

# M N

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United Mitochondrial Disease Foundation

# MITOCHONDRIAL NEWS

Volume 11 • Issue 1 • Winter 2006

## Results of the "Families Dealing with Mitochondrial Disease" On-line Questionnaire

Depression, Dysmotility and Migraine Are Common in the Matrilineal Relatives of Patients With Maternally Inherited Mitochondrial Disease

*Richard G. Boles, M.D. and  
Brittany B. Burnett, M.S.  
Childrens Hospital Los Angeles and  
California Pacific Medical Center, San  
Francisco*

From February 2002 to July 2003, an on-line questionnaire was linked to the UMDF website ([www.umdf.org](http://www.umdf.org)).

Families were asked to participate in this questionnaire if at least one member (the "patient") was diagnosed with a mitochondrial disorder by a physician. The questionnaire contained 27 questions regarding the health of the patient, and 15 yes/no questions regarding potential diagnoses in each of 10 different relatives (parents, grandparents, aunts and uncles). The responses were sent to us without names or other identifying information. This study started as a genetic counseling (master's) thesis project by Brittany (then, Brittany Boldt) at California State University Northridge, with the study continuing past her graduation. Rare for a master's thesis, the results of this study were significant enough for publication, and in fact were just recently published by the *Journal of Affected Disorders* as a Preliminary Communication entitled "Mitochondrial Inheritance in Depression, Dysmotility and Migraine?" (Burnett et al., 2005, 88:109-116). The *Journal of Affected Disorders* is dedicated to research and patient care in depression. With the validation that peer-reviewed publica-

*Continued on page 11*

## Charles A. Mohan, Jr. More than 10 Years of Passion and Dedication Toward the Quest for a Cure



*Chuck with Heidi Marie Daniel  
in San Diego during the 2001  
conference*

Prior to 1990, Chuck Mohan was living the American Dream - owner and operator of Mohan's Restaurant, husband to a beautiful wife, and father of two healthy children. In December of that year, his 11-year-old daughter, Gina, had her first seizure and thus began the Mohans' journey into an endless nightmare of

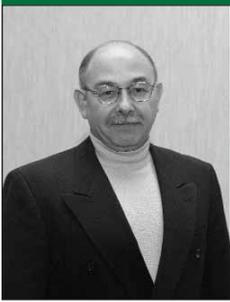
*Continued on page 8*

## Atlanta 2006 Mastering the Mitochondrial Maze

Mark Your Calendars!

Sheraton Atlanta Hotel  
Atlanta, Georgia, USA  
June 14-17, 2006  
Did you get your brochure?  
Register online at  
[www.umdf.org](http://www.umdf.org)

*Continued on page 11*



## Chairman's Message

As my first "Chairman's Message", I would like to take this opportunity to thank the Board of Trustees for entrusting me to serve in this capacity for the United Mitochondrial Disease Foundation (UMDF). It is with great honor that I accept the challenge to continue the great works that the foundation has accomplished over the past 10 years under Chuck Mohan's leadership.

In 2006, we will celebrate ten years of helping patients and families better care for their loved ones - through information and referral, patient registry and networking, hosting international symposia, and resource connections. In ten years of promoting RESEARCH, the UMDF has awarded more than \$2,700,000 in grant money dedicated to mitochondrial research and will present more than \$1,000,000 in research grant money at the upcoming conference in June.

Have we found a cure yet? Unfortunately, the answer to that is "no," however, many physicians and researchers agree that the field is growing and promising new projects are submitted each year to our grant program. What mysteries will be unlocked in the next 10, 15, 20 years that will move us closer to better treatments and ultimately to a cure?

The Board of Trustees and the UMDF staff are dedicated to continuing the mission - *to promote research and education for the diagnosis, treatment and cure of mitochondrial disorders and to provide support to affected individuals and families* - so that the researchers can put the missing pieces together and unlock those mysteries.

I look forward to working with the Board, its committees, and the UMDF staff in the upcoming year and building on the successes we have accomplished in the past ten years.

Sincerely,

John A. DiCecco  
Chairman, UMDF Board of Trustees

## Board Update

### New Officers (pictured below)

Please help us welcome our new board officers:

Chairman - *John A. DiCecco*

Vice Chairman - *Stanley Davis*

Treasurer - *W. Dan Wright*

Secretary - *Sharon Shaw*

### Newly Elected Board Members

Marty Lyman (see page 9)

Robert Polsky (see page 9)

### Chair Emeritus

The UMDF Board recently created the position of Chair Emeritus of the Board of Trustees of The United Mitochondrial Disease Foundation. Appropriate changes will be made to the bylaws and voted by the general membership in the future. The Chair Emeritus will serve as a permanent, non-voting, position on the UMDF Board. It was also agreed that, until such time as the position is formally created in the bylaws, the Board of Trustees shall recognize Chuck Mohan as the Chair Emeritus.

### Upcoming Board Meetings

Although the Executive Committee meets via conference call every 4-6 weeks, the full board will meet by conference call the end of April and then physically meet again during the 2006 conference in Atlanta, GA.

### Outgoing Board Members

Chuck Mohan, *Chairman, term 1996-2005*

Nick Rillo, *Trustee and Officer, term 1996-2005*

We honor these wonderful, devoted volunteers and look forward to their continued commitment to the UMDF Mission (See pages 8 and 9).

## United Mitochondrial Disease Foundation Trustee Officers



John A. DiCecco  
Chairman  
Apollo, PA



Stan Davis  
Vice Chairman  
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W. Dan Wright  
Treasurer  
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## Some Thoughts at the Tenth Anniversary of the United Mitochondrial Disease Foundation

J. Thomas Viall  
CEO/Executive Director



It hardly seems possible - 10 years ago The United Mitochondrial Disease Foundation was created through the consolidation of several smaller "mito" disease groups. We are observing our 10th anniversary in 2006, and I think it offers a good opportunity to reflect. Following are some random thoughts ...

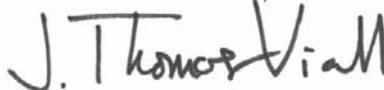
- Ours is a bittersweet anniversary; much sadness is mixed with joy. Too many of our children and too many of our friends have succumbed to mitochondrial disease. And yet we are all better for having known these good people; joy can coexist with sadness.
- No matter the depth of the challenge - it is better to rise each day with a sense of purpose than to muddle aimlessly about. Each of our "Mito" families understands the precious gift of life and - while the tasks faced on a daily basis may seem overwhelming at times - each has a passionate commitment to make the most of every moment of togetherness (a lesson others would do well to learn).
- We have come to not only believe - but expect - there is a technological solution to almost any problem. The fact of the matter is that science is hard work and ten years is not a long time when we think in terms of medical research. Our real challenge is to not weaken in our resolve to find treatments and cures for mitochondrial diseases despite this particular moment's lack of success. It is in the next moment that triumph may yet be found.

- An anniversary is often "celebrated" and that may, at first, seem inappropriate for an organization such as ours. Yet, I suggest we have much to celebrate. Mito Ambassadors are volunteering and Mito Groups are being formed all around the country. We anticipate - for the 2nd year in a row - putting more than \$1,000,000 into research grants. More and more people are becoming aware of mitochondrial disease and are willing to offer support by donations of time and talent as well as money.
- Collaboration is almost always better than the alternative. Together we leverage each other's talents to accomplish far more than we ever could individually. The model we established 10 years ago was the right model, and that is also something worth celebrating.

I look to the next ten years when we might have the opportunity to change our mission statement. Oh, we'll still provide support to families who are faced with a diagnosis of mitochondrial disease ... but wouldn't it be terrific if we were ensuring "access to effective treatments" rather than seeking a cure?

The first step toward achievement is the vision.

With all best wishes,



J. Thomas Viall

### Board of Trustees

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W. Dan Wright - *Treasurer*  
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J. Thomas Viall - *CEO/Executive Director*

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Kendall B. Wallace, Ph.D.  
David Whiteman, M.D.

### 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.

### Newsletter Editor

Kara Strittmatter  
kara@umdf.org

# Ask the Mito Doc

Living with mitochondrial disease presents many twists and turns – a maze of questions. UMDF is pleased to offer answers to some of those questions. All questions and responses are taken from [www.umdf.org](http://www.umdf.org) – Ask the Mito Doc. Please note that information contained in Ask the Mito Doc is for informational and educational purposes only. Such information is not intended to replace, and should not be interpreted or relied upon, as professional advice, whether medical or otherwise.

*Responders for this issue: Gregory M. Enns, MB, BCh University of California San Francisco, Stanford, CA and Sumit Parikh, The Cleveland Clinic Foundation, Cleveland, OH*

## The Question is:

Explain to me the caution to use Tylenol because it depletes glutathione peroxidase levels. My daughter is 16 months old and is teething. Should I give her Motrin instead?? Please explain and advise.

