

# M N

United Mitochondrial Disease Foundation

# MITOCHONDRIAL NEWS

Volume 11 • Issue 2 • Spring/Summer 2006

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UMDF Families  
definitely go the  
extra MILE for Mito

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### Depression and Anxiety in Mitochondrial Disease

Richard G. Boles, M.D.  
Childrens Hospital Los Angeles

The previous newsletter article titled "Results of the Families Dealing with Mitochondrial Disease On-line Questionnaire" discussed the results of a study in which depression and anxiety were found to be very common among the matrilineal relatives of patients in families with probable maternally inherited mitochondrial disease. Matrilineal relatives are individuals related entirely through women and include one's mother, siblings and maternal aunts/uncles and grandmother. As mitochondrial DNA (mtDNA) entirely comes from the mother, not from the father, in the absence of a recent mutation (genetic change), these individuals all share the same mtDNA sequence. We set out to validate our findings by conducting a second study, which was also recently published (Boles et al., 2005, American Journal of Medical Genetics Part B, Neuropsychiatric Genetics, 137B:20-24).

In this second study, 15 families with maternally inherited mitochondrial disease (our "MIMD" group) were recruited from the Genetics Clinic at Childrens Hospital Los Angeles. Although the MIMD group is very similar to the PMI group of the previous study, a key advantage of this second study is that we know a lot more about the families. The main drawback is that there are far fewer families. Another key difference between the two studies is that the control group in which to compare data is different, consisting of 18 families with known diagnoses of non-

### Atlanta 2006: Mastering the Mitochondrial Maze Attracts 400 Attendees



During the Friday night banquet, John DiCecco, UMDf Chair, and Michael Friedberg present the Chairman's Prize to Vishal Gohil – one of UMDf's 2006 funded researchers.

The Atlanta 2006: Mastering the Mitochondrial Maze conference has come to a close. On behalf of our course director, Dr. John Shoffner, the Scientific Planning Committee, Mitochondrial Medicine Society, Mitochondria Research Society, Children's Healthcare of Atlanta, and the United Mitochondrial Disease Foundation, special thanks goes to all of our financial supporters, exhibitors, faculty, volunteers and our attendees for making the event a success.

More than 150 physicians, scientists and clinicians have a new perspective on mitochondrial

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Special Thanks to  
**The Sage Foundation** for  
Their Continued Support of  
the United Mitochondrial  
Disease Foundation.

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# 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.umd.org](http://www.umd.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: Andrea Gropman, MD, FAAP, Georgetown University Medical Center, Washington, DC and Michio Hirano, MD, Neurological Institute, New York*

### The Question is:

Our 13-year-old son, presumed mito, has had significant cognitive trouble over the past few years and tested recently in the mild MR parameters. This has been a progressive difficulty, and it frightens us that if we don't turn it around, we don't know how far the cognitive dysfunction will progress. He uses O<sub>2</sub>, and also bi-pap to blow of CO<sub>2</sub> retention. We want to aggressively seek out the problems and solutions. Our questions: What suggestions do you have as far as testing that should be done, and is it just inevitable to see progressive cognitive impairment in mito kids? Would it help to aggressively seek out a specific type mito disorder? Thank you for your time.

### Response From: Andrea Gropman, MD, FAAP

Thank you for your question. I am sorry to hear that your son is having cognitive issues.

Cognitive decline can be a feature of mitochondrial disorders as well as result from a variety of other causes. Because I don't know your son's history, nor do I know which testing was done and whether it was performed during optimal conditions and/or whether you believe it was a true representation of your son's abilities, I cannot answer except in a general manner.

Cognitive decline in neurologic disorders may be static (unchanging), progressive (getting worse with time) or waxing and waning (gets worse with an episode of illness or event and improves during recovery either to baseline or below baseline). In terms of reversibility, it is important to rule out conditions which may cause or look like cognitive decline but may be potentially treatable. This would include, for example, epilepsy or seizure disorders, medication effects or the presence of other illnesses.

Either clinically evident or subclinical seizures may present with apparent cognitive decline and may be improved with medications in some cases. Therefore, if there is concern that your son could be having seizures (changes in behavior, staring, shaking spells, etc.), an EEG can be requested.

You mentioned that your son is on CPAP and has a tendency for CO<sub>2</sub> retention. Hypoxia (low oxygen and high CO<sub>2</sub>) can cause cognitive slowing, therefore it would be important for your son's pulmonologist to ensure that his oxygen status is adequate.

Medications can have cognitive side effects. If your son is taking any medications, you should review the list with your son's physician to determine if medication side effects may be an issue.

Chronic diseases (other than mito), such as liver or kidney disease, may lead to secondary cognitive decline due to toxins. Endocrine disorders can also potentially cause cognitive problems (thyroid, diabetes, etc.)

MRI imaging can give a picture of the degree of anatomic injury to the brain and whether it appears fixed or potentially reversible. However, a completely normal scan does not necessarily denote normal brain function.

Lastly, the choice of cognitive test can be important in giving a clear picture of his true abilities. For example, in a nonverbal child, use of a test that is heavily language based (as are most IQ tests) would underestimate abilities and IQ and may not be appropriate.

### The Question is:

What are the most recent (2006) recommendations for nutritional supplements and their dose range for adults with MELAS?

### Response From: Michio Hirano, MD

The recommendations for nutritional supplements for mitochondrial patients have not changed significantly over the last few years. Our recommendations are as follows: Coenzyme Q10 (CoQ10) 50-200 mg three times daily (although some patients with primary CoQ10 deficiency have taken up to 1000 mg three times daily); levo-carnitine (L-carnitine) 300-1000 mg three times daily (many patients develop gastrointestinal side-effects at high doses); Thiamine (vitamin B1) 50-200 mg daily; Riboflavin (vitamin B2) 50-600 mg daily; Vitamin C 100-400 mg daily (usually divided into 2-3 daily doses); Vitamin E 200-1200 IU daily; Vitamin K3 5-80 mg daily; Folate 1-10mg daily; Alpha-lipoic acid up to 400mg three times daily; Creatine monohydrate 5-10 grams daily; Idebenone 45-360 mg three times daily (Sometimes used instead of coenzyme Q10).



## Chairman's Message by John DiCecco

The entire board, membership, staff, and scientific and medical partners of the UMDF have, over the last 10 years, been focused on the foundation's mission – always supporting research for a cure, better treatments, less invasive diagnostic procedures, and better methods to educate and expand the awareness of mitochondrial disease throughout the United States and other countries.

I have been associated with the UMDF since its inception and have seen the evolution of the foundation, watching it grow in size, strength and effectiveness. This transformation from a small organization into a multi-million dollar foundation has been the result of everyone remaining focused on the mission and the future.

The continued success of the foundation, and ultimately the achievement of its mission, is directly dependent on strong leadership – setting high goals and working with a sense of urgency to achieve them. More and more individuals are being diagnosed everyday, and yet we have only the hope that some day we will be successful. Yes, we have made some strides as evidenced at this year's Atlanta conference:

- An increase in new and younger researchers are entering the field as a result of our grant program.
- The foundation continues to educate hundreds of people every year.

- An increased interest in Mito Groups, Chapters and Ambassadors. Our most recent addition, the Chicago Chapter, was introduced during the conference.

We have just begun to scratch the surface only to realize how much more needs to be accomplished. The foundation continues to get requests daily from other organizations, researchers, doctors, patients and members for more and more information, support and funding.

The UMDF continues its commitment of supporting information technology to assist us in better addressing the needs of our membership as well as the national office. Trustee Marty Lyman was recently appointed as the chair for a new Information Technology Steering Committee so that we can ensure that we wisely invest our limited resources into the technology needed for the future.

The board has also created a Governmental Affairs Committee, chaired by Rick Leach, a professional political consultant, who lives and works near Washington, D.C.

The UMDF board has approved a major reorganization of the Scientific Advisory Board, expanding its scope and responsibilities. The chairman of the newly named Scientific & Medical Advisory Board will now have a seat on the board of UMDF.

Michelle Lawler (see page 18) has joined the UMDF team as director of development and John Elias recently started as our new director of member services.

The foundation has continued to search for the right people to lead the UMDF to the next level necessary to support the continued growing needs of the organization and its partners.

