

# M N

United Mitochondrial Disease Foundation

# MITOCHONDRIAL EWS

Volume 9 • Issue 2 • Spring 2004

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**Mitochondrial  
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**Scientific Sessions:**  
August 4-7, 2004

**Family Sessions:**  
August 6-7, 2004

**Clinician Sessions:**  
August 7, 2004

**Standards Workshop:**  
August 7, 2004

**Westin Hotel-Convention  
Center, Pittsburgh, PA**

**Brochures have been mailed  
to all UMDF Members and to  
our first-time callers!!!!**

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## **Supplemental Health Care Coverage for Children in Pennsylvania with a Severe Medical Condition**

Bruce Molyneaux, MSW, LCSW  
Social Worker

Division of Child Neurology  
Children's Hospital of Pittsburgh

**Editor's Note:** *Although this article is specific to Pennsylvania, members may be able to use this information in their respective states.*

Even with insurance, caring for the medical needs of a child with a mitochondrial disorder can quickly drain a family's financial reserves. A state-sponsored health insurance program called Medical Assistance can provide a degree of financial relief for medical costs, for the families of many of these children. There is a less than well-known "loophole" in the Pennsylvania Medical Assistance law. This "loophole" allows children who have a disabling condition (sufficient to meet SSI criteria for the disability but whose parents' income make them ineligible) candidates for this program. This definition of disability includes many children with mitochondrial disorders.

For children with private insurance, the Medical Assistance serves as a

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**Fundraising is a Blast!**  
*Shelly's Heroes 2004 - Page 5*

## Ask the Mito Doc

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

*Responders for this issue: Richard Boles, MD, Childrens Hospital Los Angeles, CA; Russell P. Saneto, DO, PhD, Children's Hospital and Regional Medical Center/University of Washington, Seattle, WA; and Amy Goldstein, MD, Children's Hospital of Pittsburgh, PA.*

### **The Question Is:**

I am getting ready to get my son's kindergarten shots in the next couple of weeks. I have read that immunizations can cause problems in Mito kids. We have always done fine in the past, just ran a pretty high fever of 103 for about 24 hours. Is it just a fluke thing that happens in some Mito kids, or can it be

*Continued on page 2*

common? I am really kind of concerned. We do not have a Mito doc that could explain it to me.

I would like to know what to watch for.

**Response From:  
Richard Boles, M.D.**

The medical literature has absolutely no articles on immunizations/vaccinations in individuals with mitochondrial disease. In the absence of any studies, there is only clinical experience and opinion. Personally, I know a few cases of severe complications following routine immunizations in children with mitochondrial disease, generally in those who were later diagnosed as such. However, in almost all of these cases the child stopped eating because of feeling ill, and I believe that most of the complications were actually provoked by fasting.

Fever may be more common following immunizations in mito kids than in children in general, possibly because abnormal autonomic nervous system responses (dysautonomia) are very common in mito disease. Of course, febrile children are fussy and may not want to eat much. Immunizations protect against serious diseases that could really cause complications if a mito kid were to get them, and my own clinical experience is that over a hundred mito kids safely received immunizations when certain precautions were taken. With my own patients, my practice is as follows:

Immunizations act like common viral infections in that they can cause a child to have fever, nausea, poor appetite, and/or malaise (generally feeling bad). At these times, pay extra attention that your child is getting adequate calories. Fruit juices are one option to get quick calories in a child who is

eating poorly. Fever increases energy demand, and should be treated with the proper amount of acetaminophen (Tylenol, etc.) or ibuprofen (Advil, Motrin, etc.). Seek prompt medical attention for continued vomiting, inability to take almost any calories for more than 24 hours, and especially for lethargy (excessive tiredness) or an otherwise altered behavior (including excessive fussiness, confusion, etc.). Occasionally, IV fluid with D10 (10% sugar) may need to be given.

Any mito kid with a severe immunization reaction in the past should probably avoid immunizations altogether.