## Response From: Gregory M. Enns, MB, ChB

Glutathione (GSH) is an important part of the defense system to help the body combat stress caused by the production of toxic chemicals called reactive oxygen species (ROS) and reactive nitrogen species (RNS), so-called free radicals. As you know, mitochondria provide energy to cells and by doing so, function as a "cellular engine." In addition, mitochondria produce free radicals as a by-product of energy production, similar to a car engine producing exhaust fumes. Car engines that do not work correctly make an abnormal amount of exhaust. Similarly, dysfunction of

the mitochondrial respiratory chain can result in an increased production of toxic free radicals ("metabolic smoke"). Although the glutathione system works well to detoxify ROS and RNS under normal circumstances, in cases where there is increased free radical production, this defense system may be overwhelmed. Acetaminophen (Tylenol) is known to cause severe liver damage in cases of overdose. Acetaminophen is converted into a highly reactive chemical, abbreviated NAPQI, that depletes GSH in liver cells. Some researchers think that the net result of acetaminophen toxicity is the creation of free radicals followed by mitochondrial and cell death. If a toxic dose of acetaminophen is ingested, GSH levels fall, allowing NAPQI to cause damage by binding to various proteins inside the cell. Following this damage, free radicals are formed, leading to a vicious cycle of increased mitochondrial and cellular damage. Because acetaminophen causes GSH depletion, increased free radical production, and mitochondrial damage if taken in overdose, some people have raised concerns about the possible deleterious effects this medicine could have if taken by individuals who have decreased mitochondrial function. However, to my knowledge there have been no reports documenting acetaminophen toxicity in mitochondrial disease. At the usual dose, acetaminophen is likely a safe medication for pain relief and lowering fevers. Ibuprofen (Motrin) is also a safe medication when taken as directed by a physician.

## The Question is:

My son has MELAS. Our doctor is recommending Magnesium Orotate among the other normally prescribed vitamins. Has this been helpful for others? And, is there any new research about the use of Mg Orotate?

## Response From: Sumit Parikh, MD

Magnesium Orotate is still under investigation. It is a drug which is given at lower doses for magnesium supplementation. It was considered as a treatment for mitochondrial disease since it is converted to dihydro-orotate in the body, and an electron donor to Coenzyme Q10 (in theory it helps CoQ10 work better). It is also a potent anti-oxidant and helps the body synthesize more DNA precursors (purines) This drug is not yet standard of care for mitochondrial disease patients since it has not been studied enough. Most studies of this drug have been in animal models, and for treatment of heart disease. In these studies it has shown varying benefits in decreasing cardiac injury in times of stress and increasing exercise tolerance in those with an injured heart muscle. It has also been studied for treating muscle weakness related to "statin" drugs used to treat elevated cholesterol. There are no current US trials of this medicine for mitochondrial disease (or for any other disease for that matter). Dr. Anthony (Tony) Linnane, who spoke at the recent UMDF conference, is a researcher/physician from Melbourne, Australia. He studies the effects of aging, cancer and cardiac disease on the mitochondria, and is studying Magnesium Orotate. But again, these studies are not on individuals with primary mitochondrial disease. So - while there are no obvious contraindications to this medicine, it's true benefits and toxicities for individuals with mitochondrial disease are not yet known. The only obvious risk is that of magnesium poisoning. This has been reported in the medical literature.

# Chapter Activities

## ATLANTA AREA CHAPTER

Atlanta, GA

**President: Chris Swinn**

**Phone: 770-270-5337**

**Email: AtlChapter@umdf.org**



### Holiday Fun -

• Atlanta Chapter held their 2nd Annual Holiday Party at the Peachtree Club in Midtown Atlanta.

15 families (40+ guests) gathered to celebrate the holidays with each other and Santa!

• **October 23, 2006** - 3rd Annual Fore-A-Cure Golf Tournament at Standard Club in Duluth, GA. For more info, please contact Chris Swinn at 404-817-0999.

### Special Events - Thank YOU!

• **October 2005** - D. Morgan's Restaurant (Chef Derek Morgan pictured with Sherry) gave food away and asked for donations in honor of Sherry Mathison at the Art Festival in downtown Cartersville, GA. More than \$650 was donated to UMDF. Thanks Sherry and Chef Derek!



• Meineke Car Care Center in Cumming, GA ran a coin collection and raised \$205 in honor of two-year-old Megan Sheridan.

• The Ingram Family took 4th Place at the Polk Country Fair in Cedartown, GA, with their mitochondrial disease awareness booth and UMDF received their \$60 prize.

### Upcoming Events:

• **April 29** - 2nd Annual Race for Riley 5K Run/Walk and 1 Mile Fun Run/Tot Trot. Location: Georgia Baptist Children's Home Palmetto Campus. For more information, contact Waynette Peek at 770-463-0714 or visit [www.raceforriley.org](http://www.raceforriley.org).

• **September 2006** - watch for more info in the next newsletter regarding an upcoming Fun Walk at Piedmont Park. Event organizer - Sheri Seldes, 404-885-4882 or [sheri.seldes@turner.com](mailto:sheri.seldes@turner.com).

## Fundraising Tips – RE: eBay and Walmart

UMDF has developed a relationship with eBay that can help raise dollars to support the UMDF mission. Did you know that Walmart can provide matching dollars for your next fundraiser?

For more information, contact Jodie Tabano at 412-793-8077, ext. 106 or [jodie@umdf.org](mailto:jodie@umdf.org).

For activity/info for Southern California and Arizona Chapters,  
email [SCalChapter@umdf.org](mailto:SCalChapter@umdf.org) or [AZChapter@umdf.org](mailto:AZChapter@umdf.org)

### **Want to Get Involved?!**

Contact your local chapter or group **today**. Chapters and Groups will continue to grow with your HELP.

**YOU can make a difference.**

## NEW YORK METRO CHAPTER

New York Metro area

**President: Mary Pisani (North Haven, CT)**

**Phone: 203-287-0655**

**Email: NYMetroChapter@umdf.org**

### Upcoming Events:

• Saturday, May 7 - Mito Hope Run in North Haven, CT, in honor of Nicholas Pisani. For more info, contact Mary Pisani at 203-287-0655 or email [Mkpisani@aol.com](mailto:Mkpisani@aol.com).

• Saturday, May 13, 2006 - 6th Annual Matthew Dudgeon Memorial Walk, 7K Run, and Dinner Dance - partial proceeds benefit UMDF. Run begins at 8:30am with walk at 9:30am at Chester Train Station in Chester, NY. Dinner dance to be held at Brookside Manor in Middletown, NY at 7:00pm. For more info, contact Gina Dudgeon at [gdudgeon@mw.k12.ny.us](mailto:gdudgeon@mw.k12.ny.us) or visit [www.themattyfund.org](http://www.themattyfund.org).

# Chapter Activities

## DELAWARE VALLEY CHAPTER

Philadelphia, PA

**President: Maripat Shelly**

**Phone: 215-256-0273**

**Email: DelValChapter@umdf.org**

### Mark your Calendars

• **3rd Annual Brew at the Zoo** - Saturday, July 29, 2006 at Elmwood Park Zoo, Norristown, PA. Tickets are \$35. For more info, call 610-275-2775, email BrewAtTheZoo@msn.com or log onto [www.BrewAtTheZoo.net](http://www.BrewAtTheZoo.net).

### Looking Ahead

**Saturday, September 9, 2006**  
**6th Annual "Go! For Mito"**  
**Shelly's Heroes Walk Run**  
**at the Philadelphia Art Museum.**

### In the News

Maripat Shelly wins Philadelphia 76ers Hometown Hero award. See page 19 for more info.

## INDIANA CHAPTER

Indianapolis, IN

**President: Sue Ann Bube**

**Phone: 317-894-9099**

**Email: INChapter@umdf.org**

### Events/Fundraisers:

• **Special Thanks** - The Indiana Chapter *Pack the House* event was held February 25th. Joint promotion between the Indiana ICE and Penn Station created tons of exposure for UMDF. More details to follow. Special thanks to Sue Ann Bube for her tireless dedication to UMDF.

### Miles for Mito 2006 - Tentative Route -

• June 10 - Start Indianapolis, IN (Riley Hospital for Children) - Follow US 31 through Indiana. Possible cities: *Columbus, Seymour, and Scottsburg.*

• Route will follow low traffic highways and state roads parallel or near US 31 or I-65 through Kentucky. Possible cities: *Hodgenville, Munfordville, Bowling Green, and Franklin.*

## Miles for Mito Rides Again

**June 10-16, 2006**



• Route will continue into Tennessee - possible cities: *Westmoreland, Harsville, Woodbury, McMinnville, Monteagle/ Sewanee and South Pittsburg.*

• Following state roads in the vicinity of US 24/US 27 and the Silver Comet Trail, the bicycle riders will possibly go through these cities on their way to Atlanta, Georgia: *Summerville, Rome, Cedartown, Rockmart, and Marietta.*

• **June 16 - Arrive in Atlanta at the 2006 symposium.**

If you live near any of the above cities and would like to join the riders or help with promoting the event, please contact UMDF at 412-793-8077 or email [info@umdf.org](mailto:info@umdf.org).

• **Looking Ahead** - July 10, 2006 - *2nd Annual Indiana Chapter Golf Outing* at the Hawthorns Golf & Country Club in Fischers, IN. (Indiana Chapter)

*Special Thanks to Bob Thomas for organizing the Miles for Mito each year – creating awareness about mitochondrial disease along their route is PRICELESS!! Visit [www.umdf.org/milesformito/](http://www.umdf.org/milesformito/)*

## NEW ENGLAND CHAPTER

Boston, MA

**President: Bridget Willis**

**Phone: 413-593-5920 (Beverly Ingram)**

**Email: NEngChapter@umdf.org**

### Upcoming Events

- May 20, 2006 - *1st Annual Golf Outing for UMDF New England Chapter* at Easton Country Club in Easton, MA. 1:00pm shotgun start. Contact Bill Naughton, event chairman, at 781-982-9350.
- August 17, 2006 - Friends of Cameron picnic in honor of Cameron Genie at the Chicopee Falls Moose Family Center in Chicopee Falls, MA.

