,634	93,964
Grants	5,000	11,480	16,480	173,170
Total support	1,200,035	90,705	1,290,740	1,025,811
Revenue:				
Symposium and seminars	1,690	0	1,690	5,230
Membership	32,844	0	32,844	34,859
Miscellaneous	2,810	0	2,810	2,455
Total revenue	37,344	0	37,344	42,544
Investment income	26,458	0	26,458	35,958
Net unrealized gain (loss) on investments ..	75,704	0	75,704	42,274
Net realized gain (loss) on investments	28	0	28	(58,969)
Net assets released from program restrictions	108,705	(108,705)	0	0
Total public support and revenue	1,448,274	(18,000)	1,430,274	1,087,618
FUNCTIONAL EXPENSES				
Program services				
Research	851,765	0	851,765	535,989
Public awareness	188,632	0	188,632	96,065
Education/member support	253,303	0	253,303	245,368
Total program services	1,293,700	0	1,293,700	877,422
Supporting expenses:				
Administrative and general	76,153	0	76,153	100,850
Fundraising	222,202	0	222,202	197,242
Total supporting services	298,355	0	298,355	298,092
Total expense	1,592,055	0	1,592,055	1,175,514
CHANGES IN NET ASSETS	(143,781)	(18,000)	(161,781)	(87,896)
NET ASSETS - Beginning of year	1,102,269	175,794	1,278,063	1,365,959
NET ASSETS - End of year	\$ 958,488	\$157,794	\$ 1,116,282	\$1,278,063

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

**STATEMENTS OF CASH FLOWS
FOR THE YEARS ENDED JUNE 30, 2004 AND 2003**

	2004	2003
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in net assets	\$(161,781)	\$(87,896)
Adjustments to reconcile change in net assets provided by (used in) operating activities:		
Depreciation	15,332	13,952
Realized (gain) loss on sale of investments	(28)	58,969
Unrealized (gain) loss on investment	(75,704)	(42,274)
Changes in assets (increase)/decrease:		
Contribution receivable	49,020	(87,770)
Interest receivable	(4,249)	7,965
Prepaid expenses	(38,085)	(5,510)
Changes in liabilities (decrease)/increase:		
Accounts payable	(11,617)	(136,228)
Grants payable	603,488	116,099
Deferred revenue	12,215	52,164
Net cash provided by (used in) operating activities	388,591	(110,529)
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchase of equipment	(796)	(24,893)
Purchase of investments	(16,286)	(416,732)
Proceeds on sale of investments	0	412,590
Net cash provided by (used in) investing activities	(17,082)	(29,035)
NET INCREASE (DECREASE) IN CASH AND CASH EQUIVALENTS		
CASH AND CASH EQUIVALENTS - Beginning of year	973,683	1,113,247
CASH AND CASH EQUIVALENTS - End of year	\$1,345,192	\$973,683
SUPPLEMENTAL INFORMATION		
Interest paid	\$0	\$0
Income taxes paid on unrelated business income	\$0	\$0

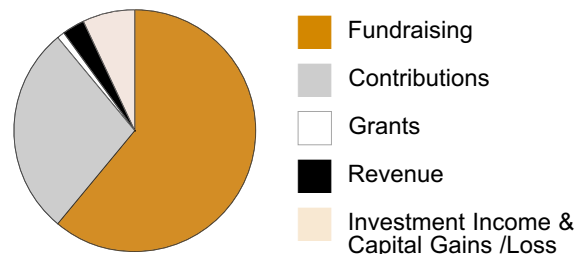
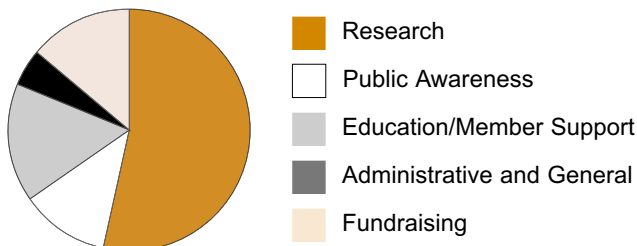
See Independent Auditor's Report and Notes to the Financial Statements

2004 EXPENSES

Research	\$851,765	54%
Public Awareness	\$188,632	12%
Education/Member Support	\$253,303	16%
Administrative and General	\$76,153	5%
Fundraising	\$222,202	14%
Total Expense	\$1,592,055	100%

2004 REVENUE SOURCES

Fundraising	\$869,924	61%
Contributions	\$404,336	28%
Grants	\$16,480	1%
Revenue	\$ 37,344	3%
Investment Income & Capital Gain/Loss	\$102,190	7%
Total Public Support and Revenue	\$1,430,274	100%



**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEARS ENDED JUNE 30, 2004 AND 2003**

1. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIESOrganization and Nature of Activities

The United Mitochondrial Disease Foundation, Inc. ("the Foundation") was organized on April 28, 1995, and is the result of a merger between a number of specific Mitochondrial disease organizations to form a larger, more cohesive united foundation representing all mitochondrial diseases and all sufferers, adult and children alike. The Foundation's mission is to promote research and education for the diagnosis, treatment, and cure of mitochondrial disorders and to provide support to affected individuals and families.

