

# M N

United Mitochondrial Disease Foundation

# MITOCHONDRIAL EWS

Volume 10 • Issue 2 • Spring 2005

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**Physical, occupational,  
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pet therapies for  
mitochondrial disease**

## Part I

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By Tracey J. Millhouse-Flourie

### Introduction

Despite years of study, the current medical and surgical approaches to the treatment of mitochondrial disease are limited. Treatments are generally symptomatic or geared toward slowing the progression of the disease process. In addition to these and the often-used vitamin and cofactor supplementation and dietary modifications, there also exist an array of supportive or complementary therapies that might be overlooked or undervalued. These include, but are not limited to, the 'allied health professions' of physical, occupational, speech and respiratory therapy as well as treatments in which animals are used: equine or 'hippotherapy' and animal-assisted, or 'pet therapy'.

In truth, there is no scientific proof that these therapies can be efficacious in treating the symptoms of mitochondrial disease. In this way, they join the ranks of other commonly used empirical treatments. But the multisystemic nature of mitochondrial disease surely deserves the efforts of a

## Countdown to Mitochondrial Medicine 2005 Gateway to a Cure

**Scientific Sessions:**  
June 15-17, 2005

**Family Sessions:**  
June 17-18, 2005

**Clinician Sessions:**  
June 18, 2005

**Hyatt Regency Union Station**  
St. Louis, Missouri

**Scientific Program Chair**  
Bruce H. Cohen, MD

**REGISTER NOW!!!**

[www.umdf.org/conferences](http://www.umdf.org/conferences)

**See Pages 8**

multidisciplinary team whose goals are the preservation, and if possible, the improvement of an individual's existing strength, mobility and functioning.

Of course physicians should communicate to patients that these therapeutic interventions will not change the underlying mitochondrial problem, but rather assist in the adaptation to the condition. As with all such treatments, the utilization of

*Continued on page 10*



**Energy Bands**  
See Page 18!



# 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: Richard Boles, MD, Childrens Hospital Los Angeles; Carol Greene, MD, Children's National Medical Center, Washington, DC; and Annette Feigenbaum, MD, The Hospital for Sick Children, Toronto, Canada.*

## The Question is:

My 5-year-old granddaughter has recently been diagnosed by frozen muscle biopsy to have mitochondrial disease due to Complex III deficiency. She has cognitive delay, tremor in her right hand and ataxia. All symptoms are worse during illness, during which she often becomes nonverbal with excessive irritability. For example, she screams, tries to bang her head, bites herself and others, and pulls her hair out. This behavior can last for up to an hour. In addition, during these episodes she is wild-eyed, her pupils are dilated, she doesn't respond to anything, and she often repeats words and phrases. How do we know if these episodes are tantrums? Is behavioral modification adequate? How likely is it that these episodes are a result of the disease and the way it affects this child, and how can that be proven?

## Response From: Richard Boles, MD

Temper tantrums are common in toddlers in general. In children with developmental delay secondary to mitochondrial disease, temper tantrums can be seen in older children as a combination of emotional and speech delays (from frustration in not being able to express their thoughts and needs). Some children have very loud and active tantrums and do not listen to others during them, however, tantrums rarely last an hour. Behavioral modification is the appropriate manner to deal with temper tantrums.

On the other hand, many children with mitochondrial disease have pain crises, in which severe pain can suddenly develop in the head, abdomen, or limbs. If the child is not very verbal, these can manifest as sudden outbursts of screaming and aggressive behaviors that can look a lot like a temper tantrum. These episodes can last up to several hours. In my clinical experience, anti-migraine medications, particularly caffeine, amitriptyline or cyproheptadine, can treat or prevent these episodes.

Both of these situations can be worse during illness. How do you tell the difference? One usually occurs when the child is frustrated (e.g. told that she can't have something), and the other usually occurs at apparently random times.

Very rarely, behavioral episodes can be a sign of a more serious condition, such as certain forms of epileptic, psychiatric or neurodegenerative disorders.

## The Question is:

I have been told that my 11-month-old daughter has hypomyelination throughout the brain and that there is atrophy of the cerebellum and volume loss also in the pons about 4 months ago. And now I was told the other day that she has a Complex I defect. Are the two related? Can a mitochondrial disorder cause the brain to shrink?

## Response From: Carol Greene, MD

Some people with disorders of the respiratory chain do not have any neurologic problems. However, we do know that disorders of the mitochondrial respiratory chain can cause brain damage in a variety of ways. Sometimes this brain damage cannot be seen on radiologic studies like CT or MRI. Other times the CT or MRI shows visible changes including findings called "hypomyelination", "volume loss" or "atrophy." As the words "volume loss"

and "atrophy" suggest, the brain can get smaller or "shrink" in some people as a consequence of mitochondrial disorders. In addition, the structures in the brain (pons and cerebellum) that you mention in your question can specifically be affected by disturbances of mitochondrial energy production. So the answer to your question is yes, the brain findings you describe as being seen in your child can certainly be related to problems with Complex 1 function. It is important to understand that there is always the possibility of some more complicated explanation, but the simplest explanation here – assuming that the diagnosis of Complex 1 deficiency is correct – is that the Complex 1 deficiency is the cause of the brain findings.

## The Question is:

My daughter is 9 years old and was diagnosed as having MELAS (A3243G). Her symptoms started when she was 7. She has high lactic acid, ptosis, and seizures. At this moment (Jan/2005) she is very well. Her mother and her grandmother (mother of her mother) are healthy. I also have a son who is 5 years old. He is healthy too, with no symptoms of MELAS.

I would like to ask if it is possible to evaluate the probability of my son having or not having MELAS.

## Response From: Annette Feigenbaum, MD

The issue of whether someone without symptoms or signs "has MELAS" is not a straight forward answer. Does one want to check if he carries the mutation or has the disease or is at risk of developing the disease? For the mutation, it depends on which tissue is checked and how invasive testing is. It MAY also depend on whether the egg transmitted by mom had a high or low percentage mutation. One could check blood, and if that is negative, hair follicles/buccal mucosa and if necessary muscle biopsy, etc., but this will ONLY tell you if he carries the mutation and will not tell you if he is at risk of developing symptoms and if so, which symptoms. That can only be done clinically by monitoring over time although if a high percentage heteroplasmy of the mutation (usually more than 80-90%) is found in a certain tissue, there is a higher risk of developing symptoms related to that tissue/organ at some time but one cannot be more specific than that.

# Chairman's Report

Summer is rapidly approaching and, for many of us, it is time to start planning for summer vacations with family and friends.

Whether it is a weekend camping trip or a week long excursion to the beach, there is nothing more precious (and tiring) than spending quality time with loved ones.

A vacation can have many meanings – it can be a time of rest, a holiday, a break, an escape or a special trip. Unfortunately, there is no break or escape for many of our families battling mitochondrial disease. Vacations are still taken, however, and we know that one special trip can create memories that will last a life time.

The UMDF Staff and our many volunteers continue to work diligently during the summer months. Many of our staff will be adjusting their schedules, working evenings instead of days, to accommodate their families this summer. As you can see on page 18, there are numerous events happening throughout the summer and the dedication of staff and our members is a winning recipe making these events successful.

The UMDF is fortunate to bring four new talents to the national office to maintain our momentum heading into the summer months – and beyond!