### Special Thanks

- Thank you to our friends in the Southampton, MA area for hosting a skate-a-thon raising \$388 for UMDF.
- Barbara Howard, neighbor to Ryan Shea and his family, raised \$770 through a door-to-door solicitation campaign. Thank you, Barbara, for your continued support!!
- Donna Veccharelli and Dan Rodriguez at PAC television in Plymouth, MA, continue to provide valuable media coverage for the New England Chapter and UMDF as a whole. Awareness is PRICELESS!!!

## KANSAS CITY CHAPTER

Kansas City, MO

- **Looking Ahead** - June 24, 2006 - 3rd Annual Mito-What? 5K Run/Walk One Step Closer to a Cure at Corporate Woods Founders Park, Overland Park, KS. 5K race begins at 8am with 1 mile walk at 8:15am. For more info, contact Theresa Edwards at 816-587-1375 or Brian Johnson at 913-631-3070.
- **Thanks** to a generous donation this past holiday, Santa was able to visit the home of each affected child of

**President: Pam Johnson**  
**Phone: 913-631-3070**  
**Email: KCChapter@umdf.org**

Kansas City Chapter members. Kids told Santa what they wanted and magically, a few items from their list appeared for them to open. Pictured right is Kierstin Honeycutt with Santa. What a great experience for the kiddos!



## OHIO CHAPTER

Cleveland, OH

**President: Bill Hodges**  
**Phone: 440-235-2451**  
**Email: OHChapter@umdf.org**

**Mark Your Calendars!**

**5th Annual KFC/UMDF**

**5K Run/1 Mile Walk - One Step Closer to a Cure**  
**Saturday, June 3, 2006**



*Marty Lyman, Ohio chapter member and UMDF Trustee, pictured with Brad Miehl President / CEO of MicroCorp at the 2005 MicroCorp One-on-One™ Conference*

### **Special Thanks -**

- The United Mitochondrial Disease Foundation - Ohio Chapter would like to recognize MicroCorp for choosing UMDF as the 2005 Charity Benefactor for the One-on-One™ Conference in October at Stone Mountain Resort in Atlanta. Once they became aware of the UMDF mission, MicroCorp quickly stepped up to the plate and generously invited UMDF to use their annual One-on-One™ conference as a platform to raise in excess of \$1,200 and raise awareness of our mission. We sincerely appreciate and respect their compassionate and proactive efforts.
- As part of a Bat Mitzvah project, Hannah Roberts (pictured right) of

### **UMDF Ohio Chapter Photo Project “The Many Faces of Mitochondrial Disease”**

The Ohio Chapter is creating a portable photo board of Ohioans affected by Mitochondrial Diseases. If you have someone that you would like to see included, please submit a photo and brief bio to be included in the photo board. Please include an exact diagnosis if available and info about how this disease affects the individual.

The board will be on display at the 5th Annual "One Step Closer to a Cure" Race and all other Ohio Chapter events. This board will be an excellent way to spread awareness of Mitochondrial Diseases and to focus some attention on the diversity of the symptoms and effects. Please mail your submission to: Ohio Chapter, P.O. Box 39416, Solon, Ohio 44139.

### **Upcoming Events**

- April 29, 2006 - 3rd Annual Family Spaghetti Dinner from 4-8pm at Pilgrim Lutheran Brethren Church in Mentor, OH. The dinner is hosted by the Arnold and Keeney families in honor of Maiya and Sadie. For info, call Jack at 440-968-3956.

### **Take Me Out to the Ballgame and Get a Haircut to Benefit UMDF**

New Image Haircutters, of Willowick, Ohio, will once again hold a cut-a-thon in honor of Jonathan Kucarcic during the following Lake County Captains games :

**Friday, April 28, 2006**  
**Friday, May 26, 2006**  
**Friday, June 23, 2006**  
**Friday, July 28, 2006**  
**Friday, August 25, 2006**

Head out to the ballpark with the family, stop by New Image Haircutters and support UMDF!

North Canton, OH created a 52 page Jewish holiday cookbook to raise funds and awareness for mitochondrial disease. Hannah donated \$1,000 to UMDF from her cookbook sales. Well done, Hannah!

- Thank you Carrie Roberts (friend of Amy Kalk) for hosting a Southern Living Party in honor of Molly Kalk and raising \$228.42.



Continued from page 1

hospital visits to reach a diagnosis. Four years later, Gina was finally diagnosed with M.E.L.A.S. (Mitochondrial Encephalomyopathy Lactic Acidosis and Stroke-Like Syndrome).



In 1994, Chuck reluctantly took over the COX Foundation, which was a fledgling organization at the time. COX is also a form of mitochondrial disease. He felt that the information he obtained through running this foundation would prove useful in the care of his daughter and he could help others at the same time. Unfortunately, on January 20, 1995, Gina Marie Mohan lost her battle with mitochondrial disease.

Determined to help other parents, Chuck lobbied other mitochondrial disease non-profits to join forces and form a united front in the quest for a cure. The United Mitochondrial Disease Foundation was officially born in 1996 and has been successfully growing into the most recognized foundation dedicated to mitochondrial disease research and providing support to patients and families in the United States.

What started in the basement of a father seeking answers is now a fully staffed, professionally run organization. Chuck Mohan led the way as chairman.

To accomplish great things, we must not only act, but also dream; not only plan, but also believe.

- Anatole France

## Through his leadership, 10 years later, the UMDF has...

- ...helped thousands of patients and families by providing resources to better care for themselves and/or their loved ones.
- ...raised more than \$2,700,000 to support mitochondrial disease research.
- ...organized eight international conferences to encourage the exchange of information and cultivate networking among physicians, researchers, patients and families.
- ...developed nine chapters and more than 20 Mito Groups across the United States to help families on the local level.

## Did you know ...

... in 1996, Chuck and Bob Bolewitz rode motorcycles to Corinth, MI, to meet with Charles Wilbanks to discuss a possible merger between the National Leigh's Disease Foundation and the United Mitochondrial Disease Foundation? Mr. & Mrs. Wilbanks could not believe that they rode a motorbike all the way from Pennsylvania. Pictured below is Nick Rillo, Bob Bolewitz, and the Wilbanks.



... the first UMDF office was an 8 x 8 room in Chuck Mohan's home then later moved to his basement? Kara Strittmatter and Toni Beasley, as the first UMDF employees, spent many hours there – sometimes days, sometimes evenings – and the Mohans (espe-



cially Adrienne) would graciously let the UMDF disrupt their everyday living (sometimes dinner and ice cream were a bonuses to working there).

... that Chuck Mohan was always a "hands on" leader? Not only was he vital to the day-to-day business over the past 10 years, he willingly packed trucks and hauled materials for fundraisers, assembled (and unassembled) office fur-



niture, volunteered at events (pictured above with Stan Davis and John DiCecco working at the Ohio Chapter run), and he even played Santa for the Arizona Chapter's holiday party one year.

... Chuck traveled all over the U.S. during his tenure – attending more than 100 events, meetings, and fundraisers? He volunteered his time and contributed financially, in-kind and out-of-pocket. Trips to fundraisers, like the St.



Louis Walk/Run (pictured above), were always a highlight for Chuck.

Continued on the next page

# Spotlight - UMDF Board Members

To keep UMDF members connected to our board volunteers, we will “spotlight” our trustees from time to time in the *Mitochondrial News*. For our first Spotlight, we will feature our two newest members, Marty Lyman and Bob Polsky.



## Marty Lyman

Marty Lyman is the father of Caroline Elizabeth Lyman who is severely affected with a Mitochondrial disease. Marty and his wife, Jennifer, have been actively involved with UMDF since 1998. Jennifer is the past President of the Ohio chapter of UMDF, and together they have worked on many successful committees and projects for the benefit of UMDF. Included in the chapters accomplishments are fundraising efforts totaling in excess of \$500,000, awareness campaigns for both the general public and the medical community, and support programming for affected individuals and family members. Marty is the President of Compass Solutions, a company he founded, which designs and implements telecommunication and internet solutions for businesses. Jennifer and Marty also have another daughter, Abigail who is unaffected by Mitochondrial disease. The Lymans live in Northeast Ohio.

## Robert Polsky

Bob joined the Board in 2006 and has previously served on the UMDF Governance Committee. Bob has been active with the UMDF since 1998. He developed and runs the annual fundraiser/beer tasting event, “Brew at the Zoo” for the Delaware Valley Chapter. Bob is a chemical engineer with the Parsons Corporation's Life Sciences Division where he specifies and evaluates custom designed process equipment for the pharmaceutical and biotechnology industries. Bob and his wife, Lisa, have three beautiful children, Amanda (diagnosed with Mitochondrial Disease in 1994), Abigale and Audra. The family is also expecting a new addition in May of 2006.



## Special Thanks Nick Rillo

Nick Rillo, of Chicago, Illinois, served on the UMDF Board since 1996. He designed the database in which UMDF tracks its members, donors, and other supporters. He has chaired the Database Committee and provided insight on technical concerns. Nick is a computer consultant and manages computer services for the Skin Disease Education Foundation.



Nick spent countless hours working with the UMDF staff and computer consultants to guide the office through numerous transitions over the years – web site updates, database upgrades, and much more.

The UMDF was very fortunate to have Nick Rillo as part of the computer team. He also had the pleasure of watching the office grow first-hand. Pictured above, Nick works with Kara Strittmatter in the first office space, the Mohan's basement, as consultant Bob Bolewitz looks on. Those were the days! Thanks Nick!