*Continued on page 4*

### Board of Trustees

John A. DiCecco - *Chairman*  
Stanley Davis - *Vice Chairman*  
W. Dan Wright - *Treasurer*  
Sharon Shaw - *Secretary*  
Bruce H. Cohen, M.D.  
Gerald A. Cook, Esq.  
Charles L. Hoppel, M.D.  
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Pamela Johnson, MD  
Marty Lyman  
Robert Polsky  
Joseph Rice  
CEO/Executive Director  
Charles A. Mohan, Jr.  
*Chair Emeritus*

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Georgirene Vladutiu, Ph.D.  
Douglas C. Wallace, Ph.D.  
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

## Chairman's Message Cont

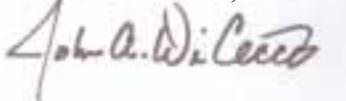
Continued from page 3

To best address the growing needs of UMDF and its sense of urgency, the UMDF board of directors has made a significant change in the leadership of the foundation. Effective July 10, 2006, the board of directors has hired Charles A. Mohan, Jr. as the new full time chief executive officer/ executive director. As the UMDF's new CEO/ED, Chuck brings to the position the qualities we all look for in a leader. He has provided the vision for the foundation in a volunteer capacity over the last ten years and has done an excellent job.

With Chuck as a full-time member of our staff, we believe that the foundation will be positioned to aggressively grow and achieve the quantum leaps in progress we all expect. We need to expand our resource base, membership, and scientific and medical partner base – generating the needed resources to allow the foundation to expand its educational programs and research grants and to move into clinical grant funding – all of which will get us closer to better treatments and cures.

Thank you for your continued support of the mission.

Toward A Cure,



John A. DiCecco  
Chair, UMDF Board of Trustees

*"I have no magic formula. The only way I know to win is through hard work."*

*- Don Shula*

## 10th Anniversary Celebrations Raised more than \$51,000



*Dr. & Mrs. Bruce Cohen, with daughter Eva, and Chuck & Adrienne Mohan attend Pittsburgh event in April to honor the 10th Anniversary*



*Kathryn Parsons, pictured with Trustee Stan Davis in 2002, was presented a special plaque (Honorary Trustee Emeritus) during the 2006 Atlanta Conference's Friday Banquet to honor her years of dedication to the UMDF Mission.*



*Ohio Chapter members present letters and a plaque during a special tribute to Chuck Mohan – UMDF's first chairman.*

## Remembering All the Sparks that Lit the UMDF Fire

As part of our 10th Anniversary, a commemorative book was distributed during the Atlanta conference, and the following is an excerpt from that tribute:

Ten years ago, several volunteer parent groups were the "sparks" in starting a small fire, coming together for a common cause - to promote research for cures and treatments of mitochondrial disease and to provide support to affected families (the original mission). The National Leigh's Disease Foundation (NLDF), PALS (People Affected by Leigh's Syndrome) and the COX Foundation were among those groups.



The fire has gathered strength over the years and we honor our first board of trustees on this 10th anniversary - for each and every one of them played a part in our progress. Special thanks go to Marsha Barnett, Mark Fleming, Sherri Greenlee, Chuck Mohan, Lee Neff, Kathryn Parsons, Catherine Higginbotham, Lauren Johnson, Kathy Malone, Tammy Monson, and Nick Rillo. Charles Wilbanks, although not a UMDF board member, was the original founder of NLDF. His work in those early years was another "spark."

We cannot thank or acknowledge all of the extraordinary people who have fueled, and continue to fuel, the fire in our quest toward cures and better treatments. We salute you all - thank you!

# Chapter Activities

## ATLANTA AREA CHAPTER

Atlanta, GA

President: Chris Swinn

Phone: 770-270-5337

Email: [AtlChapter@umdf.org](mailto:AtlChapter@umdf.org)

### Upcoming Events:

- **September 23-34** - *Going the Extra Mile for Josey* (Joseph Hendley) is a 24-hour Ultra Run! For more info, contact Tammy Vance at 404-518-1086.
- **Sunday, October 8, 2006** - *First Annual Ty's Trot Toward a Cure 5K Run/Walk* at Georgia Tech campus. For more information, call 404-885-4882, email [info@tystrot.com](mailto:info@tystrot.com) or visit [www.tystrot.com](http://www.tystrot.com).
- **Monday, 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 or visit [www.foreacuremito.org](http://www.foreacuremito.org).

### Special Events - Thank YOU!

- **June 2006** - In honor of Joshua Sellers and as a result of the Griffin Judicial Court Golf Outing, District Attorney Scott Ballard presented a check for \$1,270 – the Sellers and Swinn Families accepted the check on behalf of UMDF. Excellent!!



- **July 2006** - *Blue Devil Blue Ball Classic* raised \$1,000 in honor of Spencer Fike. Thank you!

- **September 16** - In honor of Ty Seldes, Saint Andrew Rowing Club hosted a *Row for Mito* at Riverside Park, Roswell, GA. The event raised \$5,830.06! Per Tyler's Aunt



Amber (pictured with Tyler below right), "the kids really worked hard and it was a beautiful day in the park." To see more pictures of this unique event, visit [www.standrewrowing.com](http://www.standrewrowing.com).



## Race for Riley – A Success!



**2nd Annual Race for Riley was a HUGE success and raised more than \$90,000 with hundreds of people in attendance to benefit UMDF Atlanta Chapter. You are awesome, Riley Peek, and so are your family and friends!**

### 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.**

For activity/info for Southern California, New York Metro, and Arizona Chapters, email [S-CalChapter@umdf.org](mailto:S-CalChapter@umdf.org), [NYMetroChapter@umdf.org](mailto:NYMetroChapter@umdf.org), or [AZChapter@umdf.org](mailto:AZChapter@umdf.org).

# Chapter Activities

## DELAWARE VALLEY CHAPTER

Philadelphia, PA

### Another Successful Brew!

The 3rd Annual Brew at the Zoo was a great success with over 1,200 participants in attendance. Local beer aficionados, breweries and friends of UMDF came out to the Elmwood Park Zoo in Norristown, PA, on a hot July evening to sample some of the best brews in the area. Organizers Bob and Lisa Polsky did a great job and look forward to an even bigger event in 2007.



### Special Thanks

- In memory of Kevin Blosky, Jennifer Cogan ran the *Mayor's Marathon* in Anchorage, AK, and raised \$1,565. The lower 48 deeply appreciates your work, Jennifer!



President: Maripat Shelly  
Phone: 215-256-0273  
Email: DelValChapter@umdf.org

### 7th Annual Go! for Mito Attracts Hundreds

This annual Delaware Valley Chapter event, chaired by the Shelly Family, once again attracted hundreds of participants to the Philadelphia Art Museum. Special thanks to students from Villanova University for joining UMDF families and friends – providing a vision of hope for thousands of families across Pennsylvania and the United States. To date, the event raised more than \$25,000.

## NEW ENGLAND CHAPTER

Boston, MA

### Upcoming Events

- Join the New England UMDF Chapter as they begin a *Weekend of Hope* and celebration on Saturday, October 7, for the Plymouth 5K Walk and Family Fun Zone activities. Registration begins at 9:30 a.m. with the 5K walk at 11:00 a.m. and family fun activities rounding out the afternoon. Family Fun Zone events include professional storytelling/puppet shows, magic shows, pony and train rides, music, face painting, moonwalk, refreshments and free child ID screening provided by the Plymouth County Sheriff's Office. Individuals raising \$500 or more will receive a UMDF sweatshirt. For more information, go to [www.mitowhat.org](http://www.mitowhat.org) or call 508-224-7165.
- The New England UMDF Chapter will complete the *Weekend of Hope* and celebrate on Sunday, October 8, with the 7th Annual Longmeadow 5K Walk and Family Fun day. Registration begins at 9:30 a.m. with the 5K walk at 11:00 a.m. and family fun activities rounding out the day. Family Fun activities include popcorn, balloons, clowns, raffle, LEGO building area, music and much more. For info on the Longmeadow event, call 413-872-7538.

### Special Thanks

- Life Labs-Mercy Hospital, Springfield, MA, held a *Jeans for Cause* every Friday for a dress down day. \$215 was

President: Bridget Willis  
Email: NEngChapter@umdf.org

donated to UMDF in honor of Emily Tyler. Grandma Gail Gebeau works at Life Labs – Thanks, Grandma!

- During a special yard sale and silent auction, more than \$2,900 was raised in honor of Owen Willis.



### 1st Annual Golf Outing Raises \$16,000



- The UMDF New England Chapter held their *1st Annual Golf Outing* on Saturday, May 20, at Easton Country Club in South Easton, MA. The field was full of

golfers and a fantastic auction was held for participants. Fun was had by all! Thanks to Bill Naughton (pictured above with his team) for organizing a very successful event. Outstanding Job!!!