Mark Campbell joined the UMDF staff as our first Chief Financial Officer (CFO) in November of 2004. Mark brings 30 years of business management and accounting experience from working in the

industrial sector. Mark has a Bachelors degree in Business Administration with Masters work in Public Administration and

Accounting. Mark is amazed at the dedication, commitment, and energy of the UMDF members responsible for the foundation's success.

The first voice you may hear when you call the national office could be Barbara Podowski as she now serves as our new Administrative Assistant. Barb has been with UMDF since February and brings with her many years of experience in administrative support.

This past March, Jodie Tabano came on board to tackle the position of Manager of Special Events. Jodie was raised in Ohio but has lived in the Pittsburgh area since 1998. She comes to UMDF with 13 years of experience in fundraising – working at organizations such as Muscular Dystrophy Association, La Roche College and the American Lung Association.

Jodie is married and has a Bachelors degree in Communication Arts/PR/Marketing and a Masters in HR Management. She will be calling you soon!

Becky DiLettuso is our new Member Services Director and brings over 15 years of experience in member services and administration. Becky hails most recently from Catholic Charities of the Diocese of Pittsburgh. Becky has a Masters

*Continued on page 9*



Mark Campbell



Barb Podowski



Becky DiLettuso



Jodie Tabano

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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.

## Newsletter Editor

Kara Strittmatter  
kara@umdf.org

# Chapter Activities

## NEW ENGLAND CHAPTER

Boston, MA  
President: Bridget Willis  
Phone: 413-593-5920 (Beverly Ingram)  
Email: NEngChapter@umdf.org

### Upcoming Events



The chapter will hold a Yard Sale on Saturday, June 25 from 9 a.m. to 2 p.m. at the Plymouth Public Library. If you want to volunteer or donate an item, call Bridget Willis at 508-224-7165.

- Saturday, June 4, Recharge Your Energy and Redefine Hope Dinner Event at First Parish-Milton. Join the Sullivan family, friends, and the community for a dinner event to benefit UMDF. Sponsored by Outback Steakhouse and Super Fitness. For more info, call 617-696-6860.

### Special Thanks

In February, the chapter had a silent auction in honor of Bridget's son, Owen and raised more than \$1,600.

### More Events Coming Up

- May 25, 2005 - The Lego Company in Enfield, CT will hold its 2nd Annual on-campus walk for UMDF in memory of Matthew Bailey and Stig Toftguard.
- October 1, 2005 - 6th Annual Mito-What? 5K Walk/Run in Longmeadow, MA at Baypath College on Route 5. The chapter hopes to add another Walk/Run on the same day to be held in Plymouth, MA.

## NEW YORK METRO CHAPTER

Manhattan, NY  
President: Mary Pisani  
Phone: 203-287-0655  
Email: NYMetroChapter@umdf.org

### Upcoming Events:

- Saturday, May 21 - 2 Mile Walk to Create Awareness in Chatham, NJ. Loantaka Brook Reservation, Morris Twp. For more info, contact Tom and Caroline Shubeck at 973-635-6354 or email tpshubeckphd@optonline.net.
- Saturday, May 21 - 5K Race and 1 Mile Fitness Walk at North Haven Middle School on Bailey Road, CT. For more info, contact Mary Pisani at 203-287-0655 or email Mkpisani@aol.com.
- Saturday, June 4 - Kain's 5K Walk in Greenwich, NY. For more info, contact Bethany Buell at 518-692-1764 or email BBuell437@hotmail.com.

**Special Thanks to the Matthew Dudgeon Memorial Fund for donating \$20,000 from their 2004 Memorial Walk and Dinner Dance. We appreciate your continued support in UMDF's quest to find a cure for Mitochondrial Disease.**

## ATLANTA AREA CHAPTER

Atlanta, GA  
President: Holly Capp  
Phone: 770-506-7441  
Email: AtlChapter@umdf.org

### Two Major Events Rule in Atlanta

Atlanta chapter members were busy this past month with two fundraisers – Race for Riley, organized by the Peek Family, and the 2nd Annual Speaker Dinner event with guest speakers, Dr. Bruce Cohen and Dr. John Shoffner.

Final totals for both will be printed in the next issue but it looks like Race for Riley could hit close to \$83,000 and the dinner more than \$4,000. We look forward to seeing the final results! See page 11 for pictures of the race.



### ME

I can't run fast.  
I have braces.  
I fall a lot.  
I can do math.  
I can climb.  
I can slide.  
I am ME.

by 9-year-old Emily Swinn,  
enthusiastically read by Emily  
during the Race for Riley Event.  
Emily has a mitochondrial disease.



Atlanta chapter members busy greeting and raising funds at May 2<sup>nd</sup> Speaker Dinner!

## DELAWARE VALLEY CHAPTER

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

### Upcoming Events:

- **Brew at the Zoo 2005** is set for Saturday, June 11 at Elmwood Park Zoo in Norristown, PA. The event starts at 6:00 p.m. and tickets will be sold in advance. To purchase tickets or for more info, contact Lisa and Bob Polsky at 610-275-2775 or email BrewAtTheZoo@msn.com. Or visit <http://mysite.verizon.net/vze6vr65>.
- **September 10, 2005 - 6th Annual Energy for Life Walk/Run** (formerly Shelly's Heroes). The event is now taking place at the Art Museum & continues along West River Drive -Philadelphia, PA

**Successful Events - Thank YOU**  
• The Breslow Family has hosted

## KANSAS CITY CHAPTER

Kansas City, MO  
President: Pam Johnson  
Phone: 913-631-3070  
Email: KCChapter@umdf.org

### Energy Bands Hit Stores in Oklahoma and Kansas

Thanks to Deidra Atchley, Star Fuel Stores will be selling UMDF Energy Bands in the 50 stores in Oklahoma and in 10 stores in Kansas. Yes - Awareness!!!!

### Successful Events

- Friend of Sophia Edwards made scarves and sold them in honor of Sophia and raised \$115.
- Candice Ruddell, of Greenwood, MO, is 14 years old and the cousin of Joseph Atchley. Candace sold Energy Bands at her local High School.

### Upcoming Event

- September 10, 2005 - 1st Golf Outing - More information to come.

two dinners so far this year in honor of their daughter Sydney and have raised a total of \$2,846 to benefit UMDF. Keep up the great work.

- The chapter raised \$344 during a dress down day and a craft sale through the St. Maria Goretti School and Parish.

### Crystal Beaded Bracelets

Beautiful crystal beaded bracelets are still available through the chapter. You can choose between three sterling silver messages (Hope, Miracles, Cure) or a single message (Hope). All bracelets have the awareness ribbon near the clasp. Pictures and order forms are available on the Delaware Valley Chapter web page at [www.umdf.org](http://www.umdf.org).

Bracelet sales have raised \$1,090 for the chapter to date. Beautiful!

## ARIZONA CHAPTER

Phoenix, AZ  
President: Suzanne Perryman  
Phone: 480-419-0167  
Email: AZChapter@umdf.org

### Designs for Dollars

Chapter President Suzanne Perryman has recently started a fundraiser to benefit AZ UMDF. Please take time to visit [www.embroideryjournal.com](http://www.embroideryjournal.com) and check out *Designs for Dollars*. As of March 15, the fundraiser has raised \$200.