## Charles A. Mohan, Jr. *continued*



Meeting the families is very special to Chuck and, as the Chair Emeritus, he will continue to volunteer his time to outreach efforts – fundraising events,

special events, physician meetings, and more. Below, Chuck speaks to families in South Carolina in January of 2006.



**Thank you Chuck, Adrienne and Chuckie for being such a vital part of the UMDF Family. Chuck, you may not be chairman but, we know where you live and your work (as it is for all us) is not done!!!**

If you would like bios on other UMDF board members or staff, please visit [www.umdff.org](http://www.umdff.org) ([http://www.umdff.org/about\\_umdff/generalinfo.aspx](http://www.umdff.org/about_umdff/generalinfo.aspx)).

## ★ Mark your Calendars ★

See pages 5-7 for more details on chapter events

- April 22, 2006 - *3rd Annual Family Fun Day at the Shrine of Our Lady of the Snows in Belleville, IL.* For more info, go to [www.umdf.org/stlouisrace](http://www.umdf.org/stlouisrace) or call Joni Schnitzler at 618-624-0216.
- April 28, 2006 - *2nd Annual Chris Schindler Memorial Cutting* at Washington County Fairgrounds, Brenham, TX. For info, contact Joe Schindler at 713-542-2843 or email [cutterjoe@sbcglobal.net](mailto:cutterjoe@sbcglobal.net).
- April 29, 2006 - *Race for Ellie* (In honor of Ellie Kovalcik) at Library Park in Powell, OH. For more info, go to [www.premierraces.com](http://www.premierraces.com).
- April 29, 2006 - *2nd Annual Race for Riley 5K Run/Walk and 1 Mile Fun Run/Tot Trot* (Atlanta Chapter)
- April 29, 2006 - *2nd Annual Wine Tasting Event, Medford, NJ.* The event is in honor of Rachel Kindbom. For more info, contact Sharon Kindbom at [chrisnsharonk@comcast.net](mailto:chrisnsharonk@comcast.net).
- April 29, 2006 - *3rd Annual Family Spaghetti Dinner* hosted by the Arnold and Keeney families in honor of Maiya and Sadie. (Ohio Chapter)
- April 29, 2006 - *Break the Barriers Dinner* hosted by Brittany Wilkinson, a mito teenager in Fresno, CA. For more information, contact Brittany at 559-299-1767.
- April 30, 2006 - *Golf Outing* (Brighten Crest Golf Course) - also hosted by Brittany. For more information, contact Brittany at 559-299-1767.
- May 6, 2006 - *Silent Auction & Art Show* in memory of Carolyn Russell at the Mitchell Auditorium, Duluth, MN. For more info, contact Mary Russell at [RUSSELL4733@msn.com](mailto:RUSSELL4733@msn.com).
- May 7, 2006 - *Mito Hope Run* in North Haven, CT (NY Metro Chapter)
- May 13, 2006 - *6th Annual Matthew Dudgeon Memorial Walk, 7K Run, and Dinner Dance* - partial proceeds benefit UMDF. For more info, visit [www.themattyfund.org](http://www.themattyfund.org). (New York)
- May 13-21, 2006 - *6th Annual Kites for Kristen at St. Daniel of the Prophet School* in honor of Kristen Charleston in Chicago, IL. For more info, call Pat Charleston at 773-229-0605.
- May 19, 2006 - *2nd Annual Wipe Out Mitochondrial Disease Walk* at Merrill Crest Park/Bethesda Elementary in Waukesha, WI. 1 Mile Walk and 5K Run in memory of Sam Juhlmann. For more information, contact Deb Grabow, Bethesda PTO at 262-574-1550.
- May 20, 2006 - *1st Annual Golf Outing for UMDF New England Chapter* at Easton Country Club in Easton, MA. Contact Bill Naughton at 781-982-9350. (New England Chapter)
- May 25, 2006 - *9th Annual Pittsburgh UMDF Golf Outing at Churchill Valley Country Club.* For more info, contact Jodie at 412-793-8077 or email [jodie@umdf.org](mailto:jodie@umdf.org).
- May 25, 2006 - *2nd Annual Friends of AJ (Albert Jacob Floriano IV) Dinner Dance & Raffle* in Fall River, MA.
- June 3, 2006 - *4th Annual Pittsburgh One Step Closer to a Cure 5K Run/1 Mile Walk* at North Hills Boat House in North Park, Pgh, PA. For more info, contact Gillian McTiernan at 412-793-8077 or email [gillian@umdf.org](mailto:gillian@umdf.org).
- June 3, 2006 - *5th Annual KFC/UMDF 5K Run/1 Mile Walk* at Forest Hills Park in Cleveland Heights, OH. For more info, visit [www.umdfohio.org](http://www.umdfohio.org). (Ohio Chapter)
- June 24, 2006 - *3rd Annual Mito-What? 5K Run/Walk One Step Closer to a Cure* at Corporate Woods Founders Park, Overland Park, KS. For more info, contact Theresa Edwards at 816-587-1375 or Brian Johnson at 913-631-3070. (KC Chapter).
- June 14-17, 2006 - *Atlanta 2006: Mastering the Mitochondrial Maze* in Atlanta, GA at the Sheraton Atlanta Hotel on Courtland Street. Registration brochures have been mailed - call 412-793-8077 if you have not received a brochure!
- June 10-16, 2006 - *Miles for Mito* will travel from Indianapolis, IN to Atlanta, GA. See Indiana Chapter page for more detail! (Indiana Chapter)
- July 10, 2006 - *2nd Annual Indiana Chapter Golf Outing* at the Hawthorns Golf & Country Club in Fischers, IN. Call Mike Hanlon, event chair at 317-858-6356 or visit <http://umdfgolfouting.golfreg.com> (Indiana Chapter)
- July 17, 2006 - *7th Annual Ohio UMDF Golf Outing* at Kirtland Country Club in Willoughby, OH. For more info, please contact the event chair, Stan Davis, at 216-581-0000.
- July 29, 2006 - *3rd Annual Brew at the Zoo* at Elmwood Park Zoo in Norristown, PA. (Del Val Chapter)
- August 17, 2006 - Friends of Cameron picnic in honor of Cameron Genie at the Chicopee Falls Moose Family Center in Chicopee Falls, MA. (New England Chapter)
- August 19, 2006 - *Shadow Woodstock* in Auburn, OH. Contact Ohio Chapter for more info.

tion allows, we now wish to discuss our findings with the UMDF membership.

In order to understand the results of this study, it is important to have some familiarity with Mitochondrial Genetics. Mitochondrial disorders can be caused by mutations (genetic changes) in either the DNA that resides inside the mitochondria (mtDNA) or the DNA in the nucleus (chromosomes). The DNA in the nucleus is the "regular" DNA you probably heard much more about in your biology classes in school. mtDNA is inherited only from the mother, not from the father. Thus, unless there was a recent mutation, a child carries the same mtDNA as does his mother, brothers, sisters, maternal grandmother (mother's mother), and maternal aunts and uncles. These individuals who share the same mtDNA are called "matrilineal" relatives.

When a mtDNA mutation is inherited from that patient's mother, the disease is said to be "maternally inherited". Because of the unique and complicated nature of mitochondrial genetics, matrilineal relatives carrying a mtDNA mutation are frequently affected with symptoms, although often the disease is mild and can be very different from that found in the patient. Thus, a typical family with a mtDNA mutation might include a child with mental retardation and seizures, a sister with cardiomyopathy (heart muscle weakness), a mother with leg weakness and fatigue, and a maternal grandmother with deafness and hypothyroidism - all because of the same mutation!

Mutations in the chromosomes ("regular" DNA) that cause mitochondrial disease can be inherited in many different ways. However, in most cases the inheritance is "autosomal recessive", in which both parents are healthy carriers. In most cases, the patient is the only affected family member, although a brother or sister may also be affected.

Although the method is not full-proof, we can use family history data to determine which families are probably maternally inherited (thus, likely having a mtDNA mutation related to their medical problems). This is because, if the disease in a family is maternally inherited, one would expect disease manifestations to be present in the matrilineal relatives (mother, mother's brother, mother's mother, etc.) far more often than in the non-matrilineal relatives (father, father's brother, father's mother, etc.). Non-maternally inherited families should not demonstrate this "maternal bias". Our job was made more complicated because no family is perfect, and non-mitochon-

drial-related disease is expected to be randomly distributed among the relatives in maternally and non-maternally inherited families alike.

In this study, we received complete questionnaire responses from 171 families, and 55 of them (one-third of the total) were assigned by us to the "probable maternally inherited" (PMI) group.

The group assignment criteria were complicated, and involved a review of the entire family history provided. In almost all PMI cases, the mother and at

**Table 1. Potentially-mitochondrial-disease-related conditions used to define the probable maternally inherited (PMI) group**

<b>Anxiety Disorder</b>	<b>Depression (clinical)</b>	<b>Hypotonia</b>
<b>Bowel Disease</b>	<b>Episodic/Cyclic Vomiting</b>	<b>Kidney Disease</b>
<b>Cardiomyopathy</b>	<b>Hypoglycemia</b>	<b>Migraine Headaches</b>
<b>Deafness</b>	<b>Hypothyroidism</b>	<b>Seizures</b>

least one other first or second-degree matrilineal relative were reported as being affected with at least one condition on a list of potentially-mitochondrial-disease-related conditions (Table 1), while there were far fewer of these conditions among non-matrilineal relatives.