**The Question Is:**

The field of mito disorders is one in which not many medical professionals specialize. This makes it frustrating as a parent when new progression of this illness occurs. The local pediatrician refers the child to see a neurologist. After finally getting in to see the neurologist, he refers the child to a mito specialist, who is hard to get an appointment with because of all of the referrals. If it is not an immediate life-threatening issue but serious, what should a parent or adult mito patient do to resolve the situation? Should we research and find a solution ourselves or call the local pediatrician or neurologist or specialist? Do you feel more doctors will begin to specialize in this field in the future? What could parents do to get the word out to more physicians about patients' needs without coming across as pushy?

**Response From:  
Russell Saneto, DO**

I am sorry that you are having difficulty in finding physicians who both understand and try to care for

patients with mitochondrial disease. Unfortunately, you are among a growing population of patients and their families.

The number of physicians actively taking care of mitochondrial disease is limited. Reasons for this state of affairs are numerous. The disease as an entity is young; the first mitochondrial DNA mutation was only discovered and described in 1988. It is so young, that there isn't even a specific ICD-9 code (what we physicians use for billing and the government and researchers use to track diseases) for mitochondrial disease.

However, this doesn't answer your current needs for your child. I think there are several ways to approach the medical care of your child. One is to meet with (however long it takes) a mitochondrial specialist who will work with your primary care physician to help manage parts of your child's medical care as it pertains to mitochondrial disease.

Read as much as you can, ask as many questions as you have, and learn what kind of medical care pertains to your child's particular mitochondrial disease. Develop action plans when illness occurs, such as IV hydration during an illness or glucose containing IV fluids during catabolic states. Since you probably know more about the particular mitochondrial disease your child has, gently begin teaching your primary care physician concerning your child's disease. Care is needed as the information needs to be factual and not just "what you got over the internet." Certainly, you will find resistance. Most physicians have a desire to care for their patients and you will find that many will educate themselves in this disease as they

*Continued on page 10*

# Chairman's Report

I want to share the following e-mail I received the other day.

Dear UMDF,

*I read the following story and thought I'd pass it on as a thank you for the work you do.*

*Charles Plumb was a U.S. Navy jet pilot in Vietnam. After 75 combat missions, his plane was destroyed by a surface-to-air missile. Plumb ejected and parachuted into enemy hands. He was captured and spent 6 years in a communist Vietnamese prison. He survived the ordeal and now lectures on lessons learned from that experience.*

*One day, when Plumb and his wife were sitting in a restaurant, a man at another table came up and said, You're Plumb! You flew jet fighters in Vietnam from the aircraft carrier Kitty Hawk. You were shot down!" "How in the world did you know that?" asked Plumb. "I packed your parachute," the man replied. Plumb gasped in surprise and gratitude. The man pumped his hand and said, "I guess it worked!" Plumb assured him, "It sure did. If your chute hadn't worked, I wouldn't be here today."*

*Plumb couldn't sleep that night, thinking about that man. Plumb says, "I kept wondering what he had looked like in a Navy uniform: a white hat, a bib in the back, and bell-bottom trousers. I wonder how many times I might have seen him and not even said 'Good morning, how are you?' or anything because, you see, I was a fighter pilot and he was just a sailor."*

*Plumb thought of the many hours the sailor had spent at a long wooden table in the bowels of the ship, carefully weaving the shrouds and folding the silks of each chute, holding in his hands each time the fate of someone he didn't know.*

*Now, Plumb asks his audience, "Who's packing your parachute?"*

*Everyone has someone who provides what they need to make it through the day. He also points out that he needed many kinds of parachutes when his plane was shot down over enemy territory - he needed his physical parachute, his mental parachute, his emotional parachute, and his spiritual parachute. He called on all these supports before reaching safety.*

*Sometimes in the daily challenges that life gives us, we miss what is really important. We may fail to say hello, please, or thank you, congratulate someone on something wonderful that has happened to them; give a compliment; or just do something nice for no reason. As you go through this week, this month, this year, recognize people who pack your parachutes.*

*I am sending you [UMDF] this as my way of thanking you for your part in packing my parachute!*

*Thank you*

UMDF's motto, "Redefining Hope," is demonstrated in many ways. Raising money to support research toward a cure is just the tip of the iceberg. UMDF staff spends countless hours putting together information packets and educational materials for thousands of members but perhaps the most important and least recognized is that little extra time our staff takes out of their busy day to listen.