*UMDF Zoe's Heart - just one sample from the Designs for Dollars web site. Check it out!*

## INDIANA CHAPTER

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



**Bob Thomas is at it again and plans to ride 3 days and over 300 miles from June 14-16, 2005. Ten fathers have already signed up to join Bob on this fantastic journey. If you are interested in signing up or would like to donate to Miles for Mito, please visit [www.milesformito.org](http://www.milesformito.org).**

### More Upcoming Events:

- May 14, 2005 - Equipment Fair at Riley Hospital.
- Monday, August 15, 2005 - The First Annual Indiana UMDF Golf Outing will take place at The Hawthorns Golf and Country Club in Fishers, IN. Registration web site: [umdfgolfouting.golfreg.com](http://umdfgolfouting.golfreg.com).

### Symposium Scholarships available for Indiana Chapter Members

To be considered, you must be a resident of Indiana and a paid member of UMDF. For more information, contact Sue Ann at 317-894-9099.



### Pack the House

On February 12, Indiana Ice Hockey supported the chapter by donating a portion of each ticket sold. This year's check was almost \$6,000. Outstanding!

# Chapter Activities

## Upcoming Events

- June 4 - Fourth Annual KFC/UMDF 5K Run/Walk, Forest Hills Park in Cleveland Heights, Ohio. Please visit [www.umdfohio.org](http://www.umdfohio.org) for more information!



## Guest Bartender Night a Success

- In honor of Kyle Kobunski, family and friends gathered at the Main Street Grill & Pub in North Royalton, OH and raised \$3,800 to benefit UMDF. The owner, Tom Marzella, was more than generous. Anita Barker, pictured above with Diane Kobunski, initiated this event last year and it has really taken off.

## OHIO CHAPTER

Cleveland, OH  
President: Jennifer Lyman  
Phone: 330-929-4430  
Email: [OHChapter@umdf.org](mailto:OHChapter@umdf.org)

**Shadow Woodstock 2005**  
**Sunday, May 29, 4pm to 2am**  
**Auburn Twin Oaks Farm, Beth and Jay Schabel (proprietors).**  
For more info, contact the chapter.



## 2nd Annual Bet on Baylee Casino Night Raises \$8,010

- Gary and Jody Thompson's family and friends enjoyed an evening of casino games, live auction and Texas Hold'em. "All in" for UMDF - outstanding!

## 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 during the following Lake County Captains games:

**Friday, May 20, 2005**  
**Friday, June 17, 2005**  
**Friday, July 29, 2005**  
**Friday, August 12, 2005**  
**Friday, September 2, 2005**

If you would like to volunteer to help hand out information about UMDF and Mitochondrial Disease, please contact the chapter.

## Hope Bracelets

The Ohio Chapter is still selling bracelets. For ordering information, contact Melissa Nadja at La'Jules 440-937-9947. A picture of the bracelet is available online on the chapter webpage at [www.umdf.org](http://www.umdf.org).

## SOUTHERN CALIFORNIA CHAPTER

Lakewood, CA  
President: Linda Cooper  
Phone: 714-921-2324  
Email: [SCalChapter@umdf.org](mailto:SCalChapter@umdf.org)

## Upcoming Events

- May 14 - 2nd Annual Wine Tasting Event and Silent Auction. The event will include over 50 auction gift baskets, a wine connoisseur, live music, hors d'oeuvres, and a UMDF Trustee to speak to our guests regarding mitochondrial research.

## Special Thanks

- The Los Angeles Marathon Run created awareness and raised funds of \$1,650 to benefit UMDF. In honor of his nephew, Conner, Kyle DeVriendt ran his first L.A. Marathon to help raise awareness and funds to benefit UMDF. Kyle finished the 26.2 mile run in little over four hours. And for a first time runner, THAT is a great accomplishment. What an inspiration -- Great Job, Kyle!



- Alison DeVriendt organized a fun afternoon of scrap booking and raised \$150. Thanks, Alison!

## New Family Group Meeting

**Saturday, July 23, 2005**

**Please contact the chapter for your "Calendar of Events."**

## 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.**

## Charitable Gifts That Keep on Giving - Back to YOU!

There's an old adage that "charity begins at home" and for several months now we've been discussing how charitable giving programs can be of benefit to YOU as well as to UMDF. Probably no charitable instrument can illustrate the potential of that premise as easily as the Charitable Gift Annuity ... truly the gift that keeps on giving - to UMDF and back to the donor.

For many donors, a Charitable Gift Annuity (CGA) is a way to contribute money or property to a charity. A contribution that results in tax benefits and the security of a generous, steady and reliable income stream for the donor ... an income stream they can't outlive!

For many older individuals who are past the generally higher risk investment "accumulation" phase, more concerned with ensuring income than building additional wealth, a charitable gift annuity may provide the answer. Even those persons of more modest means who are concerned with the extreme swings of the financial markets over the past few years may benefit from a CGA.

By definition, a CGA is a contract, part gift (not investment), and part annuity ... an arrangement by which the charity agrees to provide the specified annuitant or beneficiary a fixed payment, monthly, quarterly, semi-annually, or annually .... for life! It's an income stream you can't outlive and a way to support UMDF without financial sacrifice. Simple

and uncomplicated, with no need to redo your will or trust. You can have more than one beneficiary and you can start the income stream now, or in the future. You can establish a charitable gift annuity with a relatively small amount of money, the older the beneficiary, the higher the payment. You get an immediate tax deduction to lower your tax bill on current income, with a portion of the payments received treated as a "return" of your original basis, coming back to you tax free!

As with any charitable gift, suitability, applicability, tax benefits, rates, proceeds, and more will be determined by your specific circumstances. With this kind of potential, why not find out if a CGA is right for you, or how other charitable giving tools can fit into your family's financial plans. Call UMDF today!



## Taking Control

UMDF has developed an initiative called "Taking Control." Nick Nicholson is spearheading the development of all components of "Taking Control" to develop, coordinate, and implement the necessary financial planning strategies and instruments for our members. Nick is a Senior Financial Advisor with The Monteverde Group, a member of Partners Financial, and is a Registered Representative and Investment Advisor, offering securities and advisory services through NFP Securities, Inc. of Austin, Texas. He can be reached by phone at 800.722.0098, or via e-mail at [stnick333@aol.com](mailto:stnick333@aol.com).

### NEWSLETTER FEEDBACK FORM

Mitochondrial News contains the following sections in every issue. Please rate your interests in these sections, 5 = high interest and 1 = least interest (Circle one for each).

Sections	Rating				
Lead Medical Article	1	2	3	4	5
Ask the Mito Docs	1	2	3	4	5
Chapter Activities	1	2	3	4	5
Adult Corner	1	2	3	4	5
Secondary Article <i>(Research Updates, UMDF Development, Various Topics of Interest)</i>	1	2	3	4	5
Fundraisers	1	2	3	4	5
Chairman's Report	1	2	3	4	5
Donor Acknowledgements <i>(from past issues-NOT IN THIS ISSUE)</i>	1	2	3	4	5

Please provide topics of interest to you and your family:

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# Gateway to a Cure

## Scientific Meetings

June 15-17, 2005

## Clinical Meetings

June 18, 2005

## Family Meetings

June 17-18, 2005

### UMDF Symposia can ...



... give parents a chance to learn together as a team about their child's disease.



... give researchers many opportunities to meet others in the field.



...give families the opportunity to meet with some of the top specialists in mitochondrial medicine at the *Doctor Is In* booth.

## REMINDERS

**Send in your registration - if you did not receive a registration brochure, please contact the office at 412-793-8077.**

### Submit *Ask the Mito Doc* Questions

On Saturday, June 18, there will be a family session titled *Ask the Mito Doc Panel*. In order to make the session run smoothly, we are asking registrants to submit their questions ahead of time. Please complete the form below (use additional paper if necessary) and submit with your registration form. You may email your questions to [info@umdf.org](mailto:info@umdf.org) any time before June 8, 2005.