## KANSAS CITY CHAPTER

Kansas City, MO

President: Pam Johnson

Phone: 913-631-3070

Email: [KCChapter@umdf.org](mailto:KCChapter@umdf.org)

*3rd Annual "Mito-What?" 5K Race/Walk One Step Closer to a Cure* – Families and friends across Kansas and Missouri came together on June 24 to raise an astounding \$47,000 for the Kansas City Chapter. More than 500 runners and walkers were registered, joining more than 1,000 adults and children for a day of hope. Thank you to everyone who made the event a success!



## OHIO CHAPTER

Cleveland, OH

President: Bill Hodges

Phone: 440-235-2451

Email: [OHChapter@umdf.org](mailto:OHChapter@umdf.org)

### Special Thanks -

- Jake Gold of Pittsburgh, PA, sold energy bands for his Bar Mitzvah in honor of his cousin Mollie Kalk from Cleveland, OH, and raised \$200. Thanks, Jake!
- In honor of his brother, Kyle, Student Council Treasurer Nick Kobunski initiated "Dress Down Days" at St. Albert the Great School in North Royalton, OH, this past spring and raised \$2,000. Excellent!



- A fun-filled evening was had by all at the *3rd Annual Guest Bartender Night* on Friday, March 10. The event was held at the Main Street Grill & Pub in North Royalton, OH, in honor of Kyle Kobunski. The dynamic duo of Anita Barker and Diane Kobunski were the guest bartenders filling drink orders, having fun and raising \$5,430 for UMDF!

## More than \$130,000 Raised for the Foundation



The *5th Annual UMDF One Step Closer to a Cure* event was a great success. A special thanks to our presenting sponsor, KFC; Lisa Arnold, Race Chair; and the many families, sponsors, donors and volunteers who helped make this event possible.

**THANK YOU  
RYAN PONTBRIAND**  
Cleveland Browns Long Snapper, Ryan Pontbriand, signed autographs and was a big hit with the crowd!!!

- The *3rd Annual Family Spaghetti Dinner* was held on April 29 at Pilgrim Lutheran Brethren Church in Mentor, OH, in honor of Sadie and Maiya Keeney and raised more than \$3,000. Thank you, Arnold and Keeney Families and Friends!

### Upcoming Events

- Saturday October 14, 2006 -- *2nd Annual Clams for a Cure*, 7:00 p.m. at Hoggy's Restaurant, 5975 Canal Road, Valley View, OH. For tickets, reservations, and/or questions, contact Daryn Adelstein at 440-349-5889 or [DarynA@adelphia.net](mailto:DarynA@adelphia.net), or Amy Kalk at 440-498-9142 or [AmyKalk@aol.com](mailto:AmyKalk@aol.com).

# Chapter Activities

## INDIANA CHAPTER

Indianapolis, IN

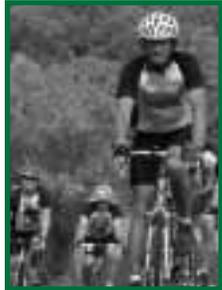
President: Sue Ann Bube  
Phone: 317-894-9099  
Email: INChapter@umdf.org

### Events/Fundraisers:

- **Special Thanks** - In honor of Ellie Bube's brother, Jacob, three enterprising young girls raise money for UMDF. Madeline Cole, Ellie Bube and Natalie Wiesinger raised \$50 by selling ice cold drinks to their neighbors.
- Led by Mike Hanlon, chapter members hosted another very successful UMDF golf outing on July 10 at Hawthorns Golf & Country Club in Fischer, IN. The event raised \$9,472.
- *Pack the House* - The chapter, in conjunction with 24 Penn Station stores promoted the *Pack the House Night* on February 25 and raised more than \$10,000 for UMDF.
- President Robert Vrugink of Praxair Surface Technologies presented Jacob and Sue Ann Bube with a check for \$2,500. Praxair held a silent auction for four Brickyard ticket packages and all proceeds were donated to UMDF.



## Thank YOU Miles for Mito Riders



Three years ago, Bob Thomas, Indiana Chapter vice president, started the *Miles for Mito* ride. This year, he and the other courageous riders

illustrated their love and dedication to the children and adults battling mitochondrial disease by bicycling from Indianapolis, IN, to Atlanta, GA, to attend this year's UMDF symposium, *Mastering the Mitochondrial Maze*. See page 20 for more details on this inspiring event.

## CHICAGO AREA CHAPTER

Chicago, IL

President: Patrick Kelley  
Email: ChicagoChapter@umdf.org

- In honor of his brother, Charlie, William Darche (with mom's, Tracy, help) held a Coins for a Cure Campaign in his kindergarten class at George F. Cassell Elementary School and raised \$1616.09 for UMDF. Super job, kids!!!



From right to left: Patrick Kelley, Zaza Khuchua, PhD (UMDF grant recipient), Gail Wehling and UMDF chair, John DiCecco pose during Atlanta Friday night banquet.

### 6th Annual Kites for Kristen Decorate the Walls and Raise more than \$15,000

*Kites for Kristen* Charleston was another success this past May. More than \$15,000 was raised to benefit UMDF. Gianna Fodelka, who just graduated from Kindergarten, held a lemonade stand and dedicated her earnings, \$23.25, to the *Kites for Kristen* event. Thanks, kids and Charleston Family for another job well done!

### ★UMDF'S NEWEST STARS!★

#### Chicago Officially Becomes a Chapter!

Please join us in welcoming our newest chapter and their officers:  
*Patrick Kelley - President; Cheryl Lawson - Vice President; Vicki Ternberg - Treasurer; and Mary Beth Kelley - Secretary*

## 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*. In this issue, we will spotlight our Chapter Liaison position on the board.

First, what is a Chapter Liaison? The UMDF Board realized many years ago that the chapters were one of the life lines to the success of the foundation and decided to add a position to the board for chapter representation. Our first chapter liaison was Jennifer Lyman, then Sharon Shaw, Maripat Shelly and most recently Mary Pisani. In June 2006, Pam Johnson became our newest liaison. We will spotlight our past two liaisons in this issue.

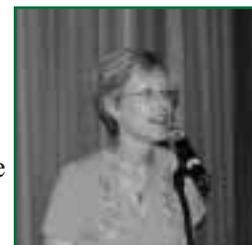


Mary Pisani, of North Haven, CT, was appointed to the UMDF Board in 2004 as the liaison. She serves as the vice president of the New York Metro Chapter of UMDF and has successfully organized a *Walk to Create Awareness* over the past few years.

Mrs. Pisani and her husband, Matt, have two children, Nicholas (diagnosed with mitochondrial disease in 2001) and Andrew. Thank you, Mary, for serving as

liaison and for your continued dedication to the UMDF mission.

Pam Johnson, MD, of Lake Quivira, KS, accepted the liaison position in June and has had the responsibility of Kansas City Chapter President since 2005 -- even though her disease symptoms cause her to tire often. She willingly organized and reorganized the chapter to bring back key members to the board and works hard to motivate and support the KC Chapter board as well as striving to meet the needs of the families that call her. Pam is a pediatrician but can no longer practice because of her mitochondrial disease. Instead of being discouraged by what she can no longer do, Pam channels her energy and knowledge to help parents and other adults. Pam and her husband, Brian, work together on the KC run/walk and golf outing.



The board has recently extended the term of office for chapter liaisons – Pam will now serve on the board for two years. Welcome to the board, Pam!

## Trustee Stan Davis Honored During Annual Outing For Carly & Katie Platt, Papa Stan is Quite the Hero

On July 17, UMDF Trustee Stan Davis was honored during the *7th Annual Ohio UMDF Golf Outing* at Kirtland CC in Willoughby, OH. After seven years and more than \$600,000 raised to benefit UMDF, Stan decided to take a break from the golf outing that has proven so successful over the years – and he thanks his family, friends and specifically his daughter Jill for assisting with these successes.

During a very special tribute, Stan’s granddaughters, Carly and Katie, gave the following heartwarming speech to the golf outing attendees:



Carly:  
“Having a mitochondrial disease can be very hard at times. But I know that the money Papa and Mommy (Jill) have raised with

your support is going to make it easier for me and others like me. For those of you who do not know me well, mitochondrial disease does not allow me to go outside

when it is above 80 degrees unless I can be in a pool to stay cool, or below freezing where I can stay warm. It also can make it hard for me to get better as fast as other people when I get sick. And a lot of times I am tired.