Most of the remaining families (111) did not appear to have maternal inheritance and did not meet our criteria. While many of these families likely have nuclear DNA mutations with autosomal recessive inheritance, there are other possibilities including rare inheritance patterns, new mtDNA mutations (not present in the mother), and misdiagnoses (not mitochondrial disease). We assigned these 111 families to the "probable non-maternally inherited" (PnMI) group. Finally, there were 5 families that did not fit the criteria of either of the groups, and therefore were not placed into either group. In order to avoid a logical circle, group assignment for each condition was performed independent of the presence or absence of that condition in that family. Thus, for example, when migraine was being evaluated, families were assigned to either the PMI or the PnMI group based upon the presence or absence of the other 11 conditions, excluding migraine.

The patients themselves had generally undergone multiple tests before the diagnosis of a mitochondrial disorder was reached, including in most cases muscle biopsy and DNA testing. As expected, almost all (exactly 95% of both the PMI and PnMI groups) had some kind of nerve (including brain) or muscle disease. This indicates that both groups had patients that

*Continued on page 14*

# Fundraisers

## Bet on Baylee Deals Out Another Successful Event Raising more than \$10,000

Pictured right, Baylee Thompson is surrounded by sister Jade and her two cousins, Peyton and Jordyn at the *3rd Annual Bet on Baylee Casino Night* in Roseville, OH. More than one hundred came out to get a better "deal" for Baylee and others battling mitochondrial disease. Thank you, Jody and Gary, and your entire circle of friends and family for their continued support!

This past winter, Baylee and her mom, Jody, also had the privilege to meet Ohio State University Football Senior, AJ Hawk, and receive numerous OSU items for their auction -- such as a football signed by all the senior players. After meeting Baylee, AJ walked away proudly wearing a UMDF Energy Band.



## 2nd Annual Ally Brunk Memorial Run Raises \$4,000

To honor the memory of their sister, Allyce Daniel Brunk, Laynee and Carson Brunk wear their event t-shirts with great pride. Thank you, Brunk Family!!

**If you have an event announcement or an idea for an article for the Mitochondrial News, please email [kara@umdf.org](mailto:kara@umdf.org). We want to hear from YOU!**

**For information on starting a fundraiser in your area, email [jodie@umdf.org](mailto:jodie@umdf.org).**

## Gifts from the Heart - Thank You ALL

- *Friends of the Rudy Burki Invitational Classic (RBIC) Golf Tournament* in Burlington, Ontario, selected UMDF to receive \$1,449.11 in honor of Lindsay Firlotte -- Hal Firlotte is a longtime player in the RBIC. Thank you *Friends of RBIC* and the Firlotte Family!
- *LSI Dress Down Day* in December in Coraopolis, PA, raised \$1,149.14 in honor of Kendall Obley.
- *House of Horrors* - Lauren Allred and University of South Carolina students raised \$432 by volunteering time at the Jaycee haunted house. Excellent!
- *Pampered Chef* - In memory of Heidi Marie, Cindy Thompson, friend of Heidi's mom, Norma Gibson, hosted a fundraising event and donated \$276 to UMDF.
- *Max & Erma's UMDF Day* - In honor of Ellie Kovalcik, family

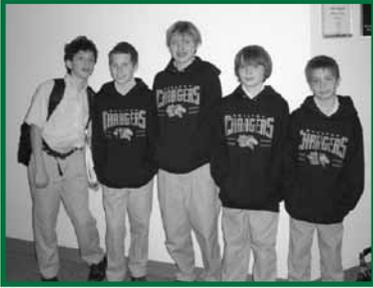
and friends of Ellie joined together at Max & Erma's and raised more than \$500. Eating out never sounded so good!

- *The Red Hat Society* donated \$80 in honor of Turner Trimbath, of Dunbar, PA.
- Friends and family of Fran Russell contributed \$520 to UMDF to celebrate Fran's 60th Birthday and to honor the memory of Carolyn Russell, Fran's daughter.
- The Buffalo Public Schools Native American Magnet School 19 contributed \$215 in memory of Leah Janusz. Grandmother Elizabeth Scholz is a member of their school community.
- *Entertainment/Enjoy Book Sales* - thanks to Ron Miklos, of Plum Boro, PA, the UMDF received \$3,000 in profits from sales this year. Thanks, RON!!



- *Charity Basketball Game* - Brian Werner, 4th grade teacher at Ramsey Elementary in Monroeville, PA, has organized this charity game for the past six years and chose UMDF and National Alliance for Autism Research (NAAR) as the beneficiaries this year. Teachers played against local VIPs and Ramsey cheerleaders (pictured above) provided entertainment throughout the evening. The event raised more than \$2,000 for UMDF! Thanks Brian and everyone at Ramsey for helping!

## Outstanding Youth in Action



### Matthew Johnston & Friends

On December 11, Tova & Topher Sido ran the Dallas White Rock Marathon to honor the memory of their son and daughter, Charlie and Louisa. The Sidos collected pledges and raised more than \$7,000. Matthew Johnston, a neighbor of the Sidos, wanted to collect pledges as well and then talked his friends into joining the cause. And so they did -- pictured from left to right, Schaffer Ochstein, Cameron Casey, Holden Novak, James Graass, and Matthew Johnston ran the marathon and collected more than \$1,000 in pledges. Outstanding job, guys!



### Nina Quinn

Another outstanding youth comes to mind: Nina Quinn, of Monroeville, PA (pictured above with Chuck Mohan) had to convince her class to choose her "disease project" and her charity. Nina chose UMDF and mitochondrial disease as her project and did an excellent job gathering facts, which paid off. The class chose her project and raised more than \$300 to benefit UMDF.

## Fundraisers

### Zachary Foundation Donates \$30,000 to UMDF!



On October 16, 2005, more than 500 people came to run, walk and support research for Mitochondrial Disease at the **Second Annual Zachary Foundation Walk/Run**.

The Zachary Foundation was founded in July 2004 to support research for Mitochondrial Disease and in particular Pyruvate Dehydrogenase Deficiency.

Zachary is 8 years old and – despite his disease – is a fun, active, and loving child. Zachary is supported by a large community of hard-working friends and family in the Marlboro, New Jersey area – including his brother Benjamin and sister Rebecca (pictured above with Zachary, parents Michael & Rhonda Friedberg, and UMDF CEO/ED, Tom Viall). The Zachary Foundation has donated \$30,000 to UMDF this fiscal year – from the proceeds of this event and an annual golf outing. Thank you to all who have made these events a success – especially Zachary's family!

### For Lorenzo

The Scavio Family of New York contributed \$10,000 to UMDF in memory of their first-born son Lorenzo Gregory Scavio, who lost his battle with mitochondrial disease on April 10, 2005. The family raised money through bracelet sales.

## Special Thanks to MORE

### ★ Fundraising Stars ★

- In memory of Paul Buczinski, of Murrysville, PA, Catherine Federline and Monica Buczinski donated their birthday money to UMDF. Thank you Catherine for sending \$81 and Monica for the \$380. Happy Birthday, girls!
- Emily Fischer and her fiancé, Joe, hosted some special activities at the Nessun Dorma in Milwaukee, WI – raising \$500 in memory of Sam Juhlmann.
- In lieu of wedding gifts, Patrick and Karon Sullivan, of Florida, accepted contributions to UMDF in honor of Sam and Zachary Juhlmann. More than \$4,000 was raised. To read their story, visit [www.umdf.org/sammy](http://www.umdf.org/sammy).
- The Missouri Senior America Cameo Club donated \$250 to UMDF in honor of Bert Cohen, grandparent of a child with mitochondrial disease.
- In honor of Michael Pastorelli (Ron & Peg Donohoe's grandson), staff and volunteers of St. Charles Parish and School in Woburn, MA contributed \$1,570 to UMDF as part of their annual Christmas Grab Bag exchange fundraiser.
- Texas Hold 'em at Bella Notte in Pittsburgh, PA raised \$1,335 in memory of Gina Marie Mohan – special thanks to the Sunseri Family!
- In honor of Hailey Charbonneau of Ashburnham, MA, patrons at the Horse Shoe Pub were charged \$1 every time their cell phones rang – \$200 was donated to UMDF. Can you hear me now? You bet!

had fairly severe, and typical, mitochondrial disease.

However, it was the symptoms within the adult relatives that were the real focus of this project. As we believe that most of the PMI mothers carry mtDNA mutations, they might be expected to have some symptoms related to this. This is not the case with either the PnMI mothers or the fathers in either group. This is exactly what we found, as is shown in Table 2:

**Bold font highlights data from mothers in the probable maternally inherited group, corresponding to individuals expected to exhibit some degree of mitochondrial dysfunction.**

with probable maternal inheritance, each being reported in over one half of the mothers. Although the numbers in the other three categories may seem large, bowel disorders, migraine and depression are very common conditions in general, and our numbers are consistent with the known frequencies of these conditions in the population at large. Our data regarding bowel disorders, migraine and depression is very highly statistically significant (for those that are interested, p values vary between 0.0004 and 0.00000001). These conditions were reported frequently in the patients as well, but in many cases their presence was likely overshadowed

What does this study tell us? Take another look at the conditions in Table 2. Among maternally inherited families, you (the families) are telling us (the health professionals) that the most common problems that you suffer from are conditions that cause pain and distress, but which will not show up on a physical examination or laboratory testing. These conditions were reported several times more frequently in those individuals that presumably carry mtDNA mutations (mothers, and maternal aunts, uncles and grandmothers in probable maternally inherited families). Thus, we have come to the conclusion that the mtDNA must be predisposing (increasing the risk) towards the development of these conditions.