Question(s) for the Saturday <i>Ask the Mito Doc Panel</i>

### Make Your Hotel Reservations

Special hotel rates of \$125 single or double occupancy are available to conference attendees. Please make your reservations directly with the hotel as early as possible and prior to May 23, 2005 to receive this special rate. After the cut-off date, reservations will be accepted on a space available basis only.

Hyatt Regency St. Louis  
 One St. Louis Union Station  
 St. Louis, MO 63103 USA  
 Phone: 314-231-1234  
 Fax: 314-923-3970  
 Website: [www.umdf.org/conferences](http://www.umdf.org/conferences)

### Networking

A special networking room will be available throughout the conference! We will provide a message board for attendees to help connect members by geographic location or by disease. Please feel free to bring photographs of your loved ones to share with others and post them on the message board.

# Inspirational Stories

## A Sister's Love

Emily Kusuhara, of Osaka, Japan, recently raided her piggy bank and realized that she had enough to buy a new game for her Gameboy. She came to her mother later with a large handful of money for UMDF. She decided to keep only \$10 for herself and give the rest to UMDF.

Emily's eyes welled up with tears as she explained, "Even if I have lots of games, it's not fun if I can't play with Riki!"

Emily gave a heartfelt donation of \$55.88 in honor of Riki's starting 1st grade. "It comes with all her hopes and prayers that a cure will be found soon."

Thanks, Emily - you are a very special big sister!

## Earning "A"s for Charlie Sido

Fifteen-year-old Craig Leslie, a neighbor of Tova and Christopher Sido, raised \$1,205 by asking neighbors to donate to UMDF's research grant program (in memory of Charlie Sido) for every "A" he earned.

Thank you, Craig - you are not only a very smart young man but you have a HUGE heart!

## Chairman's Report

*Continued from page 3*

degree in Social Work and is a Licensed Social Worker.

Mark, Barb, Becky and Jodie have already made a huge impact in the office and compliment our current staff of exceptional individuals very well. All of our staff will be busy working together to continue the UMDF Mission!

There is no "vacation" from our quest toward a cure! Fundraising, research, and support continue without interruption.

Remember to take UMDF Energy Bands and car magnets (see page 18) with you on vacation. What better way to spread awareness. (I always leave one with my tip at restaurants). And don't forget, if you do not have vacation plans yet, you can always win a vacation and still help fund research by buying a raffle ticket for our *Vacation Toward a Cure* raffle (see page 17).

## THERE'S A GLIMMER OF HOPE

There's a glimmer of hope somewhere out there.  
I know in this night as I sit and stare.  
There's one shining star; bright - that beckons me;  
Saying come, "you'll find strength and health, just see."

The daylight dawns fresh with a hope anew;  
Can I look ahead to a cure then too?  
The road's not been easy, the process long,  
It took "forever" to find out what's wrong.

Try this; try that, or a little more WHAT?  
I'm a patient: A guinea pig, I'm NOT!  
I've been poked and prodded for one more test,  
Please, let it suffice; let me have some rest!

I found the right clinic, the doctors too,  
They knew exactly what next they should do.  
Somehow, deep down inside, I could believe,  
My questions, my fears, they'd soon all relieve.

I got the news; they said it was MITO;  
It affected me from my head to my toe.  
With perspective in place it all made sense,  
For now I knew that ominous presence.

There's a glimmer of hope for me out there,  
I know in my nights as I sit and stare.  
Though they may not find it in time for me,  
The cure will be found for someone, just see.

*Written for the United Mitochondrial Disease Foundation  
By Joy E. Krumdiack, B.A.Ed., Poet  
April 2005*

### A thought...

Give me a Stock Clerk with a goal (mission), and I will give you a wo/man who will make history.

Give me a wo/man without a goal (mission), and I will give you a stock clerk.

*-J.C. Penny*

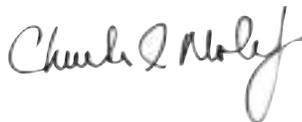
### UMDF Mission

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

THIS IS WHAT WE DO EVERY DAY  
THIS IS THE REASON WE ARE HERE

### What's your goal (mission)?

Yours Toward a Cure,



Charles A. Mohan, Jr.

# Physical, occupational, respiratory, speech, equine and pet therapies for mitochondrial disease, Part I

Continued from page 1

**Table 1. Benefits of supplementary therapies to common symptoms of mitochondrial disease**

<b>Physical Therapy</b>	<b>Hypertonia, hypotonia, dystonia, spasticity, muscle weakness, mobility deficits, exercise intolerance, myalgia, dysphagia, developmental delay, stroke, ataxia</b>
<b>Occupational Therapy</b>	<b>Motor control, developmental delay, learning disabilities, dementia, dysphagia, mobility deficits, stroke, ataxia</b>
<b>Speech Therapy</b>	<b>Developmental delay, dysphagia, feeding disorders, hearing impairments, stroke</b>
<b>Respiratory Therapy</b>	<b>Apnea, respiratory insufficiency</b>
<b>Hippotherapy</b>	<b>Neuromotor functioning, sensory processing, muscle weakness, increased quality of life</b>
<b>Pet Therapy</b>	<b>Motor function, cognitive function, increased quality of life</b>

any therapy should be prescribed and evaluated by a physician. Given the heterogeneity of symptoms even amongst patients with the same diagnosis, all treatments should be individualized toward each patient's specific needs.

This article -- Part I in this issue of Mitochondrial News and Part II to be printed in the Summer issue -- will review supplementary therapies that have potential to improve some symptoms of mitochondrial disease. Table I pairs a list of symptoms commonly associated with the syndromes: Kearns-Sayre (KSS); Leigh's; Pearson; mitochondrial encephalomyopathy, lactic acidosis and strokelike episodes (MELAS); myoclonic epilepsy with ragged-red fibers (MERFF); myogastrointestinal encephalomyopathy (MNGIE); neuropathy, ataxia and retinitis pigmentosa (NARP); and progressive external ophthalmoplegia (PEO) with the appropriate therapies for each. Until disease-modifying treatments are available for mitochondrial disorders, there can be a focus on treating symptoms; helping patients to cope with disabilities, and improving quality of life.

## Physical Therapy

Physical therapy can play an integral role in treating the symptoms of almost any neuromuscular disease.

Functional movement and mobility, injury prevention, pain management and where possible, strengthening of the large muscle groups are the goals of this therapy. Physical therapy is a clinical science, and licensed therapists must have a minimum of a 4-year baccalaureate degree. These therapists treat patients across the lifespan in hospitals, clinics, schools, work and home settings, with various programs of stretching, exercise and skills development. Working in conjunction with referring physicians and other allied health professionals, physical therapists may specialize in such areas as pediatrics, geriatrics, orthopedics, neurology, and cardiopulmonology.

A physical therapy evaluation involves the testing and measuring of strength, range of motion, balance and coordination, posture, motor function and respiration, all of which can be adversely affected by muscle weakness. The bases of treatments are therapeutic exercise and functional training from both 'hands-on' and instructional approaches. While physical therapy cannot arrest the disease process, it can help to maintain strength in unaffected muscle tissue and delay the onset of muscle shortening and contracted joints.