Katie: “Sometimes it is very hard to have a sister that has mitochondrial disease. It can be really hard because she needs so much help from all of us and sometimes I do not know how to help her. And sometimes I think Mommy and Daddy have to spend more time with Carly. But as a family we are learning together.”

Together: “Papa and Mommy have shown us that if you work hard and look to people like all of you to open your hearts we can make a difference. We love you both and thank you all.”

The patients and families of UMDF agree with your granddaughters, Stan. You are one in a million, and we’re sure your fundraising days are far from over! Thank You!!!



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

**Table 1. Results of Questionnaire for Mothers of Children with Genetic Metabolic Disease**

	<b>MIMD Mothers</b>	<b>ARMD Mothers</b>	<b>P-value*</b>
Mother ever diagnosed with a mental health condition by a health care professional	6/15	2/17	0.08
Mother diagnosed with or suspects that she may have a mental health condition <sup>a</sup>	10/15	2/17	<b>0.001</b>
Current psychotropic usage in mother <sup>b</sup>	4/15	2/17	0.3
Any mental health disorder in first-degree matrilineal relatives	8/15	1/17	<b>0.004</b>
Any mental health disorder in patient	5/15	0/17	<b>0.01</b>
Any mental health disorder in sibling	5/15	1/17	0.06
Any mental health disorder in at least one second degree matrilineal relative	5/15	0/17	<b>0.01</b>
Any mental disorder in at least one	13/15	3/17	<b>0.0001</b>

\* **Green numbers** indicate probability (P) values that are considered to be significant, P is less than 0.05  
<sup>a</sup> Four additional MIMD and no ARMD mothers indicated that they "suspect" that they "have a mental health condition not yet diagnosed by a healthcare professional."  
<sup>b</sup> Dominated by serotonin selective reuptake inhibitor (SSRI) anti-depressant medications

mitochondrial, autosomal recessive metabolic disorders (our "ARMD" group). Furthermore, questionnaires were filled out on paper during a clinic visit, instead of over the internet. Despite the differences, both studies were similar in that we asked about mental health in the relatives of families that we think have maternally inherited mitochondrial disease, as well as in a "control" group of families we think do not have MIMD.

Our data supports our finding in the first study in that there are significantly more mental health conditions diagnosed among the matrilineal relatives of families with maternally inherited mitochondrial disease (MIMD) than in the corresponding matrilineal relatives of our control group (ARMD, with non-mitochondrial genetics disorders). Depression dominated the mental health conditions reported and was found equally among the relatives of patients who are mildly or severely affected with mitochondrial disease.

*Editor's Note: Special thanks to Dr. Boles for sharing his 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 provide the results. As always, we ask that you continue to discuss any diagnoses, treatments or medications with your personal physician.*

**Mito Adults Corner - by Karen Ortiz**

**Mito and Depression Can Walk Hand and Hand**

When I was first told that the ill effects that I was experiencing were due to depression, I wanted to laugh the physician right out of the room. In fact, I do believe my response was: "Of course I am depressed. I am the mother of an infant that no one knows just what is wrong with. She is not growing well, pukes up everything I put into her, and does not breathe on her own when she falls asleep, and I haven't slept in the four months since her birth because she screams non-stop for hours at night, every night!" I remember my thoughts being, "I am paying this man to tell me this!" I blew off what the doctor had to say and headed for home even more depressed, thinking that the person who was supposed to know how to help me was totally clueless and instead dismissed my daughter's problems as my own "mental illness." So in my head, I was not only bone-weary tired, but now I was "crazy" too? I was so angry. After all, who wouldn't be half crazy doing what I was doing?

The months ticked on, and my child seemed to get only worse, with the amount of sleepless hours only growing. As she got worse, so did my "depression." I felt very alone and very misunderstood by family,

*Continued on page 11*

friends and the doctors who were supposed to be there to help me. I suffered a miscarriage of twin boys, which only added to my depression at the time, but I still was not willing to acknowledge that it was depression that I was experiencing. Then, my second child was born. He also began having signs that he too was not "normal." However, whenever I said anything, I was told by my daughter's physicians, "Now, Mom, just because she is sick doesn't mean he is sick as well. Just relax!" I was so frustrated that I couldn't get anyone to listen. It was during one of my daughter's visits with Dr. Boles at Childrens Hospital Los Angeles that my son had an "unexplained fit of rage" in front of him that he realized that maybe he had a problem as well. I was so angry because I had been trying to get someone to listen to me, and the response was far less than favorable. After Dr. Boles and his nurse were able to calm me down, Dr. Boles suggested to me that maybe I was in fact dealing with depression and that it might not hurt seeking some professional advice. I can remember being hurt by his comments, not able to fully understand what he was saying due to being overwhelmed by my circumstances, and to be honest, thinking that he was the one that needed professional advice! After all, I was the parent doing all of the work with not only one sick child but two. I also had my own medical problems to deal with. I did not feel that I was depressed; I felt abused by a medical system that refused to listen and help me.

About this time, my sister was experiencing a severe bout of depression after giving birth. We couldn't figure out why she was having such difficulty, as she had not experienced this problem after her first two pregnancies. By then,

we knew that my two children had mitochondrial disease but didn't know the extent of the familial inheritance. Her depression seemed to get better, but to this day she still deals with bouts of "unexplained" depression. Later, she would be placed on Celexa (a common antidepressant medication), as was her daughter at age 15. My mother also experienced severe bouts of depression, but it was always chalked off to a tired mother raising four kids, not to a true physical problem.

As time went on, I began to see a professional to try and deal with my own depression and the stress of dealing with two sick children. During this time, my third child was born premature, and once again when I noticed that she wasn't "normal" in some areas, I was patted on the head and told not to worry. This led to my depression returning even worse than it had been before. But by this time, I discovered that my depression did not put me in bed for weeks lying in a dark room with the covers over my head wanting to die. Instead, depression made me extremely irritable and put me in a constant fight or flight pattern. While in some cases this worked for the kids' benefit as I fought hard and long for their care, I believe that this is one of the reasons that I didn't believe that I was depressed earlier. I began to explore with Dr. Boles whether taking the drug Celexa would be safe for me and my oldest daughter. She was now beginning to show some signs of depression, although her signs were very different than my own. Like her cousin, and without any apparent physical reason, my daughter did not want to get out of bed.

We sought help from Dr. Boles and her counselor, and she was started on Celexa. Thereafter, we saw a marked improvement in her

emotional well-being. Unfortunately, a year later she became extremely depressed, sleeping for up to 20 hours in a day and withdrawing from life. Because she did not make an attempt at that time to harm herself, although we all had good reason to believe that she might try, she could not be admitted for help. We were told to take her home and watch her 24/7 until it passed. This was one of the most frightening times of my life. We found out that she had not been taking her Celexa regularly, and once she was restarted on it, she improved greatly and has not had a return of her depression in the two years since. Her emotional well-being is now very much like that of any teenaged girl. I, too, have noticed a marked improvement in myself since starting on Celexa.

When Dr. Boles first suggested that I might be depressed, as when another physician told me that many years before, I was not emotionally able to accept what was said. All I heard was that this man thinks that I am crazy, and all I could think was that he was crazy thinking that anybody could handle what I was being asked to handle without being a little bit depressed. It took me some time to be able to process what he truly was saying: that my depression was real for the circumstances that I was experiencing, however, it was also real because of the physical-medical issue of being a mitochondrial patient. In other words, having a mitochondrial disease was making me more susceptible to depression. Anyone in my situation could be depressed, but my own mitochondrial disease upped my