Migraine and bowel disorders (dysmotility: including diarrhea, constipation, abdominal pain, heartburn [reflux], etc.) are well established as being frequent manifestations of mitochondrial disease. However, depression and anxiety are not. Thus, taken together, the most novel finding of our study is that the mtDNA can increase the risk for developing clinical depression and anxiety disorders. This is why the study is published in a "psychiatric" journal. This finding has many implications, which are discussed in the next article entitled "Depression and Anxiety in Mitochondrial Disease".

Turning back to some of the "physical disease" manifestations that demonstrate maternal inheritance in our study, some of you may now be thinking, "So, my migraine headaches, stomach pains, constipation, and aches and pains are all due to mitochondrial disease?" Well, "yes" and "no".

**Table 2. Clinical findings in the parents of patients**

	Probable Maternal Inheritance	Probable non-Maternal Inheritance	Probable Maternal Inheritance	Probable non-Maternal Inheritance
	Mothers	Mothers	Fathers	Fathers
Bowel disorders	<b>60%</b>	16%	16%	12%
Migraine	<b>54%</b>	26%	12%	9%
Depression (clinical)	<b>51%</b>	12%	9%	12%
Arthritis	<b>39%</b>	19%	11%	7%
Anxiety	<b>38%</b>	10%	12%	10%
Heart problems	<b>35%</b>	10%	11%	11%
Hypoglycemia	<b>24%</b>	7%	2%	5%
Cardiomyopathy	<b>18%</b>	1%	0%	3%

Based upon personal experience, in PMI mothers, "arthritis" is often muscle cramps, and "heart disease", when not cardiomyopathy, is often an arrhythmia, especially tachycardia (rapid heart rate).

The frequencies of the other conditions listed in Table 1 were low (< 10% in all groups), and were not statistically more common among the PMI mothers.

As can be seen in Table 2, bowel disorders, migraine headaches and clinical depression are very common among the mothers in families

owed by the more "serious" neuromuscular disorders.

Our results for the extended relatives demonstrated the same findings: that the conditions listed in Table 2 were far more frequent in the maternal grandmothers, aunts and uncles in PMI families, those individuals who presumably share the same mtDNA mutations as do the patients. Among the PMI maternal aunts and uncles, the most common conditions were, in order: depression, anxiety, bowel disorders and migraine.

Continued on page 15

## Results of the "Families Dealing with Mitochondrial Disease" On-line Questionnaire

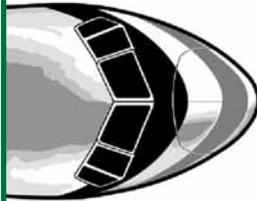
Continued from page 14

These conditions are "multi-factorial", meaning that they have many causes, only one of which is "mitochondrial" in nature. Therefore, the optimal therapeutic regiment addresses all potential causes, both mitochondrial and non-mitochondrial alike. For example, in migraine headache, combining traditional non-mitochondrial therapies (e.g. the avoidance of flashing lights and certain processed foods, and the use of various prescription and non-prescription drugs, including caffeine, ibuprofen and/or amitriptyline) with "mitochondrial therapies" (e.g. co-enzyme Q10, L-carnitine, and the avoidance of high-energy demand situations, especially fasting) can be a powerful combination in the treatment of "mito relatives" with migraine. Of course, therapy is individualized and depends on many factors, including the frequency and severity of symptoms as well as the presence of other medical problems and those drugs already taken. So, before doing anything, it is important to discuss it first with your doctor (and I do realize how impractical this recommendation can be, but it is nonetheless important).

We wish to give special thanks to the families that participated in this research, and to the UMDF for their help and the use of their website.

*Editor's Note: Special thanks to Dr. Boles and Brittany Burnett for sharing their findings. The UMDF's intent is to keep you informed and since the project's data was collected through the UMDF web site, we were pleased to see the results. As always, we ask that you continue to discuss any diagnoses, treatments, or medications with your personal physician.*

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#### 2nd Prize

- A two night stay and complimentary spa passes to the **Catamaran Resort Hotel** in San Diego, CA and \$500 in American Express Travelers Cheques.\*\*

#### 3rd Prize

- Luggage Set

\*\* Please note that the 2007 UMDF Conference will be held at the Catamaran Resort Hotel!

**Drawing Date: June 16, 2006**

Drawing will take place at the **Atlanta 2006: Mastering the Mitochondrial Maze at the Sheraton Atlanta Hotel**

**\$5 per ticket  
\$25 for book of 6 tickets**

For more information or to order tickets, please contact UMDF at 412-793-8077. Contest rules are available on the UMDF web site and/or noted on the raffle tickets.

**Individuals who sell ten books of tickets  
will receive a UMDF Polo Shirt!**

All proceeds to benefit the  
United Mitochondrial  
Disease Foundation.

**Attention Groups and Chapters:  
See Page 21 for incentives!**

# Donors - Thank YOU!

## Appreciating the People Along the Way

*"We are often so caught up in our destination (a cure and better treatments) that we forget to appreciate the journey – especially the goodness of the people we meet along the way."*

- Margaret Malone

The United Mitochondrial Disease Foundation has not forgotten and deeply appreciates each and every individual, organization, and corporation that has generously donated money to support our mission. While we would like to list ALL our donors in the newsletter, please understand that it would be difficult to do so. If we did, we typically have more than 8,700 names that donated \$1-99 (THANK YOU); 2,000 names that donated \$100-249 (THANK YOU) and more than 550 names that donated \$250-499 (THANK YOU). We know who you are and you are appreciated. Your contributions continue to make a difference in the lives of those affected with mitochondrial disease.

The following acknowledgements include **donations of \$500 or more (entered into the system) between July 1, 2005 to December 31, 2005**. If your name or company's name is not listed, please contact kara@umdf.org. We continue to move through a database transition and we need to hear from you if our information is not accurate!

### **Benefactor \$10,000 and over Corporations, Organizations and Foundations**

Black & White Productions  
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Union Bank of California  
Virginia Friedhofer Charitable Trust

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Molly Auth  
Dr. & Mrs. Charles Babbush  
Mr. Gary S. Bluestone  
Alex R. Bobick  
Karmen Booker  
Michael Brewster  
Dan & Julie Brunk  
Keith Butler  
Chuck Carroll  
Dr. Art Caylor, M.D.  
J. Donald Childress  
Sean & Donna Collins  
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Burton Garret  
David & Phyllis Gray  
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Andy Thomas McDonald  
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Strecker Eye Care Center  
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### **Individual/Families**

Stephen & Rosalind Atkins  
Debra Baak  
Heidi & Robert Bailey  
William & Kathryn Baker  
Stacy & Wayne Block

## Donor Acknowledgement Continued - THANK YOU

Carrie & Bradley Boericke  
Dave Boncek  
Eileen & Thomas Brennan  
Mr. & Mrs. Randall Brown  
Maurice & Betty Burgener  
Eliot & Susan Charnas  
Patrick & Dawn Chase  
Robert & Mary Jean Cloherty  
Richard & Sharon Cohen  
Dr. & Mrs. Bruce Cohn  
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Theresa McNamara  
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Robert & Jill Platt  
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Paul & Paula Quinn  
Gail R. Rader  
Mary & John Raterman  
Kay & Mel Resnick  
Seymour Resnick  
Judith & George A. Rothbard  
Theodore Rudolph  
Linda & William Schecter  
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James Sr. & Nancy Sido  
Marla S. Silberman  
Peggy Slappey  
Rodney & Deborah Slump

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Philip Steele  
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Mrs. Florence Subin  
George & Kathy Svlar  
Winston C. Taylor  
Kerry Tobin  
Jay & Karen Tompkins  
Sandra & Rick Trottier  
Lois Ann & Bruce A. Tyler  
Diane & Michael Vincent  
William & Kerri Waddell  
Robert Wagner  
Peter Jake Wallace  
Joe & Clara Waller  
Helen & John Ward  
Stephen J. Weinberg  
Kelsey Wright  
Mike & Piper Wyatt  
Brian Yamaato  
James Yoder  
Tina Zadrozny

The following was pulled from the Oley Foundation web site, and since Zachary is one of our "mito" kids, we would like to share his achievement! The Oley Foundation helps people whose daily survival depends on home intravenous or tube-fed nutrition.

### Oley Foundation Young Adult of the Year Winner Sponsored by Pediatric Services of America Zachary Juhlmann of Waukesha, WI

Zachary Juhlmann is an exceptionally sunny, optimistic 13 year old boy, who smiles often and thinks positively despite a multitude of health issues and some hard knocks no one should have to deal with. His road became rocky at 5 weeks old, and eventually mitochondrial cytopathy was determined to be the cause of his challenges. He has gradually lost the ability to eat, then to be fed by J-tube, so now he is wholly dependent on TPN. Additionally, he requires a continuous cardiac drip and two other infusions. His biggest loss, though, has been his younger brother Sam, who succumbed to the same diagnosis this past year. Zachary was a wonderful model to Sammy, who was also

completely dependent on TPN for most of his 7 years and 9 months. Zachary taught Sam in word and action that being on TPN was just the way it was and that did not mean life should not be lived. They were "best brothers," shared a room, and did everything together. Zachary is fiercely independent, and determined when he started TPN full time that "I am never going to get better, and never going to get off TPN, so I better learn how to give myself my meds and TPN; because I don't want you to come to college with me, and I am definitely growing up and going to college." To know you will never get better at the age of 13 is quite a burden to carry. Zachary carries this burden with

grace, while doing his homework, going to robotics club, playing piano, and playing with friends. When his class studies nutrition, Zachary shares how his therapies work, helping his classmates understand nutrition support. Zachary's mom Anne states, "His hope, despite the incredible reality he lives with, and his love of life, are inspirational and humbling to those around him. He is the most courageous, resilient person I know." We are proud and honored to award Zachary Juhlmann with the Young Adult of the Year Award.