True satisfaction comes not from getting what you want, but from helping others get what they want.

Yours towards a cure,



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## UMDF MISSION

To promote research for cures and treatments of mitochondrial disorders and to provide support to affected individuals and families.

# Chapter Activities

## KANSAS CITY CHAPTER

Kansas City, MO  
President: Heidi Harmon  
Phone: 816-554-8530  
Email: KCChapter@umdf.org

### SAVE the DATE!

#### 1st Annual 5K Mito-What? 5K Race and 1 Mile Walk

Saturday, June 26, 2004  
8:00 a.m.

Corporate Woods Founders Park  
Overland Park, Kansas  
Kids Dash - 9:15 a.m.

Visit [www.umdf.org/Fundraiser](http://www.umdf.org/Fundraiser) to register or call 816-554-8530.

#### Chairman Visits Chapter and Meets with Local Physicians

At the request of the KC Chapter, Chuck Mohan recently gave a presentation about UMDF to 20 physicians in the KC area and then addressed 40 plus chapter members.

Upon his return to Pittsburgh, Mohan informed the UMDF staff that he was extremely impressed by the chapter and how far they have come in such a short time. Well done, KC!

## SOUTHERN CALIFORNIA CHAPTER

Lakewood, CA  
Vice President: Kathy Fares  
Phone: 858-271-9000  
Email: SCalChapter@umdf.org

### Wine Tasting Big Success

The chapter hosted their 1st annual Wine Tasting and Silent Auction and raised more than \$5,000. Final total will be noted in the next issue.

#### Upcoming Events:

- Bowl-a-thon in Fall of 2004

## ARIZONA CHAPTER

Phoenix, AZ  
Interim Leaders: Sharon Shaw, Thom Montgomery and Jane Shumaker  
Phone: 480-563-8562  
Email: AZChapter@umdf.org

The Arizona Chapter is still in the process of reorganizing and welcomes additional volunteers to serve on the board. Dr. Bruce Cohen and Chuck Mohan, UMDF Chairman, spoke to the chapter on April 24, 2004.

## NEW ENGLAND CHAPTER

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

### New Leadership - Congrats!

Welcome aboard to the following new officers for the New England Chapter:

**President:** Bridget Willis  
**Vice President:** Heidi Bailey  
**Treasurer:** Bill Naughton  
**Secretary:** Greg Sullivan  
**Family Support:** Beverly Ingram

### Coins for a Cure

J.W. Martin School, of North Attleboro, MA, raised \$1,025.58 in honor of Ryan Blaisdell. Way to go, kids!

### Bruce Cohen, MD, Visits Chapter

Cohen spoke to more than 70 families on May 11. Cohen is a pediatric neurologist, President of the Mitochondrial Medicine Society and a UMDF Trustee.

### Upcoming Events

- July 17, 2004 -- Friends of Cameron Picnic, Chicopee, MA
- October 3, 2004 -- Mito-What? 5K Run/Walk, Longmeadow, MA

## Want to Get Involved?!!

Contact your local chapter or group **today**. Chapters and Groups will continue to grow with your HELP. **YOU can make a difference!**

## NEW YORK METRO CHAPTER

Manhattan, NY  
President: Tom Shubeck  
Phone: 973-635-6354  
Email: NYMetroChapter@umdf.org

### Matthew Dudgeon Memorial Walk

**May, 8** -- Gary Lasinski, UMDF Assistant ED, attended the Walk and Dinner Dance and declared the event a success once again. The Pisanis and Nunnos, two of the NY Metro Chapter families, were present to show their support of this super event! More information to follow.