*Continued on page 15*

**★ Mark your Calendars ★**  
**See pages 5-8 for more details on chapter events**

- **Sunday, October 1, 2006** - The *6th Annual Olivia Lauren Steele Memorial Golf Outing* will be held at Royal American Links in Sunbury, OH. A contribution of \$300 includes entry fees and dinner for two golfers and a tee or green sponsorship. For more information, contact J.R. Steele at 614-846-4149.
- **Monday, October 2, 2006** - Please join Kovalcik & Geraghty Wealth Partners LLP in Columbus, OH, for the *1st Annual KGWP Charity Golf Outing in honor of Ellie Kovalcik* at the Scioto Reserve Golf & Athletic Club. For more information, contact Lorrie Stickel at 614-222-4888 or [lorrie.stickel@raymondjames.com](mailto:lorrie.stickel@raymondjames.com).
- **Saturday, October 7, 2006** - The Idaho Mito Group is hosting a *UMDF Bowl-a-thon* at Nampa Lanes. For more information, contact Jennifer Pfefferle at 208-863-9403 or email [mitogroupofidaho@yahoo.com](mailto:mitogroupofidaho@yahoo.com).
- **Saturday, October 7, 2006** - *MPS and Mito 5K Walk/Run* to support UMDF at Thomas Lake Park in Eagan, MN. For more information, contact Kristin at 952-212-9975 or email [netsirking@yahoo.com](mailto:netsirking@yahoo.com).
- **Saturday, October 7, 2006** - Friends of Bobby Arnold, of Ohio, will run in the *University of Miami Delta Gamma Race* in Miami, FL. For more information, contact Kelly Pierce at [k.pierce@umiami.edu](mailto:k.pierce@umiami.edu).
- **Saturday, October 7, 2006** - Join the New England UMDF Chapter for the Plymouth 5K Walk and Family Fun Zone activities. For more information, go to [www.mitowhat.org](http://www.mitowhat.org) or call 508-224-7165.
- **Sunday, October 8, 2006** - The New England UMDF Chapter will complete the *Weekend of Hope* with the 7th Annual Longmeadow 5K Walk and Family Fun day. For info on the Longmeadow event, call 413-872-7538.
- **Sunday, October 8, 2006** - *First Annual Ty's Trot Toward a Cure 5K Run/Walk* at Georgia Tech Campus. For more information, call 404-885-4882, email [info@tystrot.com](mailto:info@tystrot.com) or visit [www.tystrot.com](http://www.tystrot.com).
- **Saturday October 14, 2006** - *2nd Annual Clams for a Cure* at Hoggy's Restaurant. For tickets, reservations, and/or questions, contact Daryn Adelstein at 440-349-5889 or [DarynA@adelphia.net](mailto:DarynA@adelphia.net), or Amy Kalk at 440-498-9142 or [AmyKalk@aol.com](mailto:AmyKalk@aol.com).
- **Monday, 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 or visit [www.foreacuremito.org](http://www.foreacuremito.org).
- **Sunday, October 29, 2006** - *UMDF Steps to a Cure (Walk) in Honor of Brittany Wilkinson* at Woodward Park, Fresno, CA. For more info call 559-299-1767 or email [dotoheaven@aol.com](mailto:dotoheaven@aol.com)
- **Friday, November 3, 2006** - *An Enchanted Evening of Magic, Martini's and Music*. In honor of Mary Rose Zuzzolo, this event will be hosted by the Strathmore Vanderbilt Women's Club in Manhasset, NY. For more information, call 516-627-2433.
- **Saturday, March 10, 2007** - *4th Annual Bet on Baylee Casino Night* in Zanesville, OH. For more information, contact Jody Thompson at 740-982-1244.
- **Friday and Saturday, March 9-10, 2007** - *The Writers at the Beach: Pure Sea Glass 3rd Annual Writers Conference*, held in Dewey Beach, is sponsored by the Rehoboth Beach Writers' Guild, a non-stock, non-profit organization incorporated in the state of Delaware. 100% of net profit from this annual conference is donated to the United Mitochondrial Disease Foundation. For more information, visit [www.writersatthebeach.com](http://www.writersatthebeach.com).

## Coins for a Cure Campaigns



There is an easy way to raise money for mitochondrial disease research. The answer is **Coins for a Cure**. It's an easy way to make a difference in the world, one coin at a time. All you need is a few coin collection containers and some willing participants. Simply approach your schools or local business owners you may know and ask for their approval to hold a **Coins for a Cure** campaign for UMDF. Then set out the containers and let the fun begin! When the campaign is completed, collect the containers, count your coins, and rest assured that you have made a difference in the lives of thousands of affected children and adults!

For more information on how to start a campaign in your community, email [taniah@umdf.org](mailto:taniah@umdf.org) or call 412-793-8077.

# Fundraisers

## UMDF Holiday Card Campaign

Annual mailing will be arriving in mailboxes in November. For more information, email [info@umdf.org](mailto:info@umdf.org).

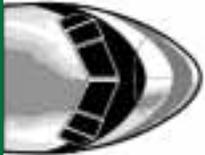
## 1st Annual Caroline's on My Mind Raises \$20,000



Caroline Pulliam cuddles with mom, Donna, during the evening festivities.

## Vacation Toward a Cure Winners

During the Atlanta conference, the winners of the Vacation Toward a Cure were pulled and congratulations go to:



American Airlines

Exclusive Airline of the  
Vacation Toward  
a Cure Raffle

- ☆ First Prize: Todd Crocker of Dacula, GA
- ☆ Second Prize: Frank Kaduc of Rochester, NY
- ☆ Third Prize: Nancy Goedecke of Birmingham, AL

Thank you to the UMDF Chapter Members, Mito Groups, Ambassadors and Volunteers who sold tickets for the 2006 Vacation Toward a Cure

campaign. Over \$36,000 was raised this year for the UMDF. Special thanks go to the Cincinnati Mito Group (Jeff & Cindy Salt) and the Chicago UMDF Chapter (Patrick Kelley) for selling close to \$15,000 in tickets each. Both groups will be awarded \$1,000 Symposium Scholarships for the 2007 conference in San Diego, CA.

Thank you also to American Airlines and the Catamaran Resort Hotel, San Diego, CA, for donating prizes for the raffle. We look forward to hosting another successful Vacation Toward a Cure raffle next year!

The 1st Annual Caroline's on My Mind Weekend was held on March 24-25. The weekend started with a Golf Tournament at the Carolina Country Club and ended with a 5K Family Walk/Run at Duncan Park with a BBQ/Band Party in the evening. All proceeds benefit the Caroline Virginia Pulliam Mitochondrial Disease Fund (CVPMDF) and UMDF. Excellent!

## Gifts from the Heart - Thank You ALL

- *The 3rd Annual Curl-o-Rama*, held in honor of Peter Lubelczyk (pictured right with Jared Goldstein) raised \$7,327. Sponsored by Chesapeake Physical and Aquatic Therapy, this year's annual event attracted 95 participants in Laurel, MD, and included a curling tournament, a silent auction and a visit from the Bowie Baysox Mascott. Thanks to all who participated and keep on curling for a CURE!



- *Preston's March for Energy* – once again the lonely leprechaun ran 26.2 miles to raise money and awareness for mitochondrial disease. Amy and Jerry Frostick, organizers of the Shamrock Sportsfest Marathon in Virginia Beach, VA, encouraged participants to raise funds for the UMDF in honor of Preston Buenaga (pictured right). Through the outstanding efforts of Deb and Steve Buenaga of Wilmington, DE, this annual event raised \$20,353 this spring. For more information about this annual marathon, please visit [www.shamrockmarathon.com/preston-march.php](http://www.shamrockmarathon.com/preston-march.php). Thank you Shamrock Community!!!!



**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).**

# Fundraisers

## Youth in ACTION Against Mito – 2006 Spr/Sum

- St Bernadette's Annual Coins for a Cure campaign in Monroeville, PA, raised \$1,122 in memory of Gina Marie Mohan.
- In a *Coin War*, Butler Middle School 7th and 8th graders in Waukesha, WI, raised \$1,500 in honor of the Juhlmann family.
- Hosted by mito teenager Brittany Wilkinson of Fresno, CA, the *Break the Barriers Dinner* and *Golf Outing* weekend raised more than \$10,000. Way to go, Brittany (pictured below center)!



- Minnechaug Regional High School in Wilbraham, MA, raised \$2,350 with a themed gift basket raffle. Outstanding!
- Council Rock School District in Newtown, Bucks County, PA, raised \$280 with their *Casual Days for a Cause*.
- Clemson Elementary School (CES) students sold Chick-Fil-A calendars for a service learning project. \$278 was raised in honor of Alex Newton by his older brother, Russell, and his 3rd grade class at CES. Participating classes included Mr. Hooker's, Mrs. Richardson's, Mrs. McDowell's, Mrs. Moore's and Mrs. Ellenburg's classes.

- "A's for Charlie & Louisa" raised \$902 for UMDF. Craig Leslie has made this event an annual one in memory of Charlie and Louisa Sido.



- St. Thomas Aquinas School (3rd grade class) - Isabel Taylor and her friends organized a bake sale at St. Thomas Aquinas School in Michigan and raised \$209.07 for UMDF in honor of her brother Simon.
- The 2nd Annual Walk/Run to Wipe Out Mitochondrial Disease, held at Merrill Crest Park/Bethesda Elementary in Waukesha, WI, raised \$11,400 in memory of Sam Juhlmann, a beloved Bethesda student who lost his battle with mitochondrial disease on March 3, 2005. Outstanding work, kids!