Basis of Accounting

The accompanying financial statements are prepared on the accrual basis of accounting, and accordingly, reflect all significant receivables, payables, and other liabilities.

Comparative Financial Information

The Statements of Activities and Changes in Net Assets include certain prior-year summarized comparative information in total, but not by net asset class. Such information does not include sufficient detail to constitute a presentation in conformity with generally accepted accounting principles. Accordingly, such information should be read in conjunction with the Foundation's financial statements for the year ended June 30, 2003, from which the summarized information was derived.

Financial Statement Presentation

The Foundation's financial statements are prepared in accordance with Statement of Financial Accounting Standards (SFAS) No. 117, "Financial Statements of Not-for-Profit Organizations." Under SFAS No. 117, the Foundation is required to report information regarding its financial position and activities according to three classes of net assets: unrestricted net assets, temporarily restricted net assets and permanently restricted net assets.

Contributions

The Foundation records contributions and grants in accordance with SFAS No. 116, "Accounting for Contributions Received and Contributions Made." Under SFAS No. 116, contributions received are recorded as unrestricted, temporarily restricted, or permanently restricted support depending on the existence or nature of any donor restrictions. Contributions that are required to be reported as temporarily restricted support are then reclassified to unrestricted net assets upon expiration/satisfaction of the donor restrictions.

Cash and Cash Equivalents

For purposes of the Statement of Cash Flows, the Foundation considers all highly liquid investments with an initial maturity of three months or less to be cash equivalents. For the years ended June 30, 2004 and 2003, the Foundation had no noncash investing or financing activities for cash flow purposes.

Estimates

Management uses estimates and assumptions in preparing financial statements. Those estimates and assumptions affect the reported amounts of assets and liabilities, the disclosure of contingent assets and liabilities and the reported revenues and expenses. Actual results could differ from those estimates.

Investments

The Foundation records investments in accordance with SFAS No. 124, "Accounting for Certain Investments Held by Not-for-Profit Organizations" which established standards of financial accounting, reporting and disclosures for certain financial securities held by not-for-profit organizations. Under SFAS No. 124, investments are presented in these financial statements at their current market value. These current market values are established using published market prices.

Fixed Assets

Fixed assets are recorded at cost and depreciated using the straight-line method over estimated useful lives of 5 to 7 years.

Depreciation expense, totaling \$15,332 and \$13,952 for the years ended June 30, 2004 and 2003, respectively, is allocated to the various activities based on usage.

Revenue and Expense Recognition

Income from membership dues and program service fees are deferred and recognized over the periods to which the specific types of income relate. Costs and expenses related to such activities are also deferred as prepaid expenses and recognized in the period when the programs are held.

Functional Allocation of Expenses

The costs of providing the various programs and other activities have been summarized on a functional basis in the statement of activities and changes in net assets. Accordingly, certain costs have been allocated among the programs and supporting services benefited.

Income Tax Status

The Foundation is exempt from federal income tax under Section 501(c)(3) of the Internal Revenue Code. However, income from certain activities not directly related to the Foundation's tax-exempt purpose is subject to taxation as unrelated business income. For the years ended June 30, 2004 and 2003, the Foundation had no such income. In addition, the Foundation qualifies for the charitable contribution deduction under Section 170(b)(1)(A) and has been classified as an organization that is not a private foundation under Section 509(a)(1).

Concentration of Credit Risk

Financial instruments which potentially subject the organization to a concentration of credit risk, as defined by FASB Statement No. 105, consist principally of cash, temporary cash investments and marketable securities. The cash, temporary cash investments and marketable security accounts of the organization are maintained at high quality financial institutions. At times such accounts may be in excess of FDIC insurance limits, but pose no significant concentration of credit risk.

2. CONTRIBUTIONS RECEIVABLE (PROMISES TO GIVE)

Pledges of contributions (or promises to give) have been classified as unconditional or conditional. Unconditional promises to give at June 30 are as follows:

	2004	2003
Receivable in less than one year	\$50,000	\$50,000
Receivable in one to five years	0	50,000
Total unconditional promises to give	50,000	100,000
Less discounts to net present value	0	980
Net unconditional promises to give	<u>\$ 50,000</u>	<u>\$99,020</u>

The discount rate used on long-term promises to give was 2%. Management has deemed these promises to give to be fully collectible, and thus, no allowance for uncollectible pledges receivable has been recorded.

There were no conditional promises to give at June 30, 2004 and 2003, respectively.

3. INVESTMENTS

At June 30, investments were as listed below:

	2004		2003	
	Cost	Market	Cost	Market
Common stocks	\$36,407	\$5,091	\$33,418	\$6,647
Mutual funds	661,957	728,977	647,961	635,403
Total investments	<u>\$698,364</u>	<u>\$734,068</u>	<u>\$681,379</u>	<u>\$642,050</u>

4. FIXED ASSETS

Fixed assets are summarized as follows at June 30:

	2004	2003
Furniture and fixtures	\$39,146	\$39,146
Computer Equipment	48,536	47,740
Total fixed assets	87,682	86,886
Less accumulated depreciation	45,483	30,151
Fixed assets - net	<u>\$ 42,199</u>	<u>\$56,735</u>

5. GRANTS PAYABLE

Grants authorized but unpaid at year end are reported as liabilities in accordance with SFAS No. 116, "Accounting for Contributions Received and Contributions Made." On March 1, 2001, the Board of Trustees approved future research grants of \$250,000 to be paid to qualified recipients during the year 2002. As of June 30 2004, \$11,715 was unpaid.