An exercise regimen, developed and supervised by a physical therapist can be an important therapeutic intervention for the mitochondrial disease patient suffering from exercise intolerance, a result of declining oxidative capacity. Exercise is beneficial to cardiovascular health and some weight bearing, when possible, can slow the development of osteoporosis. Because exertional fatigue frequently leads to a sedentary lifestyle, exercise can prevent the deconditioning that could exacerbate the mitochondrial disease process (Mahoney et al., 2001). In recent studies, short-term aerobic training was shown to improve exercise and oxidative capacities in patients with both mtDNA and suspected nuclear mutations, attributable to increases in the activity of the respiratory chain. Unfortunately, the benefits of exercise therapy come with a cost of increasing the population of mutant mtDNA (Taivassalo et al., 2001). Further studies are obviously needed. But with the guidance of a physical therapist, patients can increase their strength and endurance with an exercise program that begins gradually, builds cautiously and can be performed safely without leading to exhaustion. The physical therapist is responsible for monitoring strength

Continued on page 13

# Fundraisers

## “Coins for a Cure” Campaigns



- ▲ Evergreen Elementary in Monroeville, PA raises \$863.84. Kindergarten classes took first place in total collected and won an ice cream party!
- ▼ Ramsey Elementary in Monroeville, PA raises \$1,222.92 and the Third Grade won the Ice Cream Party!!!



- St. Bernadette Catholic School in Monroeville, PA held their annual coins campaign and raised \$1,332.54, bringing their total close to \$5,000 since 2002 - Awesome!
- Lowell Elementary School in Indianapolis raised \$960.52 in honor of Jacob Bube (Indiana Chapter).
- St. Mary Catholic School children raised \$1,700 in honor of Mercedes Sawyer in Mansfield, OH.
- Fourth Grade Focus students initiated this coins campaign at Winding Creek Elementary School in Stafford, VA and raised \$1,270.40 in honor of Marisa Burnett. The kindergarten raised the most -- \$300. Great job, kids!!!

## ★ Race for Riley ★ Defies Hurricane Warnings in Atlanta and Raises Close to \$83,000 in its First Year!

More than 1,000 participants braved the storms on April 30, 2005 to attend *Race for Riley* and 300 runners/walkers crossed the finish line to help UMDF take *One Step Closer to a Cure*. Special thanks to the Peek Family and to all those that helped make the event a success!



Riley, Rodney Peek, Michael Stuart (radio station), and Waynette Peek



Chuck Mohan with Riley



Karen Thompson with her sons, Mitchell & Mason



The starting line was a little wet!



Riley with Carson and Alyssa Rogers (traveled from Greer, SC)

### Special Thanks To ...

Kathy & Bill Bell, of Tyler Mountain Water in Pittsburgh, PA, for donating water jugs for UMDF's Coin Campaigns in the Pittsburgh area!

### Tenacious D Band Apparel

Thank you Kung Fu Inc., Jack Black and Kyle Gass for donating \$5,611!



Winding Creek 4th Grade busy counting coins!!

### Council Candidate Gives from the Heart

Debbie Hartwick, of Monroeville, PA, asked that anyone desiring to financially support her candidacy for councilwoman contribute to UMDF instead. Thank you Michael Houy and Bruce Dice for donating to UMDF and supporting Debbie!



Three-year-old Asher Gould and his family pictured with C'onelle Salon owners, Gabriel Bauer and Marion Adams of Boca Raton, FL. The Salon raised more than \$3,900 this past winter.

## Writers at the Beach: Pure Sea Glass



Sam

The inaugural Writers at the Beach: Pure Sea Glass writers' conference was a huge success. The event, held in Rehoboth, DE raised \$10,255 to benefit UMDF in honor of Sam and Zachary Juhlmann, nephews of conference founder, Maribeth Fischer. Plans are already in the works for the second Writers' conference – scheduled for March 3-4, 2006. Participants consisted of both published and professional writers, graduate students in writing programs, teachers, avid readers, and novices.

In her welcoming letter, Governor Ruth Ann Minner noted that this event offered an important opportunity to build awareness about mitochondrial disease and to raise funds for UMDF. Her remarks were especially meaningful to conference organizers who had learned only the day before that Fischer's seven-year-old nephew, Sam, had died suddenly.

Despite their underlying sadness, organizers and volunteers were thrilled with the event's success and look forward to continuing Zachary and Sam's fight.

For more information about the writers' conference, go to [www.writersatthebeach.com](http://www.writersatthebeach.com).

## Fundraisers

### Wine Tasting Dinner Raises \$18,460

• Sharon and Chris Kindbom, of Medford, NJ, held their first Wine Tasting Dinner on March 19 in honor of Rachel Kindbom and did an outstanding job raising funds AND awareness! Special thanks to the Kindbom Family and all those who helped make the event a success.

### Elizabeth and Thomas Hefferon held their annual Christmas Recycling Party and raised \$5,570 in memory of David Hefferon.



### Curling Event Raises Dollars

• Chesapeake Physical and Aquatic Therapy sponsored a charity curling tournament and raffle at the National Capitol Curling Center in Laurel, Maryland and raised \$1,822 with more coming in - possibly reaching \$3,500. Special thanks to Jared Goldstein and Elizabeth Verhelle for organizing this annual event in honor of Peter Lubelczyk (pictured above with Jared).

**Correction** - D Morgans Restaurant raised \$307 for Sherry Mathison, not Mathis, of Cartersville, GA.

### Thank YOU to more of our ★ Fundraising Stars ★

- \$300 was donated to UMDF in honor of Peter Boulden Andersen in lieu of wedding favors at the wedding of Bart Rolon and Kate Andersen.
- Special Thanks to the Lonely Leprechaun for donating \$100 to UMDF and for committing to pick UMDF for next year's race in honor of Preston Buenaga. For more information, visit [www.shamrockmarathon.com](http://www.shamrockmarathon.com).
- At a recent bridge party, Carole Davis, wife of UMDF Trustee Stan Davis and grandmother of Carly Platt, and her friends asked that donations be made to UMDF in lieu of the traditional hostess gifts. A total of \$880 was donated to UMDF. Such lovely Ladies!
- Bill and Lynda Merola of Pittsburgh, PA, friends of the Mohan family, raised \$410 for UMDF by selling funnel cakes at the Motorcycle Emporium in Freeport, PA.
- Krista Wakefield held a Christmas Recycling Party on January 8 and raised \$1,065 in honor of Anthony Wakefield. Anthony unfortunately lost his battle with mito soon after the event but his memory will live on!
- Thank you to Greensburg Central Catholic School in PA for raising \$415.72 in memory of Gina Marie Mohan during a recent dress down day!
- The Talisman Garden Club donated \$600 in honor of their president, Mrs. Norman Pulliam, and her granddaughter, Caroline.

changes in the patient's condition, a common occurrence in mitochondrial disease.

When supportive aids such as braces for weakened limbs, neck supports and orthoses are needed, they may be recommended by physical therapists, who are also involved in the prescription and modification of mobility devices such as canes, walkers, and wheelchairs. The physical therapist will aid the client with sitting, positional transfers, wheelchair propulsion, and accessibility issues. Physical and occupational therapists may work together to help the patient balance the need for energy conservation with the importance of mobilization, which can greatly reduce the complications of inactivity.