*Editor's Note: Congratulations Zachary and best wishes to you and your entire family!!!*

## 2005 Holiday Card Campaign

Special thank you to EVERYONE who participated in the 2005 Holiday Card Campaign. Nearly \$64,000 was generated from this annual appeal – Outstanding!!!

**Join us in Atlanta –**  
Search the Mitochondrial Maze for Knowledge  
and Celebrate our Accomplishments

## Atlanta 2006

Mastering the  
Mitochondrial Maze



### Scientific Meetings

June 14-17, 2006

### Family Meetings

June 16-17, 2006

Sheraton Atlanta Hotel  
Atlanta, Georgia, USA

Register online at [www.umdf.org](http://www.umdf.org)

If you have not received a brochure with program details,  
please email [info@umdf.org](mailto:info@umdf.org), or download one from the web.

We hope you will join us on Friday, June 16, 2006  
to celebrate the United Mitochondrial Disease  
Foundation's 10th Anniversary.

### ***This Special Evening will ...***

#### ***... Celebrate our Accomplishments in Research***

*Help us Congratulate our 2006 Research Grant Recipients*

#### ***... Celebrate our Volunteers***

*Cheer on our 2006 Heartstrings and LEAP Recipients and Enjoy a  
Special Tribute to UMDF's First Chairman  
Charles A. Mohan, Jr.*

#### ***... Celebrate with Magic***

*Comic-Magician Sam Simon "creates a high-energy show that will  
make the audience roll with laughter and gaze in amazement."*

***Please note that we are selling extra tickets to the banquet as a  
fundraiser to offset conference expenses. Call 412-793-8077 for  
more information.***

There's a  
little  
bit  
of  
magic



#### **More Magic and Music!**

Sam will continue the magic in  
the reception area and music will  
be provided by a local DJ for  
those who are not quite ready to  
call it a night.

in  
all  
of us



It is finally official, and The United Mitochondrial Disease Foundation has a new identity (logo and tagline). Within the next few weeks, the above logo will also incorporate the new tag line of "Hope. Energy. Life."

On behalf of the UMDF Board, Staff, and membership, we would like to thank the members of the Marketing Subcommittee as well as the Planning and Marketing Committee (see below). Allison Rogers has been a dynamo in orchestrating the logo development and continues to spend countless hours with her committee on the development of a much needed Marketing Communications Plan.

As noted in the last newsletter, an exhaustive investigation went into the development of the logo and key issues for an effective new identity included *Timeless Style, Distinctive, Appealing, Strong & Impactful, Legible, Easily Identifiable and Versatile.*

Over the next six months, you will notice a slow transition to the new logo and tagline. New stationary and other print collateral are in the early stages of development.

We are all very excited about the possibilities this new identity will play in telling our story and opening doors to funding – giving each and everyone of our affected children and adults ***Hope. Energy. Life.***

#### **Planning & Marketing Committee**

Chair: Richard W. Kubach, Jr.  
Allison Rogers, Chuck Mohan,  
Tova Sido, and Michael Friedberg.

#### **Marketing Subcommittee:**

Chair: Allison Rogers (SC)  
Heidi Bailey (CT), Jason Conte (CA), Jeff Salt (OH), Karen & Bill Wilson (PA), Dave Stahler (OH), and Alison DeVriendt (CA)

## Mito Adults Corner - by Barbara Bruck



### Tribute to Chuck Mohan

I can't recall a time when I didn't know him. It is just like that with some people – where the connection runs so deep it feels as though they have always been a part of your life.

In the decade that I have known Chuck Mohan, I have probably only been in his physical presence ten times. But, the

connection was made the first time I heard him speak. Perhaps it was the sincerity in his voice that grabbed my attention, or maybe I was impressed by his overwhelming generosity in the face of the tragic loss of his own daughter. Either way, for me, Chuck Mohan's words were magical – they beckoned me to take action and forged an unspoken bond.

No, I have not had the privilege of spending vast amounts of time with this remarkable human being, but I think of him often. I think of him on those days when I feel as though I have been abandoned by a world that can't possibly begin to fathom the suffering of someone afflicted with mitochondrial cytopathy. I seek solace in the fact that one man has not forgotten me – that Chuck Mohan is out there fighting with every word he speaks for all of us who wage war daily with this pernicious disease. I think of Chuck Mohan every time there is a milestone event in the life of my wonderful seventeen year old daughter. I understand that no matter how compromised my life has been, I am fortunate to have sur-

vived to celebrate every one of those occasions. I am acutely aware that on the day that Gina Mohan lost her valiant fight for life, her family lost their bragging rights of all that could have been. While there is no compensation for the loss of a daughter, I do carry Gina in my heart ever single day. I draw inspiration from her short time on earth and the magnanimous commitment her family made so that their daughter's death would not be in vain.

Coincidentally, as Chuck Mohan prepares to retire from his position as Chairman of the Board of the UMDF, my daughter Dana is preparing to graduate from high school and enter Vassar College in the fall. It is a time for deep reflection. I celebrate my daughter and Chuck Mohan for their extraordinary contributions to the world. It is inevitable that I will miss my daughter as she embarks on the next juncture of her life, but I will also miss that man whose presence I have been in less than a dozen times. I will remain forever grateful that a man with a heart so generous reached through his own pain and mine to inspire me with hope for the future and courage to become part of a quest for the cure. On the many days when it is a struggle just to breathe, I hold Gina's memory close and pay tribute to Chuck Mohan who won my heart with the very first word I ever heard him speak.

With Deepest Gratitude,



Barbara Bruck

## Mito Adults Corner

### Calling All Mito Adults: *The Mitochondrial News Needs YOU!*

Please consider submitting an article for review or sending us your experiences with a specific topic of interest. If you are willing to help, please email Kara Strittmatter at [kara@umdf.org](mailto:kara@umdf.org) or call 412-793-8077, ext. 114. We look forward to hearing from you!

### In the News

The **Georgia General Assembly** commends UMDF through a special *Resolution* and cites the 2006 Conference: [http://www.legis.state.ga.us/legis/2005\\_06/sum/hr1683.htm](http://www.legis.state.ga.us/legis/2005_06/sum/hr1683.htm)

Thank you Sheri Seldes for sharing this and helping make it happen!



The *Philadelphia 76ers* honored Maripat Shelly of Harleysville, PA, as a "76ers Hometown Hero" at the Sixers-Hawks game on Wednesday, March 22, 2006. The "76ers Hometown Hero: In the Spirit of Alex Scott" program recognizes "an everyday hero in the community" and awards two tickets to a Sixers game.

Maripat, as well as her five children, suffers from Mitochondrial Disease, but that has not stopped her from volunteering as the Delaware Valley Chapter President or helping to orchestrate the Chapter's successful annual "Go for Mito!" Walk/Run (which is set for September 9, 2006). Maripat doesn't seek such recognition but, for many of those who know her, she deserves it. Special thank you to Dana and Alan Genetti for nominating Maripat – our heroes deserve recognition, and you helped make that happen!!

From the Desk of  
**Becky DiLettuso**

**Director of Member Services:**

We are launching a new program! Soon you will be seeing the names of our Ambassadors listed in the Newsletter, and here's why.....



We receive requests for support, information and referral from various parts of the United States and other countries in regard to mitochondrial disease, and many families want to connect with others near where they live. Often we are unable to create a Mito Group due to the limited numbers of members in a given region, the remoteness of the area of the country, the lack of readily available public transportation and limited access to medical services. In response to these requests for support, we have established a program called "UMDF Ambassador" for those persons who are willing to take the responsibility for supporting other individuals and families in their area, but due to one or more of the reasons listed above, creating and sustaining an ongoing Mito Group is currently unrealistic. The Ambassador will work to increase awareness, educate local physicians and assist others who might contact them to do the same. If through this education and awareness process, there is enough interest and membership to move to Mito Group status, this would be accomplished in conjunction with support by the Member Services Department. This new program will enable the UMDF through the Ambassador to heighten the local awareness about mitochondrial disease and expand our presence nationally. If you are interested in becoming an Ambassador, please contact us at [info@umdf.org](mailto:info@umdf.org) or call us at 412-793-8077.

## Announcements and Merchandise

### Two New Faces at the UMDF Office

#### Tania Hanscom - Data Entry/Finance



Tania Hanscom is a 2002 graduate of Slippery Rock University with a BS in Sports Management. She has experience with special events, marketing, sales, and customer service. Tania joined the UMDF staff in November 2005 and has already become

invaluable in the finance department as well as providing assistance to the other departments as needed.

#### Owen McGrann - Development



Owen McGrann is UMDF's Development Assistant. He has a BA in English and Philosophy and an MA in English Language and Literature. Before joining UMDF, he worked as an instructor at Binghamton

University, teaching courses on Professional Writing. Owen also started at UMDF in November and has already successfully tackled numerous projects. Currently, Owen is soliciting sponsors and exhibitors for the 2006 conference and orchestrating a special 10th Anniversary appeal campaign.

**Welcome Aboard, Tania and Owen!!!**



#### Energy Bands - still Available in Youth and Adult Sizes

Visit [www.umdf.org](http://www.umdf.org) for more information on how to order or call 412-793-8077.

#### Awareness Car Magnets

Awareness magnets are also available and can be purchased online at [www.umdf.org](http://www.umdf.org). The cost is \$5 each or 10 for \$25 (postage and handling included). The magnets are UMDF green with yellow trim and wording.