## More Spring and Summer Fundraising Events

- In May, Carolyn's Cabaret featured The Three Altos, Elizabeth Macaulay, The Rosewood String Band and John McLoughlin in Duluth, MN, and raised \$5,641 to benefit UMDF and raise awareness of MELAS in memory of Carolyn Russell.
- The Hefferon family's annual *Mito-What? Post-Holiday Gift Recycling Party* raised \$6,342.50 in honor of David Hefferon – excellent job, Elizabeth!
- A *Meet the Artist Art* show, featuring a collection of recent works from world-renowned artist

Peter Max, raised \$3,020 in memory of R.J. Victor in Naples, FL.

- *The Writers at the Beach: Pure Sea Glass Annual Writers Conference*, sponsored by the Rehoboth Beach Writers' Guild, raised \$10,000 in memory of Sam Juhlmann and in honor of the entire Juhlmann family. The 2006 workshop, held in Dewey Beach, DE, attracted nearly two dozen authors, editors and agents for this unique charitable event, and over 175 participants attended. For more information about the conference, go to [www.writersatthebeach.com](http://www.writersatthebeach.com).
- The St. Louis Mito Group held the 3rd Annual Family Fun Day and "Mito What?" 5K Run, Fun Walk and Kids' Run at the Shrine of Our Lady of the Snows in Belleville, IL, and raised over \$12,000 this spring. Activities included kids' entertainment, face painting, refreshments and prizes! Special thanks to Marsha Hohe for her efforts again this year.

- Jary and Kristy Carter and their friends hit the slopes in March at the Sundance Resort in Utah for a Ski Day for UMDF to raise money for the Charlie



and Louisa Sido Tanner Research Fund. Participating skiers collected pledges per run and a good time was had by all skiing for UMDF! To date, the UMDF/Sido Research Fund events have raised more than \$58,000! Excellent!

## Mito Adults Corner - Mito and Depression Can Walk Hand and Hand

Continued from page 11

chances of suffering from depression. This does not mean that I am crazy or that I can't handle it, but rather that a true physical issue (mito) was contributing toward my symptoms of depression. Once I understood this, I have to admit that I felt much better. Although we all still fight the ugly head of depression, knowing that it is not truly a "mental" illness seems to make us all feel a bit better. The stigma of a mental illness is not a pleasant burden to deal with. Having this gone is helpful to us in our daily battle with mitochondrial disease.

I personally believe that there are many "Mito Moms" who suffer from depression for two reasons – one because they are "Mito Moms" and the demands of a "Mito Mom" are incredible, and two because they are mito patients themselves. If you are suffering from depression as a "Mito Mom" or as a mito patient, get help. You don't have to worry that there is shame in your depression, and there is never shame in seeking help. Also, know that depression takes on several forms as I found out. For me, it was extreme anger and frustration. For my child, it was not being able to get out of bed. Depression seems to be part of mitochondrial disease, but you don't have to suffer from it.

*Special Thanks to Karen Ortiz for sharing her experiences with our UMDF readers!*

### Correction

*In the last issue, a donation of \$1,000 was from Larimore Wickett and Carlos Gutierrez. Thank you, gentleman!*

## 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!

**Our next Adults Corner article titled *Getting a BiPAP-A Personal Odyssey*, by Melissa Nixon, will be featured in the Fall issue.**

## Fundraisers <sup>Cont.</sup>

- Krista Wakefield, of Sayre, PA, held the *2nd annual Mito-What Post Holiday Gift Recycling Party* this winter in memory of Anthony Wakefield and raised \$800! Gift-giving at its best!
- The Kindbom Family *2nd Annual Winetasting Party* took place this past spring in Medford, NJ. The party was held in honor of Rachel Kindbom and raised \$39,900!
- The *1st Annual Race for Ellie* was held at Library Park in Powell, OH, in honor of Ellie Kovalcik in April – the event raised \$5,199. Outstanding!



- The *2nd Annual Chris Schindler Memorial Cutting*, held at the Washington County Fairgrounds in Brenham, TX, raised \$20,000 to benefit UMDF/Christopher Schindler Research Fund (event picture above).
- The Corvette Club of Western PA held a cruise at Day Chevrolet in Monroeville, PA, this spring and

raised \$1,700. Thank you to Joe Haver and the Corvette cruisers of Western PA!

- The *Gibson's 13th Annual Potluck/Barbecue*, held in June in Ukiah, CA, honored the memory of Heidi Daniels. Over the years, more than \$25,000 has been raised through this event for the United Mitochondrial Disease Foundation – with \$3,875 in 2006. Excellent!!!
- *4th Annual UMDF Pittsburgh Run/Walk* raised more than \$32,000. Thank you to our local families, sponsors and volunteers for participating and moving us *One Step Closer to a Cure*.



### Tip for Holiday Shopping

Visit [www.toysrus.com](http://www.toysrus.com) and click on the *Toy Guide for Differently Abled Children*. This online guide provides a user friendly and descriptive look at toys for special needs kids. Very cool and helpful for those holiday gifts!

# Atlanta 2006

## Mastering the Mitochondrial Maze

Continued from Page 1

medicine and current research. The networking among the scientific attendees, patients and families was quite refreshing. The 230 patient and parent attendees were extremely pleased with the opportunity to meet so many specialists in the field of mitochondrial medicine and to have new information to face the new challenges that mitochondrial disease presents to them on a daily basis. But don't take our word for it – please note the following comments from our attendees and faculty:



• *I felt yesterday that this year in Atlanta, the UMDF meeting had become a major scientific meeting for mitochondrial diseases. It is turning out to be THE mito meeting for patients, doctors and scientists. You have brought the scientific level to a hitherto unachieved level, and you need credit for that. Your idea to bring into the arena scientific apparently remote from our field was just brilliant. Brilliant organization too ...you have got the maximum mark of 20/20.*

-Arnold Munnich, MD

• *We met many families struggling with Mito. The sessions were awesome. The banquet was so*

*nicely done, with excellent food. I wish everyone I knew could come and be there and hear about mitochondrial diseases. If you or a family member suffers from MITO, please, if at all possible, try to make it to San Diego in June 2007 for next year's UMDF symposium. It is well worth it.*

- EJ and Debbie Fogel, California



• *The information provided was phenomenal, and one thing I was truly inspired by was the humbleness and respect for the parents that all the physicians seemed to convey during their presentations.*

*This was my first experience at a symposium and I cannot recommend it enough to other families. It was well worth my time -- the knowledge gained was inspiring. It would have taken me weeks via the internet to gather the info that was presented in two days.*

- Kristi Cole, Georgia

• *This year's program was incredible. Dr. Joanne Janas gave wonderful pointers for dealing with doctors our family visits regularly. Dr. Shoffner did an outstanding job of explaining the very complex world of the mitochondria. Maribeth Fischer gave me an outlet - gave great instruction on putting things in detail, written down - this has already helped us - I am able to sit and write things down and have become more descriptive so I can't forget the little things! Dr. Sumit Parikh's session was very informative. It is so difficult to enter into an emergency room with such a*



*complex disease as mito. Dr. Parikh was able to give great advice in how to deal with these situations. Since the symposium, we now have a written letter from our son's primary care physician - giving the doctors an idea of what they need to do. "Creating a Medical Home" by Anne Juhlmann, RN, BSN, was great. The information she shared regarding her very own children was so important. She really made me take a very close look at our own home - a very eye opening presentation.*

*There were so many important pieces of information that were shared this year that I could go on and on. Overall this was such a positive experience. The staff of UMDF, as usual were extremely helpful, cheerful and very knowledgeable. Thank you so much for this opportunity.*

- The Young Family - Duane, Amy, Tyler, BJ and Kaylin

• *It was really moving to see some of the patients and their families. I think the UMDF is doing some really inspirational work.*

- Vishal Gohil, PhD, Massachusetts (UMDF Grant Recipient - see page 1 for picture of Dr. Gohil)

**If you missed Atlanta 2006, audio CDs and syllabus materials are available for purchase. The order forms can be found at [www.umdf.org](http://www.umdf.org), or you can email [info@umdf.org](mailto:info@umdf.org).**

## Special Thanks to our Sponsors and Exhibitors

### Power House Level

Warren and Kathy Lammert

### Generator Level

Tishcon Corporation  
The Edith L. Trees Charitable Trust

### Supporting Level

March of Dimes  
Dominican Sisters/St. Mary of the Springs Blessings Fund  
The Mitochondrion - Mitochondria Research Society  
Mitochondrial Research Guild (Children's Hospital Seattle)