Aquatic therapy, a subspecialty of physical therapy, takes place in the novel environment of water and may be beneficial for patients with mitochondrial disease. Aquatic therapy offers advantages over traditional physical therapy in several ways. The buoyancy of the water diminishes the effects of gravity. The body is supported in the water, which allows for physical exercise with decreased stress on joints, bones and muscles, and increases independence of movement. The water also provides a natural resistance medium to promote strengthening. Muscles may relax and soreness decrease in the warm water. Even the weakest patients may be able to function better in water than on land. Psychological benefits of this medically prescribed therapy are enjoyment, relaxation, confidence and a sense of accomplishment.

For the patient with gross motor developmental delay, hyper- or hypotonia, strength or range of motion problems, mobility or rehabilitation needs, physical therapy is a vital, if not necessary, intervention.

### Equine Therapy

Equine- or hippotherapy, a term derived from the Greek root word 'hippos,' meaning horse, is a specialized intervention used by physical and occupational therapists wherein the natural, multi-dimensional movement of the horse is used as a tool for increasing physical abilities. Adults and children with mild to severe neuromuscular disabilities, developmental disorders or skeletal impairments, all common symptoms along the mitochondrial disease spectrum, are thought to benefit in the areas of gross motor function, muscle tone, posture, balance and coordination, and sensorimotor processing. Case studies, though limited in scope and size, have shown improvements in patients with cerebral palsy, Down syndrome, developmental delays, traumatic brain injuries, multiple sclerosis, etc. using hippotherapy as part of an integrated treatment program to achieve

specialized therapeutic functional outcomes (Rollandelle and Dunst, 2003). Hippotherapy has been widely used in Europe for more than 50 years and in the US since the 1970s.

It is hypothesized that the complex movement of the horse influences the rider by passive and active stretching and stimulation of the rider's balance and postural control (Sterba et al., 2002). Astride the horse, the pelvis, lumbar spine and joints are mobilized; deep muscles not accessible in conventional physical therapy are stretched and strengthened. The horse's smooth and rhythmic gait elicits motor responses in the rider that are similar to and essential for movement patterns of a human pelvis while walking. The rider's center of gravity shifts atop the moving horse, facilitating righting and equilibrium reactions that will stimulate improved trunk stability and posture. These may, in turn, generate improvement in respiratory, circulatory and digestive functions. Interactions with the horse provide visual, tactile and olfactory stimulation. Hippotherapy has also been said to improve speech, language and cognitive function and may help the rider develop patience, responsibility and emotional self-control (Rollandelle and Dunst, 2003).

The psychosocial benefits of equine-assisted therapy are plentiful and surely contribute to improvements in the overall quality of life. Increases in self-confidence, self-image and self-esteem have been reported anecdotally by caregivers of the rider. The unique and memorable experience of hippotherapy can yield feelings of control and freedom that few activities in the rider's life can provide. For the patient who spends much time in medical and other clinical settings, the horseback riding facility with its natural environment can provide a welcome break from normal routine. As an enjoyable experience, attitudes and motivation toward therapy may improve. For the patient with limited opportunities, horseback riding can provide much needed recreation and sport throughout the lifespan.

Physicians may be unaware of hippotherapy until it is brought to their attention, often by a patient's family. Skepticism, due to its unconventionality and lack of evidence-based research, hinders a broad acceptance of hippotherapy. Further confusion may abound with regard to the terminology used to describe various equine-based activities in which disabled patients may participate. Significant difference exists between 'therapeutic riding' and 'hippotherapy.' While both techniques help with muscle tone, strength and function, posture, balance, coordination and flexibility,

Continued on page 14

'therapeutic riding' focuses on recreational riding skills and basic horsemanship.

A more formal type of treatment, hippotherapy is a specialized form of occupational and physical therapy prescribed by a physician as an appropriate treatment for a disability. Before any prospective rider begins hippotherapy, a thorough evaluation of his or her needs and capabilities is performed and goals and objectives are set forth. Hippotherapy centers must follow organizational standards to maintain a safe and therapeutic environment.

Hippotherapy is administered by a licensed, credentialed therapist with an extensive treatment background in posture and movement, neuromotor functioning and sensory processing. Working with professional horse handlers and certified riding instructors, specially screened and trained horses are individually selected for the rider. The treating therapist directs the movement of the horse, maintains direct contact with the participant at all times and continues to assess and modify therapy based on the rider's responses.

Hippotherapy is used to improve mobility and strengthen the muscles in both the upper and lower body. Improvement in neuromotor function and sensory processing are the goals of this outpatient, medically prescribed therapy that uses the horse and its movement as a medium. Further and more comprehensive studies are needed to provide definitive evidence as to the efficacy of hippotherapy. Yet, the potential physical and psychological benefits of hippotherapy as outlined by its proponents suggest its appropriateness and utility for many patients with mitochondrial disease.

### Occupational Therapy

Although there are many overlaps between the fields of physical and occupational therapy, the latter focuses on functions of the upper extremities and on cognitive, fine- and visual-motor skills. The role of the occupational therapist is to enhance an individual's ability to perform an 'occupation,' be that a work-related function, hobby, particular skill, or quite often, the performance of the necessary activities of daily life.

Occupational therapists are skilled, trained and educated professionals prepared in Bachelor or Master's degrees programs, and are board certified and licensed by the states in which they practice. Therapists work with clients of all ages, an important aspect of this profession, given that the onset of mitochondrial disease symptoms can present from birth through late adulthood.

Through an individualized process, a plan of

treatment is developed, with the goal of maximizing functional independence for the client within his or her environment. A client's performance and abilities are evaluated through observations and structured assessments of the following areas of development: sensorimotor, neuromusculoskeletal, motor, cognitive and psychosocial. Interviews with other professionals caring for the client follow. These may include physicians, family members, teachers and other therapists. The occupational therapist will then develop a customized treatment plan of purposeful activities, exercises, games, instruction and adaptive strategies and devices with which to maximize independence within everyday life. This plan will include short- and long-term goals and will be relevant to the life style, environment and developmental stage of the individual.

As cognitive disorders are common in many mitochondrial diseases, for the young patient at risk for developmental delays, therapeutic interventions should be initiated as early as possible. Occupational therapists will strive to improve a child's level of performance within critical developmental areas and attempt to help him or her to meet appropriate physical, cognitive and behavioral milestones. Occupational therapy with a child may include working on physical abilities, motor control, eye-hand coordination, regulation of behavior and spatial awareness. Some therapists have special interests in feeding issues and may work with speech-language pathologists to address feeding disturbances.

Physical limitations will often prevent a child from engaging with the environment via the 'occupation' of children: play. Health impairments can deprive children of normal play opportunities, burdening them with a 'second disability' which hinders their potential for independent behavior and performance. (Missiuna and Pollack, 1991). The occupational therapist creatively makes work out of play by generating opportunity for the child to explore the environment and to reach his or her maximum potential.

The occupational therapist can help diagnose and treat specific learning disabilities and assist with the development of problem solving, perceptual and abstract reasoning skills. Within the school setting, another focus is on the ability to fully access and be successful in the learning environment. Mobility issues are addressed by occupational therapists, often working with physical therapists, in the instruction and fitting of wheelchairs and walkers. Other adaptive aids for eating and dressing, or splints to support weak

## Physical, occupational, respiratory, speech, equine and pet therapies for mitochondrial disease, Part I

Continued from page 14

muscles might be recommended. From augmentative communication equipment to environmental control devices, therapists can individualize computer-aided adaptive equipment that can assist even the client with severe limitations.