#### UMDF Windshirts

The windshirt is green nylon and cost \$30 (includes shipping).



#### UMDF Throw Blankets

The blankets come in Black, Royal Blue, Khaki, Forest Green colors and cost \$20 (shipping included).



Visit [www.umdf.org](http://www.umdf.org) for more information on how to order or call 412-793-8077.

Please note: The blankets will be available with the new logo soon.

## UMDF Chapters, Mito Groups & Ambassadors

### ARIZONA

#### ★Arizona Chapter

President: Suzanne Perryman  
Email: AZChapter@umdf.org

### CALIFORNIA

#### ★Southern California Chapter

President: T BA  
Email: SCalChapter@umdf.org

### FLORIDA

#### Ambassador (NEW) - Melbourne

Contact: Christine Golden  
Email: Goldenfamily5@aol.com

#### North Central Florida Mito Group

Contact: Alicia Kaminski  
Email: limitlesschildrenx4@yahoo.com

#### Southern Florida Mito Group

Contact: Anne Reckling  
Email: areckling@aol.com

### GEORGIA

#### ★Atlanta Area Chapter

President: Chris Swinn  
Email: ATLchapter@umdf.org

### IDAHO

#### Idaho Mito Group

Contact: Jennifer Pfefferle  
Email: mitogroupofidaho@yahoo.com

### INDIANA

#### ★Indiana Chapter

President: Sue Ann Bube  
Email: INchapter@umdf.org

### ILLINOIS

#### Chicago Area Mito Group

Contact: Gail Wehling  
Email: GailMW333@aol.com

#### Central Illinois Mito Group

Contact: Crystal Smith  
Email: bandcsmith@insightbb.com

### KENTUCKY

#### Ambassador (NEW) - Louisville

Contact: Krystena Richards  
Email: Krystena@bellsouth.net

### MARYLAND

#### DC Area Mito Group

Contact: David Hamm  
Email: admin@datm.org

### MASSACHUSETTS

#### ★New England Chapter

President: Bridget Willis  
Email: NEngChapter@umdf.org

### MICHIGAN

#### Western Michigan Mito Group

Contact: Suzanne Marous  
Email: marousx4@charter.net

### MISSOURI/KANSAS

#### ★Kansas City Chapter

President: Pam Johnson  
Email: KCChapter@umdf.org

#### St. Louis Area Mito Group

Contact: Marsha Hohe  
Email: marshamarshamarshah@charter.net

### NEW YORK

#### ★New York Metro Chapter

President: Mary Pisani  
Email: NYMetroChapter@umdf.org

#### Ambassador (NEW) - New Paltz

Contact: Beth and James DeArce  
Email: dearsej@earthlink.net

### OHIO

#### ★Ohio Chapter, Cleveland, OH

President: Bill Hodges  
Email: OHChapter@umdf.org

#### Columbus Mito Group

Contact: Shawna Steele  
Email: ssteele817@sbcglobal.net

#### Cincinnati Mito Group

Contact: Jeff & Cindy Salt  
Email: salthouse@aol.com

### OREGON

#### Pacific Northwest Mito Group

Contact: Gretta Cole  
Email: Glou68@aol.com

### PENNSYLVANIA

#### ★Delaware Valley Chapter

President: Maripat Shelly  
Email: DelValChapter@umdf.org

#### Pittsburgh Mito Group

Contact: Karen Wilson  
Email: bwilson@cvzoom.net

#### Ambassador (NEW) -Central PA

Contact: Kim Olenderski  
Email: gabby244@dejazzd.com

### SOUTH CAROLINA

#### Ambassador (NEW) - Chapin

Contact: Karis Mott  
Email: karismott@yahoo.com

#### Carolina Foothills Mito Group

Contact: Allison Rogers  
Email: allisonrogers@hotmail.com

### TEXAS

#### Dallas Mito Group

Contact: Tova Sido  
Email: ttsido@hotmail.com

#### Houston Mito Group

Contact: Deb Schindler  
Email: jls@pomellp.com

### VIRGINIA

#### Richmond/Norfolk

Contact: Seeking new leaders  
Email: info@umdf.org

### **OUTSIDE OF THE UNITED STATES**

#### **AUSTRALIA**

Contact: Rob Ryan  
Email: grra1@bigpond.com

---

*New groups are getting started in Idaho, Houston (TX), Raleigh/Durham (NC), Louisville (KY), Northern California, New River Valley (VA), and Central Pennsylvania. Call us if you are interested in becoming an ambassador or starting a Mitogroup in your area. Contact becky@umdf.org.*

**Attention Mito Groups and Chapters:  
Sell Vacation Toward a Cure Tickets and WIN!!!  
(See Page 15)**

#### **Grand Prize**

*Group or Chapter selling the most raffle tickets  
(at least \$5,000 in ticket sales)*

will **WIN** \$1,000 in scholarship money for Chapter/Mito Group members to attend the 2007 UMDF Symposium in San Diego

## United Mitochondrial Disease Foundation LEAP Award

### Living, Encouraging, Achieving & Persisting

**Purpose:** To recognize an individual living positively with mitochondrial disease, highlighting the person's accomplishments and volunteer service.

**Eligibility:** Age 14 years or older

**Criteria:** Individual with confirmed or suspected mitochondrial disease who overcomes daily challenges to achieve goals in career, family, and volunteer service. The individual demonstrates a positive attitude, hope for a brighter future, and an enthusiasm that inspires others.

**Instructions:** Any UMDF member can nominate an individual for this award. Fill out the form below and attach the requested information. UMDF will announce the LEAP Award winner at the annual symposium and will present the winner with a plaque. The LEAP Award winner will be featured on the UMDF web site and recognized in the UMDF Mitochondrial News newsletter.

In 100 words or less, please explain how this individual overcomes daily challenges to achieve goals in career, family, and volunteer service. Please provide examples of how the individual demonstrates a positive attitude, hope for a brighter future, and an enthusiasm that inspires others. You may also attach copies of articles about the nominee and lists of projects, activities, or clubs the nominee is involved with.

**Please type your essay and attach it to the nomination form. Mail the nomination by April 28, 2006 to:**

**LEAP Award**

**UMDF**

**8085 Saltsburg Road, Suite 201**

**Pittsburgh, PA 15239**

**Or fax to 412-793-6477 or email the nomination by April 28, 2006 to [bethany@umdf.org](mailto:bethany@umdf.org).**

---

## Person Nominating

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

## Nominee for the Award

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Diagnosis (if known): \_\_\_\_\_

Age (must be at least 14 years old): \_\_\_\_\_

## ... Identify Everyday Heroes

### United Mitochondrial Disease Foundation Heartstrings Award Recognizing a youth commitment that tugs on the heartstrings

**Purpose:** To recognize a child or teen who has donated or raised funds for UMDF, enabling UMDF to continue its mission.

**Eligibility:** The individual recognized must be under 18 years of age at the time of the donation or fundraising activity.

**Criteria:** The winner is chosen based on related criteria of age, time invested, talents demonstrated, effectiveness, and generosity. For nominees who implement fund raising projects, the judges will consider the uniqueness and creativity of the project, communication, the time invested, and the amount raised in comparison to the age of the individual. For nominees who donate funds, the judges will consider the generous spirit shown, communication, and amount donated in relation to the age of the individual.

**Instructions:** Any UMDF member can nominate an individual for this award. Fill out the form below and attach the requested information. UMDF will announce the winner at the annual symposium and will present the winner with a plaque. The Heartstrings Award winner will be featured on the UMDF web site and recognized in the UMDF Mitochondrial News newsletter.

In 100 words or less, please explain how this individual has "tugged at your heartstrings" through fundraising for or a donation to UMDF. Identify important features of the nominee's activity, such as the time invested, creativity, communication skills, determination, effectiveness, and generosity. You may also attach supporting information on the fundraising project (published articles, pictures, comments from others involved with or participating in the project) or the communications of the nominee (letter explaining intended use of the gifted funds, thank you letters, letter sent with the donation, and so forth).

**Please type your essay and attach it to the nomination form. Mail the nomination by April 28, 2006 to:**

**Heartstrings Award  
UMDF  
8085 Saltsburg Road, Suite 201  
Pittsburgh, PA 15239**

**Or fax to 412-793-6477 or email the nomination by April 28, 2006 to [info@umdf.org](mailto:info@umdf.org).**

---

### Person Nominating

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

### Nominee for the Award

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Diagnosis (if known): \_\_\_\_\_

Age (must be less than 18 years old at time of donation or event): \_\_\_\_\_

**The UMDF Office Staff  
We're Here to Help You! 412-793-8077**

**CEO/Executive Director**

J. Thomas Viall, *tomv@umdf.org*, ext. 111

**Chief Financial Officer**

Mark Campbell, *markc@umdf.org*, ext. 110

**Director of Member Services**

Becky DiLettuso, *becky@umdf.org*, ext. 101

**Director of Communications**

Kara Strittmatter, *kara@umdf.org*, ext. 114

**Manager of Special Events**

Jodie Tabano, *jodie@umdf.org*, ext. 106

**Fundraising/Special Events**

Gillian McTiernan, *gillian@umdf.org*, ext. 102

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Donna Nameth, *donna@umdf.org*, ext. 109

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Jean Bassett, *jean@umdf.org*, ext. 105

**Administration**

Barbara Podowski, *barb@umdf.org*, ext. 100



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Volume 11 • Issue 1 • Winter 2006

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

Next issue will be Spring/Summer combined – Deadline is 6/1/06