#### Upcoming Events:

- Mito-What? Walk in North Haven, CT -- May 15, 2004. Results of this event will be in next issue.
- The Annual Nunno Dinner -- Friday, October 22, 2004



*Tom Maese, Luis and Norma Pina enjoyed this first-time event. Laese Maese, Tom's wife, and Alison DeVriendt organized the wine tasting for the chapter. Well done, ladies!*

# Chapter Activities

## OHIO CHAPTER

Cleveland, OH

President: Jennifer Lyman

Phone: 330-929-4430

Email: OHChapter@umdf.org

### Don't FORGET to Join Us!

#### 3rd Annual KFC/UMDF 5K Run/Walk

Saturday, June 12, 2004

Forest Hills Park

Cleveland Heights, Ohio

Visit [www.umdfohio.org](http://www.umdfohio.org) or

register online at

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



### Grand Night of Singing

In honor of Kyle Kobunski, Kalliope Stage, located in Cleveland Heights, shared its opening night with the UMDF Ohio Chapter raising more than \$6,800. Pictured above is Kyle surrounded by the cast including John Paul Boukis, Executive Director and Paul F. Gurgol, Artistic Director.

**Guest Bartender Night raises \$1,900 in honor of Kyle Kobunski at Main Street Bar and Grill.**

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

New Image Haircutters, of Willowick, Ohio, will be holding a cut-a-thon during the following Lake County Captains games:

**Friday, May 28, 2004**

**Friday, June 18, 2004**

**Friday, July 16, 2004**

**Friday, August 6, 2004**

### Samantha Stahler Strikes Again

One of UMDF's favorite youth fundraisers is at it again. In honor of her cousin, Bobby Arnold, Samantha made and sold bookmarks to benefit UMDF and has raised \$882 to date. Anyone interested in a GREAT bookmark? Call the UMDF office and ask about Samantha's creations.

## INDIANA CHAPTER

Indianapolis, IN

President: Sue Ann Bube

Phone: 317-894-9099

Email: INChapter@umdf.org

### Coins for Cure

Lowell Elementary School held a Coins for a Cure in honor of Jacob Bube and raised \$1,094. Way to go, Lowell Elementary!!!!

### Annual Garage Sales



It's that time of year again. The chapter will hold their annual garage sale this summer.

Last year, four garage sales raised more than \$2,500,

and one member held an auction and raised almost \$6,000. Contact Sue Ann Bube for Garage Sale Kits and let the fun begin!

### Miles for Mito

Bob Thomas, Vice President of the chapter, is planning to ride his bike all 400 miles from Indianapolis to Pittsburgh for the UMDF Conference to raise funds and awareness!!!

The chapter is planning to have a special "send off" in Indianapolis and hopes to get more members involved along his route.

(See page 9 for more details)

### 5th Annual Shelly's Heroes 5K Run/1Mile Walk

The Fifth Annual Shelly's Heroes was held on May 1st and raised more than \$30,000 for UMDF. The top pledge collectors were all members of the DeVal Chapter: Top prize went to the Hartman Family, in honor of their



## DELAWARE VALLEY CHAPTER

Philadelphia, PA

President: Maripat Shelly

Phone: 215-256-0273

Email: DelValChapter@umdf.org

daughter Haley, followed by Brad Burgener, and the Quiring Family.

Thank you to all who worked so hard to raise much needed research money for UMDF!

### 1st Annual Brew at the Zoo

• Saturday, June 19, 2004 from 5:30pm-9:30pm at the Elmwood Park Zoo, Norristown, PA.

Attendees will pay \$35 per person

and enjoy door prizes, food, beer samples, a souvenir cup and live music. Attendees will also have the opportunity to watch a Colonial Beer Brewing Demonstration.

Tickets may be purchased by credit card by calling the UMDF National Office at 412-793-8077 or by sending checks made payable to DeVal UMDF to: DeVal UMDF-Brew, 211 Alderfer Rd., Harleysville, PA 19438.