Throughout the life span, therapists will work with clients to promote independence in performing activities of daily living such as eating, dressing and grooming, bathing, toileting, and interacting. When motor problems are severe enough to interfere with self-care and communication, occupational therapists may develop plans to help the client compensate for the disabilities and/or adapt to the condition.

For the adult and elderly patient, occupational therapy continues to provide 'skills for the job of living.' Therapy will address issues of increasing muscle weakness, decreased range of motion, mobility limitations and fatigue. Therapy may focus on rehabilitation for lost abilities, such as in the case of stroke patients, when new skills for daily living, household tasks and self-care must be developed.

Low-technology adaptive equipment can make a significant contribution in an individual's ability to maintain independence and function. Solutions can include reachers and grabbers, dressing sticks and sock aids, or merely simple pieces of cylindrical foam to build up the handles of writing, grooming or eating utensils. An occupational therapy consultation can also promote safety through the instruction of techniques to improve balance for the patient with tremor or ataxia. Modifying equipment such as railings, poles or bathroom aids can reduce fall-related injury.

For the patient with memory problems and dementia, there are occupational therapy based programs to facilitate maximum engagement of the environment, in which the patient can enjoy social interaction and leisure activities. Therapists in this area may also provide guidance and support to family members and caregivers of these patients.

Occupational therapy can help individuals with mitochondrial disease to develop, maintain or recover daily living and work skills. Therapists help clients to not only enhance basic motor function and reasoning ability, but to also learn to compensate for permanent loss of function. Through support and direction, the goal of occupational therapy is to help the client establish as independent, productive and satisfying a life as possible.

*References will be noted in Part II which will be available in the Summer issue of Mitochondrial News.*

### Attention all UMDF Members!! UMDF Database Under Construction



We ask for your continued patience during our transition period in upgrading the UMDF computer system and web site. We are currently unable to process networking requests. We hope to have a new and improved system operating during this quarter. Your patience is appreciated.

## Free CME/CEU Accredited Online Seminar Teleconference

Exceptional Parent is hosting an on-line seminar titled *The Spectrum of Mitochondrial & Metabolic Disorders* on Wednesday, July 20, 2005 from 7:00 p.m. to 9:00 p.m. (Eastern).

Presenters will include Darryl DeVivo, MD, and Salvatore DiMauro, MD, both of Columbia University, New York. Ingrid Tein, MD, of University of Montreal, Canada, will serve as the moderator.

The online seminar will provide an overview of the spectrum of mitochondrial and metabolic disorders. Topics include reasons for heterogeneity, differences from classical (Mendelian) genetics, the diagnostic process, the recurrence of risks, prenatal diagnosis, treatment and therapeutic options.

The session will also cover the role of the primary care physician in the treatment of children with mitochondrial disease, as well as promising avenues of investigation.

The seminar is targeted to pediatricians, family practitioners, perinatologists, neonatologists, neurologists, OB/GYNs, genetic researchers, genetic counselors, psychologists, social workers, case managers, family members and direct support professionals.

For more current information and how to register, visit [http://www.eparent.com/web\\_seminar\\_mito](http://www.eparent.com/web_seminar_mito). You must pre-register to attend.

## **Mito Adults Corner**

Mitoldies is an online group for adults with mitochondrial disease and their caretakers ([mitoldies@yahoo.com](mailto:mitoldies@yahoo.com)). Members have put their heads together and have come up with a list of adaptations to make life easier. Not all will apply to each person, so pick out those that might help and give them a try. More tips will be printed in the next issue.

### **ADAPTATIONS TO MAKE LIFE EASIER In The Home**

- Reachers - a must and best if there is one in each room you use.
- Open doors of sink, so feet can go inside and you can get closer to sink while sitting.
- A recliner (or similar favorite place to sit) "nest" – easy to carry container with phone, snacks, book, remote, craft, paper/pencil or PDA, etc. to limit times you need to get up.
- Lift chair if unable to rise without difficulty.
- Keep appliances you use on a counter instead of in a cupboard so they don't have to be lifted.
- Freezer at bottom of refrigerator with pull out door.
- Dishwasher that is easy to reach and has easy to push buttons.
- Stove, washer and dryer with front controls if using wheelchair or scooter.
- Washer and dryer raised if needed for easy access.
- Ramps into home, even if still walking or using a walking assistive device.
- Kitchen storage for as many items as possible so everything is handy, pull out shelf units for cupboards.
- Main level laundry.
- Plastic dishes, which are lighter and don't break when dropped.
- Swiffer duster mop or something similar – they are light and easy to maneuver.
- Ergonomic utensils for kitchen such as OXO brand.
- Handrails for bed to assist in getting up. Raised bed to assist with getting up. Bed at same level as wheelchair or scooter seat if transferring.
- Non-skid mat made for lining cupboards and drawers

to keep things from sliding on various surfaces.

- Cutting boards left out at strategic spots.
- Cordless phone that can be carried with you or phones in every room (necessary for those who fall).
- Panic button device that calls police or neighbors.
- Smoke detectors that you can hear, even while asleep. Special smoke detectors which jiggle or flashing lights for those with hearing problems.
- Wheelchair garden tools or those designed for children.
- Lightweight cart or wheelbarrow that can be pulled in yard if doing yard work.
- Low sturdy step stool if using one. It needs to have a wide base. To prevent falls, it is best not to use a stool if possible.
- Foods packaged in individual portions that can be warmed in microwave.
- Microwave with touch pad and individual buttons for things like warming.
- Stool to sit on at stove or sink (avoid ones with wheels unless they can be easily locked).
- Chairs available throughout house at short intervals for resting or working.
- Cooler or small refrigerator in room where you spend most of your time to hold water and medication.
- Countertop grill (like George Foreman) for easy food preparation.
- Book holder that meets individual needs.
- When space permits, a daybed in office or family room for resting is helpful.
- Watch television using a mirror if lying down.
- Small CD or tape player for easy access to music.
- Throws/blankets in all rooms if you tend to get cold.
- Posters on ceiling if you spend a lot of time in bed.
- Headphones for telephone so phone doesn't have to be held.
- Cell phone if out and about or for caregiver when away from home.
- Shopping by catalog or internet when possible.

## **Mito Adults Corner**

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

UMDF could use more helpers. 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!



# Vacation Toward a Cure

Courtesy of

## American Airlines<sup>®</sup>

Official airline of the  
United Mitochondrial Disease  
Foundation

### You Could Win ...

- Round trip air transportation for two to any **American Airlines** destination in the contiguous 48 states, courtesy of **American Airlines**.
- \$1,500 AAA gift voucher toward any cruise or vacation.

All proceeds to benefit the  
United Mitochondrial  
Disease Foundation.

**Drawing Date: June 17, 2005.**

Drawing will take place at the  
**Mitochondrial Medicine 2005  
Conference in St. Louis, MO.**

**\$5 per ticket**

**\$25 for book of 6 tickets**

For more information on buying  
or selling the 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 win a UMDF  
throw (blanket)!**

## Attention Groups and Chapters: Sell Vacation Toward a Cure Tickets and WIN!!!



### 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  
support group/chapter  
members to attend the  
2006 UMDF Symposium in  
Atlanta

**\$\$\$Cash\$\$\$**

For all groups and/or chapters selling at  
least \$1,000 in raffle tickets.

Your group sells together and then celebrates together  
with a little extra cash for your next meeting!

## Tomato Face Foods



### YOU can help Tomato Face Foods

continue reaching thousands  
across the U.S. Do you  
know someone in your local supermarket, school  
cafeteria, college food service, or grocery chain? If so,  
please contact Barbara and Allen at 216-382-0232 or  
sebrook1@aol.com.