### Exhibitors:

Tishcon Corporation  
Aquatics by Sprint  
MitoSciences  
Olis, Inc.  
Transgenomic  
Visiting Nurse Hospice Atlanta



## Did Attendees Master the Mitochondrial Maze?



*Dr. Hemmi Bhagavan and Raj Chopra, of Tishcon (pictured above), and John Audette, of MitoSciences (pictured below), provided attendees information that could be used as they journeyed through the Maze. Thank you to all of our exhibitors for their continued support of the mitochondrial meetings and UMDF!*



*Lectures provided empowerment to all those in attendance – for doctors, patients and families. Did we “master” the maze? Maybe not, but we continue to make progress!*



*Networking with families, researchers and physicians provided a welcomed light for the many dark corners of the Maze.*



## Mark Your Calendar NOW for Mitochondrial Medicine 2007: Riding the Wave of the Future



**Mission Bay  
San Diego, CA**

**Scientific Meetings  
June 13-16, 2007**

**Family Meetings  
June 15-16, 2007**

**The scientific and family program planning is well underway. Committees will review past evaluations and build on the successful sessions from UMDF symposia over the last five years.**

**Call for Abstracts for Researchers will open on November 1, 2006 at [www.umdf.org](http://www.umdf.org).**

## We Need YOUR Help!

If you or someone you know has contacts or ideas for exhibitors and sponsors for the 2007 meeting, please contact [michelle@umdf.org](mailto:michelle@umdf.org) or call Michelle at 412-793-8077.

In order to continue offering lower fees for family attendees, we need help in finding sponsors and exhibitors – their support helps us offset symposium expenses and pass on savings to YOU!

## Development Corner

### Leaving A Legacy

A planned gift to the United Mitochondrial Disease Foundation will ensure the future of our work to fight mitochondrial disease.

#### Planned gifts can include the following:

- Wills or Bequests
- Trusts - Charitable Lead Trust or Charitable Remainder Trust
- Charitable Gift Annuities
- Real Estate
- Life Insurance
- Stocks/Mutual Funds
- Donor Advised Funds

#### Giving can offer the following advantages to you and your family:

- Reduce estate taxes
- Provide a lifetime income stream
- Allow you to make a much larger gift than you thought possible
- Receive a current income tax deduction
- Reduce or avoid capital gains tax
- Support the important work of UMDF!

We highly recommend that you consult with your tax or legal advisor to obtain more detailed information prior to making a planned gift. If you do not have an advisor with whom you currently work, UMDF can offer the services of the Montverde Group at no charge. Please contact Michelle Lawler (picture upper right), our director of development, if you would like more information about this service. A professional can help you determine the appropriate gift level based on your circumstances, the type of gift, the tax implications of your gift and how to best structure the gift in order to benefit both you and the UMDF. While the foundation always welcomes cash gifts, our first concern is that the form your gift takes is in the best interest of you and your family.

If you have already designated UMDF as a beneficiary for any of the above, please contact us to let us know of your generosity.



#### Michelle M. Lawler

Michelle M. Lawler (Braden) joined the United Mitochondrial Disease Foundation as Director of Development in May 2006. She comes to UMDF from Children's Tumor Foundation where she led the New England office, based in the Boston area. Locally, she has also

worked for Pittsburgh Voyager and Pittsburgh Dance Council. Michelle holds a BS in Journalism from Ohio University. Welcome aboard, Michelle.

### Response to Online Survey OUTSTANDING!

The Development Office recently launched an online survey to help UMDF better serve our members and the mitochondrial community.

To date, we have received more than 900 responses and they keep coming in.

If you have not completed the survey and want to have a voice, please visit [www.umdf.org](http://www.umdf.org) by **November 1, 2006**.

The survey allows respondents the opportunity to provide input in the following areas:

Membership Benefits  
Support Services  
Web Site  
Development  
Information Technology  
and much more!

### Wanted

Do you or anyone you know have skills or talents to share with the UMDF. Committee volunteers are one of the life lines in our quest for better treatments and cures!

Your family, friends, co-workers may want to help – let us know what skills or talents they have and we'll try to find a place for them on a committee! Email [info@umdf.org](mailto:info@umdf.org) and put Committee Interest in the subject line or call 412-793-8077.

## Ask Your Employer About ...

### United Way and You

Many companies require United Way giving. Why not take this as an opportunity to support UMDF? Start off by asking the employees you work closely with, and maybe they'll help spread the word.

### How to make it work . . .

The United Way campaign in your local area is designed to meet a diversity of health and human care needs. You may give an unrestricted gift, and in some areas, you may designate UMDF as the recipient of your gift to United Way. Contact your local United Way office to find out if there is a DONOR CHOICE program in your area. We have received funds from a variety of communities through the donor choice program, and we appreciate being included in this effort.

We will acknowledge each gift received unless otherwise indicated or if no address is provided.

Simply complete the appropriate form (available through your employer) as follows:

**United Mitochondrial Disease Foundation**  
**8085 Saltsburg Road, Suite 201**  
**Pittsburgh, PA. 15239**  
**Phone: (412) 793-8077**  
**Fax: (412) 793-6477**  
**Attention: Mark Campbell**

IBM Employees can now contribute a portion of their pay to UMDF as part of the *Employee Charitable Contribution Campaign* which runs August 1 through October 27, 2006. This campaign includes retirees, executives and all 300,000 plus employees. Special thanks to Partrick Sullivan for making this happen – in honor of the Juhlmann family!

### Matching Gifts

#### Double Your Gift Giving

Does your employer participate in a Corporate Matching Gift Program? If so, your gift could be doubled.

The following companies have matched gifts to UMDF in the past. If you or a loved one works for one of these companies, check out the matching gift program and help us move one step closer to a cure!!

*American International Group Inc. (AIG)*  
*American Express Gift Matching Program*  
*Ameriprise Financial*  
*Ameriquest Mortgage Company*  
*Aon Foundation*  
*AT&T Services, Inc.*  
*Bank of America*  
*BP Foundation*  
*CNA Foundation*  
*CSG Systems, Inc.*  
*DELL*  
*DePuy Spine*  
*Dupont Powder Coatings Fleet*  
*Gannett Foundation, Inc.*  
*GAP Foundation*  
*FM Global Foundation*  
*Halliburton Foundation, Inc.*  
*Illinois Tool Works Foundation (ITW)*  
*John Hancock Financial Services, Inc.*  
*Johnson & Johnson Family of Companies*  
*Johnston-Lemon Group, Inc. (JLG)*  
*Key Foundation*  
*Kimberly Clark Foundation, Inc.*  
*McDonald's Corporation*  
*MassMutual*  
*Microsoft*  
*Nationwide Foundation*  
*OppenheimerFunds Inc.*  
*PEC Solutions, Inc.*  
*PPG Industries Foundation*  
*Progressive Insurance Foundation*  
*RBC Centura*  
*Roche Diagnostics*  
*Saint-Gobain Corporation*  
*SBC Communications*  
*SIG (Susquehanna Internat'l Group, LLP)*  
*Subaru of America Foundation, Inc.*  
*The J.P. Morgan Chase Foundation*  
*The Prudential Foundation*  
*Thrivent Financial*  
*Trans Union LLC*  
*Union Bank of California*  
*Wachovia Foundation*

## Fundraisers <sup>Cont.</sup>

### The Simple Things ★ Raising Dollars for ★ Research!

- A yard sale in Allentown, PA raised \$75 in honor of Ashlyn Snyder -- LOVE it!
- To celebrate Elspeth Gray's 80th birthday, \$325 was donated in memory of Kayley McManus of Clewiston, FL. Happy Belated Birthday, Elspeth!
- Natalie Petro and Abby Kimicata, of Monroeville, PA, raised \$28 with their Kool-Aide stand for UMDF families!



### Elena's Hope Raising Dollars for Research

The Welhouse Family, of Kimberly, WI, have been busy raising awareness and dollars.

The UMDF/Elena's Hope Research Fund has held a Mother's Day Flower Sale, Youngers Community Day Sale (\$4,354) and a dinner benefit. Total raised at time of printing this newsletter was nearly \$24,000.

Special thanks to the Southwest and Southeast Outagamie County Chapters of Thrivent Financial For Lutherans for donating grant money totaling more than \$2,600 on behalf of Elena.

# Atlanta 2006

## Miles for Mito

Story Cont. from Page 8



The 600-mile ride began Friday, June 9 at 8 a.m. when a dozen riders took to their bikes at Riley Hospital for Children in Indianapolis, IN.