### Upcoming Events

- October 13, 2004 - You Go Girl Golf Outing

### Let UMDF Fund Your Retirement & Our Research!

By Nick Nicholson

Several years ago, an article in *USA Today* discussed the need for baby boomers to accumulate about a million dollars to ensure an adequate retirement. To be sure, those projections were based on decades of increasing costs of living and inflationary dollars, but a serious consideration requiring that we all become millionaires raised a very real red flag. Today, with soaring budget deficits and questions about the future of Social Security abounding, retirement planning continues to require a top priority status.

Every accountant and tax advisor can tell you why you should be contributing to your IRA, participating in your company's qualified plan, maximizing your 401(k) match...but how close to that million-dollar figure can we get with a \$3,000 annual contribution to our IRAs? A large part of our 401(k) balance comes right out of our own pockets, and there is always another concern... what if I need that money or what if I lose that money?

When advisors are called in to evaluate and design or revise a benefits program for a corporate client, especially a closely held business, the biggest questions frequently center on the retirement program.... what type of qualified plan is best suited to the client's goals: defined benefit or defined contribution, an age-weighted profit-sharing plan, a 401(k), or something else entirely?

Business owners know the advantages to establishing such a plan, and they know all too well the intricacies, complications, restrictions and regulations that accompany them. Testing, vesting, reporting, compliance, 5500's, administration, fiduciary liability, legal fees, expenses, ERISA and more. The business owner's bottom line? How much does it cost, and what percentage of that annual contribution will he and his family receive.

Despite largely unsatisfactory answers, they almost always go ahead, just as we all elect to participate in our 401(k)s or make that IRA deposit. Sure, there are drawbacks, but after all, it's the only game in town, right? ? And something is better than nothing, correct?

Here are my two favorite words.... "What if...."

What if that two-income, thirty-something couple could contribute \$12,000 each year toward their IRA, or \$18,000, instead of just \$6,000? What if they could still grow their retirement nest-egg tax deferred, get a deduction, and even make their retirement program self-completing should anything happen to one of them?

What if they could access their funds before age 59 ½ to retire early, or to meet educational expenses... without penalty?

What if that business owner could create a program without ERISA regulation, without contribution

limitations, a program that can fully, legally discriminate in favor of owners and/or key employees, that's portable, that yields a deduction and still offers tax deferred accumulation - without any excise taxes or penalties? What if there were no earned income considerations?

What if he could get more of his unused retirement funds to his kids?

What if they could have this: if they could "Take Control" of their retirement planning, and still fund crucial mitochondrial research, still support and enable acutely important UMDF initiatives?

These are just a few more examples of the possibilities open to UMDF members and benefactors through our planned giving initiative, "Taking Control."

You can control a portion of your hard-earned income, otherwise sent to Washington as tax dollars, and direct them to a specific use - mitochondria research, education and support - while at the same time, potentially improving your own retirement.

The tools to accomplish this dual imperative exist today and are available to each of us, but like various tax deductions and credits, granted only if we elect to use them.

Could a UMDF Charitable Remainder Trust be of more benefit to you than an employees profit sharing plan and trust? What are the other alternatives? You owe it to yourself to ascertain just how these tools can benefit you, your family, and our entire UMDF family. And it doesn't cost a penny to find out.

"Take Control," it's in all of our best interests.

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

#### Questions for Nick Nicholson? Join us in August for the Mitochondrial Medicine 2004 Conference

Nick will be speaking to families and physicians at various times throughout the conference -- including the UMDF Present and Future session on Friday morning. More information on his availability will be outlined in the program syllabus which is given to all attendees upon arrival at the conference.

# Fundraisers

**2nd Annual Richie Classic Golf Tournament** contributes \$10,000 to benefit UMDF -- in honor of Zachary Friedberg of Morgan, NJ. *Special THANKS goes to the Richie Foundation for their continued support!*

## Liberty Health

In honor of Zachary Friedberg, Liberty Health, of Secaucus, NJ, has held several fundraisers and contributed \$2,125 to benefit UMDF.