Allen, Barbara and Dana are still working on their goal  
to catch Oprah's attention as well as other national  
television production companies. Keep up the great  
work, Tomato Face Foods!



UMDF received \$1,610 from Charity Motors, a non-profit that allows individuals to donate their vehicle for a tax deduction and choose a non-profit to receive proceeds. Thank you, Matthew Anderson! For more information about Charity Motors, call 313-255-1000.

# Energy Bands and Ribbon Awareness Magnets Available

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



These silicone bracelets are UMDF-green and encircled with

★ ENERGY FOR LIFE ★ [www.UMDF.org](http://www.UMDF.org)

The bracelets are a great way to raise awareness and support those affected by mitochondrial disease. As of May 2, UMDF has received more than \$25,000 in bracelet sales and orders continue to flood the office. The bracelets are making a difference in other ways. Member services received a call from a lady whose child was just diagnosed with a mito disease. She knew nothing about UMDF and one of the Atlanta members gave a co-worker (the caller's brother) a bracelet. He gave it to the caller who then went online to look at the web site and then called UMDF. Awareness!!!! You can order online at [www.umdf.org](http://www.umdf.org) or contact the office at 412-793-8077 or email [info@umdf.org](mailto:info@umdf.org) for an order form.

Cost for bracelets is \$4 each (postage and handling included) OR a package of 10 bracelets for \$10 (plus \$5 in postage and handling). Get your friends together and split the cost!



## 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.

## ★ Mark your Calendars ★

See pages 4-6 for more details on chapter events

- May 25, 2005 - *Lego Walk* (New England Chapter)
- May 29, 2005 - *Shadow Woodstock 2005*, Chagrin Falls, OH (Ohio Chapter)
- June 4, 2005 - *Kain's 5K Walk* in Greenwich, NY (NY Metro Chapter)
- June 4, 2005 - *3rd Annual Pittsburgh UMDF 5K Run/Walk* at North Park
- June 4, 2005 - *4th Annual KFC/UMDF 5K Run/Walk*, Forest Hills Park in Cleveland (Ohio Chapter)
- June 4, 2005 - *Recharge Your Energy and Redefine Hope Dinner Event*, First Parish-Milton, Sullivan Family of Quincy, MA (New England Chapter).
- June 11, 2005 - *Brew at the Zoo* (DelVal Chapter)
- June 11, 2005 - *Gibson's 12th Annual Potluck/Barbecue* in Ukiah, CA. For more info, call Norma Gibson at 707-462-2208.
- June 14-16, 2005 - *Miles for Mito* heads to St. Louis (Indiana Chapter)
- June 15-18, 2005 - *Mitochondrial Medicine 2005*
- June 18, 2005 - *2nd Annual Ally Brunk Memorial 5K Walk/Run*, Pottersville, MI. For more information, email Daniel at [brunkdb@pps.k12.mi.us](mailto:brunkdb@pps.k12.mi.us).
- June 25, 2005 - *Yard Sale* at Plymouth Public Library (New England Chapter)
- July 18, 2005 - *6th Annual Ohio Golf Outing*, The Country Club, Pepper Pike, Ohio. For more information, call Stan Davis at 216-581-0000.
- July 21, 2005 - *8th Annual Pgh UMDF Golf Outing*, Churchill Country Club. For more information, call Jodie at 412-793-8077.
- August 15, 2005 - *First Annual Indiana UMDF Golf Outing*, Fishers, IN. (Indiana Chapter)
- August 17, 2005 - *5th Annual Mito-What? Cruise* in Bay City, MI in honor of Morgan Kozuch.
- August 25, 2005 - *Goobers/UMDF Golf Classic at Boscobel Golf Club*, in Clemson, SC, in honor of Alex Newton
- August 27, 2005 - *One Step Closer to a Cure Walk*, Clemson, SC, in honor of Alex Newton
- September 10, 2005 - *6th Annual Energy for Life Walk/Run* (Del Val Chapter)
- September 10, 2005 - *1st Golf Outing* in KC (Kansas City Chapter)
- September 17, 2005 - *Birmingham Alabama 2nd Annual 5K Walk* in Hearmont Park
- September 25, 2005, *5th Annual Cruisin' Toward a Cure* car cruise at CCAC Boyce Campus in Monroeville, PA. For more info, email Ron and Donna Miklos at [cruzmeisters@alltel.net](mailto:cruzmeisters@alltel.net).
- October 1, 2005 - *6th Annual Mito-What? 5K Walk/Run* in Longmeadow, MA. Possible Walk in Plymouth on same day (New England Chapter)
- October 24, 2005 - *2nd Annual Fore-a-Cure Golf Outing* in Duluth, GA (Atlanta Chapter)

## UMDF Chapters & Groups

### ARIZONA

★ **Arizona Chapter**  
President: Suzanne Perryman  
Email: AZChapter@umdf.org

### CALIFORNIA

★ **Southern California Chapter**  
President: Linda Cooper  
Email: SCalChapter@umdf.org

### FLORIDA

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Carrie Waters  
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### GEORGIA

★ **Atlanta Area Chapter**  
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### INDIANA

★ **Indiana Chapter**  
President: Sue Ann Bube  
Email: INchapter@umdf.org

### ILLINOIS

Chicago Area Group  
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St. Louis Area Group  
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### MARYLAND

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### MASSACHUSETTS

★ **New England Chapter**  
President: Bridget Willis  
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### MICHIGAN

Contact: Ann Clark  
Phone: 734-416-1115  
Western Michigan  
Contact: Suzanne Marous  
Email: marousx4@icsdata.com

### MISSOURI/KANSAS

★ **Kansas City Chapter**  
President: Pam Johnson  
Email: KCchapter@umdf.org

### NEW YORK

★ **New York Metro Chapter**  
President: Mary Pisani  
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New Paltz Group  
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Cincinnati Group  
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### OREGON

Contacts: Cathy Akins and Cori Feist  
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feiste@ohsu.edu

### PENNSYLVANIA

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### OUTSIDE OF THE UNITED STATES

#### AUSTRALIA

Contact: Tara Collyer  
Email: tarac@powerup.com.au

*New groups forming in Rhode Island and Denver. Interested in starting a group in your area? Contact becky@umdf.org.*



### Summer Time and Camps for Kids

It is that time of year and you may be considering camp for your child (ren). Take time and plan this “adventure” with your child. Try visiting these websites for ideas:

[www.kidscamps.com](http://www.kidscamps.com)

[www.eparent.com](http://www.eparent.com)

[http://find.acacamps.org/finding\\_special\\_needs.php](http://find.acacamps.org/finding_special_needs.php)

[www.mdausa.org/clinics/camp.html](http://www.mdausa.org/clinics/camp.html)

If you would like to share your camp experience with other UMDf members, please send us a letter describing the camp along with your name, address, email and phone number so that we can network you with other parents considering camp.

### From the Desk of Becky DiLettuso

#### Director of Member Services:

Becky and the entire UMDf Member Services Department would like to continue building UMDf support groups and chapters – current and future groups. Are you interested in setting up a support group or chapter? Call or email us (info@umdf.org) for information. Even if you don't want to be the leader, we will help you recruit people in your area to get things started.

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

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**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).**



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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 physician. UMDF assumes no liability for any information in the Mitochondrial News.

**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 next issue is 7/1/05