Eight grueling days later they arrived in Atlanta, Georgia, to a

large crowd of supporters. Colin Coburn said it was "one of the highlights of my life." Fellow rider John Fleck, a coworker and friend to a mito family, commented that "it was an honor to serve and participate in some small way." Special thanks to all of our riders for keeping the 2006 event alive – especially Marc Reich and Colin Coburn! Visit [www.umdf.org/milesformito/](http://www.umdf.org/milesformito/)

Pictured above are the riders and the crowd in front of the Sheraton on Courtland Street in Downtown Atlanta. These courageous young men and women continue to go the extra mile for UMDF and its families – media coverage was GREAT (Colin and Stacy Coburn with local news station pictured above)! The crew will have their challenge next year -- San Diego, CA. Anyone interested in helping with this phenomenal event, please email [info@umdf.org](mailto:info@umdf.org) or call 412-793-8077.

### Meet the Riders

Bob Thomas, Indiana Chapter Vice President - parent of affected son, Gabe Thomas

Marc Reich, Atlanta Chapter Vice President - parent of affected daughter, Hannah Reich

Karen Rossi, of Pickerington, OH - lost her sister, Nancy, to mitochondrial disease

Eric Boling, Indiana Chapter - parent of affected son, Seth Boling

John Fleck, of Indianapolis, riding on behalf of a boss with an affected child

Nicole Kernan, of Indianapolis - riding on behalf of a friend with an affected child

Ryan Shatto, of Columbus, IN - riding on behalf of a friend with an affected child

Bob Jenks, of Indianapolis - riding on behalf of a boss with an affected child

Colin Coburn, of Roswell, GA - riding on behalf of affected son, Carson

Todd Rogers, of Greer, SC - riding on behalf of affected son, Carson



### UMDF Research Liaison Awarded

#### "2006 Professor of the Year"

Associate Professor Dr. Steven Bassett, of Monroeville, PA, recently received the 2006 *Professor of the Year* award from Seton Hill University for his outstanding work in education. The UMDF congratulates Dr. Bassett on this achievement and extends deepest appreciation for his continued (volunteer) efforts in providing user-friendly information about our little friend, the mitochondria!



Mito Group of Idaho hosts a BBQ for families -- parents, kids and other loved ones enjoyed food, balloon animals, magic tricks and face painting. The group is planning a Bowl-a-Thon in October. Bender family pictured left.

## Announcements and Merchandise



**Order UMDF Merchandise for the Holidays! Visit [www.umdf.org](http://www.umdf.org) for more information on how to order, or call 412-793-8077.**



### **Baylee Thompson Meets OSU Football Seniors and AJ Hawk!**

Five-year-old Baylee Thompson, of Crooksville, OH, met nine Ohio State University football players this past winter. Baylee got autographs from all nine players. In addition, a football signed by all the senior players and Coach Tressel raised \$1000 at the 2006 *Bet on Baylee* fundraiser for UMDF. AJ was given a UMDF Energy for Life bracelet, and he was seen wearing it at various autograph signings around the state. It was a wonderful experience for the Thompson family, and it raised awareness across Ohio. Best wishes to AJ Hawk and his new position with the Green Bay Packers!

### **Moved Recently or Planning to Move?**

If so, please don't forget to give us your new address! It will save us postage (yes, more money for support and research efforts), and it will ensure that you always get your UMDF newsletters and other mailings as soon as possible. To update your mailing address, email us at [info@umdf.org](mailto:info@umdf.org). Thanks!

### **Mitochondrial Medicine Book**

*Editors - Salvatore DiMauro, Michio Hirano, Eric A. Schon*

Contact [info@umdf.org](mailto:info@umdf.org) for an order form or visit [www.informahealthcare.com](http://www.informahealthcare.com)

#### **About the Book**

Providing an authoritative update on our current knowledge of mitochondrial medicine, this text draws together world authorities from various fields to present general therapeutic strategies, as well as the treatments presently available in different specialties - thus making it essential reading for **clinicians** involved with the management of patients with mitochondrial diseases.

### **UMDF Annual Membership Meeting Notice**

Thursday, November 30, 2006 at 1:00 p.m. Eastern Time  
Location: UMDF National Office, Pittsburgh, PA

## **GoodSearch**

According to GoodSearch, last year search engines generated close to \$6 billion in revenue from advertisers. GoodSearch, powered by Yahoo, developed a way to direct some of that money to the causes you care about most. It's easy ... every time you search the Internet at [GoodSearch.com](http://GoodSearch.com), UMDF earns money and the more you search, the more dollars we make to find better treatments and cures. Add up the money generated from all your searches and those done by the millions of other people who we hope will use GoodSearch, and we can make a real difference to the people and causes that need funds most.

#### **How does it work?**

Type <http://www.goodsearch.com/?charityid=806412> into your browser. Search the Internet just like you normally would and a donation of one penny per search is

### **New Search Engine Benefits UMDF**

contributed to UMDF. We have not promoted this opportunity and still have over 1400 searches on our behalf. It is a simple concept – when searching on the internet, instead of going through a well known search engine like Google, you go through the GoodSearch engine. Individuals can also email their friends and family through GoodSearch to encourage others to use this site as well. And it is powered through Yahoo, so there is credibility to the program. Ask your co-workers, friends, family and students you may know.

**Once you reach the site, add it to your favorites for future searches! Easy money to continue the UMDF mission!!**

## UMDF Chapters, Mito Groups & Ambassadors

### ALABAMA

#### **Ambassador - Huntsville/Madison County**

Contact: Peggy Stolz Conti  
Email: UMDFHuntsville@aol.com

### ARIZONA

#### ★Arizona Chapter

President: Suzanne Perryman  
Email: AZChapter@umdf.org

### CALIFORNIA

#### ★Southern California Chapter

President: Steve Grossman  
Email: SCalChapter@umdf.org

#### **Ambassador - Southern CA/Inland Empire**

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Email: ejfdfr@sbcglobal.net

#### **Ambassador - Sacramento Valley**

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### FLORIDA

#### **Ambassador - Melbourne**

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#### **North Central Florida Mito Group**

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#### **Ambassador - South FL**

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#### **Ambassador - Southern GA/Northern FL**

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### GEORGIA

#### ★Atlanta Area Chapter

President: Chris Swinn  
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### IDAHO

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### INDIANA

#### ★Indiana Chapter

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### ILLINOIS

#### ★Chicago Area Chapter

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### MASSACHUSETTS

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### MICHIGAN

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### OHIO

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#### **Ambassador - Southeast Ohio**

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### PENNSYLVANIA

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#### **Ambassador - Kimberly, WI**

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#### **Ambassador - Waukesha, WI**

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## **OUTSIDE OF THE UNITED STATES**

### AUSTRALIA

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Email: grra1@bigpond.com

Are you ready to



We have received over 200 forms from members who are willing to Mitoconnect, and we are ready to “Connect the Dots” for you by fulfilling your networking requests!

You must be a member of UMDF in order to participate in Mitoconnect. Members will be matched based on diagnosis, location, age, or symptoms. Please let us know which one of these options is most important to you.

- I am a current UMDF member and have already completed a Mitoconnect questionnaire (see description below). Please connect me with another member.  
(Rank by importance to you. 1= most important)

- \_\_\_ Diagnosis  
\_\_\_ Location  
\_\_\_ Age  
\_\_\_ Symptoms

- I am a current UMDF member and have not completed a Mitoconnect questionnaire. Please send me a Mitoconnect questionnaire form.
- I am not a UMDF member, please send me membership information.

**Please supply us with your contact information:**

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

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

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

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

**Please complete this form and send your request to:** UMDF, Attn: Membership Services, 8085 Saltsburg Rd. Suite 201, Pittsburgh, PA 15239. Or, email all relevant information to [info@umdf.org](mailto:info@umdf.org).

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### What is MITOCONNECT?

The Mitoconnect program is a revamped patient registry that will allow members to network with others who have similar diagnoses and symptoms. Mitoconnect can be used to connect parents of affected children or affected adults.

The Mitoconnect questionnaire asks for basic information concerning the affected person’s diagnosis, age, gender, most pronounced or troublesome symptoms, and the area of the country in which they live. Based upon this information and your above request, the UMDF staff will provide you with contact information for other members so that you can talk one-on-one with others who understand what you’re going through.

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

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UMDF's intent is to keep you informed - we ask  
that you always discuss any diagnoses,  
treatments, or medications with your personal  
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**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.  
Deadline for the Fall issue is October 31, 2006