On June 17, 2003, the Board of Trustees approved future research grants totaling \$500,180 to be paid to qualified recipients during the year 2003 and 2004. As of June 30, 2004, \$252,040 was unpaid.

In addition, on May 26, 2004, the Board of Trustees approved future research grants totaling \$722,332 to be paid to qualified recipients during the years 2004 through 2006. As of June 30, 2004, the entire amount was unpaid.

6. NET ASSETS

Temporarily restricted net assets at June 30, 2004 and 2003 are available for the following purposes:

	2004	2003
2004 Symposium	\$97,020	\$11,000
Equipment	0	5,000
Restricted as to time	50,000	99,020
Scholarships	1,000	1,000
Family Support	264	264
Support Groups	9,510	9,510
Fellowship	0	50,000
Total	<u>\$157,794</u>	<u>\$175,794</u>

7. OPERATING LEASE

The Foundation leases office space under an operating lease agreement that expires October 31, 2007. The Foundation also leases a copier under an operating lease agreement that expires December 31, 2008. The future minimum rental payments required under these lease agreements are:

Year Ended June 30	Amount
2005	\$49,748
2006	50,148
2007	50,148
2008	22,379
2009	3,519
Thereafter	0
Total	<u>\$175,942</u>

Rental expense amounted to \$47,276 and \$38,154 for the years ended June 30, 2004 and 2003, respectively.

8. CONTRIBUTED SERVICES

SFAS No. 116 requires contributed services to be recognized if the services received create or enhance nonfinancial assets or require specialized skills, are provided by individuals possessing those skills, and would typically need to be purchased if not provided by volunteers. The Foundation receives such services from community members who volunteer to provide video production, website development and accounting services. The value of these services was calculated as \$19,490 and \$17,262 for the years ended June 30, 2004 and 2003, respectively, and is included in the accompanying Statements of Activities as revenue and expense.

9. CHAPTERS

In addition to the national office of the United Mitochondrial Disease Foundation, Inc., local chapters have also been formed throughout the United States. These chapters include:

- Ohio Chapter
- Delaware Valley Chapter
- Southern California Chapter
- Kansas City Chapter
- New England Chapter
- Arizona Chapter
- New York Metro Chapter
- Indiana Chapter

Each chapter is required to file an application for their own employer identification number, abide by their signed chapter affiliation agreement and by-laws and to provide the national office their monthly chapter finance report. The Foundation has received a group exemption under 501(c)(3) of the Internal Revenue Code, and accordingly, will file a group tax return for the chapters. The primary purpose of the chapters is to provide a support network and conduct charitable fundraising activities for the Foundation. The chapters meet the requirements for consolidation and accordingly, their balances are included in the accompanying financial statements.

The Statements of Financial Condition include the cash balances of each chapter as of June 30 as follows:

	2004	2003
Ohio Chapter	\$22,429	\$5,230
Delaware Valley Chapter	37,315	21,083
Southern California Chapter	6,022	773
Kansas City Chapter	37,992	0
New England Chapter	0	414
Arizona Chapter	0	685

The Statements of Activities and Change in Net Assets for the year ended June 30, includes the activity for each chapter as follows:

	2004	
	Revenue	Expenses
Ohio Chapter	\$322,240	\$62,373
New England Chapter	31,413	3,996
Southern California Chapter	14,684	1,826
Delaware Valley Chapter	77,042	11,996
Arizona Chapter	2,681	632
New York Metro Chapter	30,996	2,226
Kansas City Chapter	49,453	4,393
Indiana Chapter	8,362	49
Total	<u>\$536,871</u>	<u>\$87,491</u>

“When everything in our life is wrong, it's time to take inventory of everything in our life that is right. Hopelessness is what happens when we allow ourselves to become helpless. UMDF redefines hope by turning tragedy into tribute and tribute into triumph. UMDF redefines hope!”

- Charles A. Mohan, Jr.



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**Lighthouse Artwork on Cover
About the artist...**

Chris O'Brien didn't know the cause of the fatigue, migraines, and muscle weakness that plagued her most of her adult life. Six years ago the Iowa resident was diagnosed with a mitochondrial myopathy and those symptoms finally made sense.

Currently she is a member of the Iowa Watercolor Society. In addition to several one-person shows, Chris has won numerous awards for her work. Her watercolors are in galleries and permanent collections throughout the United States. Her watercolors have been commissioned and presented as gifts to dignitaries from around the world, as well as requested as designs for cards and calendars. Chris has taught watercolor as an adjunct professor at Ellsworth Community College. She has not let mitochondrial disease take over her life – she, too, is a Beacon of Hope!