**Thank You, Friedbergs and All of Your Supporters!!!**



## First Annual 5K Run/Walk in Bellville, IL Raises more than \$31,000

Through the efforts of Marsha Hohe, Connie Schanter, family and friends, and the St. Louis Area Support Group, the event was a GRAND success with 600 people in attendance. Ronnie & Austin should be extremely proud of their mom!

## Getting Fit and Raising Dollars

Yoga Class in St. Louis Area raises \$516 to benefit UMDF.

## Atlanta Area Group -- Busy, Busy, Busy!!!



## First Annual Motorcycle Rally

Michelle Ingram, of Cedartown, GA, and her friends threw together a 60 mile ride in just 3 weeks. On April 3, the Rally raised \$1,922. Excellent!

## Bruster's Ice Cream Coupons

The group has raised more than \$1,900 by selling coupon booklets. You scream, I scream, we all scream for Bruster's Ice Cream!



▲ Pennies for Jenny Schnitzler (posing with family, friends and Chuck Mohan) at Shiloh Village School raised \$1,317.86 -- the money was included in the St. Louis Walk/Run.

▼ In memory of Paul Buczynski, Mother of Sorrows raised \$296 in one week and plans to expand in the 2004-05 school year. Pictured below is Chuck Mohan, Dr. Patricia Sheahan, Helena and Monica (Paul's mom and sister).



## Coins for a Cure Benefiting UMDF Across the U.S.



▼ \$2,335 (to date) -- The highest amount raised yet goes to Adlai Stevenson Elementary in memory of Eric and Kevin Withum. Pictured below is Tina Withum (Eric & Kevin's mother), Kara Strittmatter, Mrs. Kristen Gestrich and two of her students.



## Not Pictured:

- St. Margaret's of Scotland, in Pittsburgh, raised \$536.46 in honor of the Deasy Family.
- Two other Coins for a Cure were held in the chapters. See Indiana and New England Chapters on Page 4-5.



▲ The 3rd annual Coins for a Cure at St. Bernadette's brings in \$1,263.49 in memory of Gina Marie Mohan. Pictured above is Mrs. Kozusko's 4th Grade Class.

▼ BJ Young's Early Childhood Special Education class at Coopersville West Elementary School raised more than \$670 through several fundraisers.



# Fundraisers



## MELAS Angels Book

\$3,399.96 has been raised through the sales of the MELAS Angels Book. This book was created with love - In Memory of Angela Yu and Betty Li. Copies of the book are available for purchase by calling 412-793-8077.

## Hot Cocoa for Mito

- In honor of Tyler Morgan, the 4th Grade CCD class of St. Peter Parish in Slippery Rock, PA, raised \$266 by selling hot cocoa mixes. Thanks so much!!!

## Casino Night

- In honor of Bayley Thompson, family and friends gathered at the Roseville Community Center in Ohio to do a little gambling (with play money) to benefit UMDF. The Thompson's raised \$1,340! Outstanding!



## Curling Event Raises \$1,627.50

Chesapeake Physical and Aquatic Therapy sponsored a charity curling

tournament and raffle at the National Capitol Curling Center in Laurel, Maryland. Sixteen teams participated in honor of Peter Lubelczyk (pictured with physical therapist, Jared Goldstein). Go Peter!!!

## Supplemental Health Care Coverage for Children in Pennsylvania with a Severe Medical Condition

*Continued from page 1*

back-up or secondary insurance. This means that the private insurance is always billed first and that the Medical Assistance would be used to cover co-payments as well as some items that private insurance may not cover. As with all insurance, there are procedures and rules that you will need understand and follow to best use this product. All details will be explained to you once your child is accepted into the program.

Among the services covered by Medical Assistance are: inpatient and outpatient hospital and clinical care, prescription drugs, laboratory tests and x-rays, some formulas, medical equipment and supplies, eye glasses, therapies such as occupational, physical and speech therapy, and diapers for children age three years and older who have been diagnosed with developmental delay.

To apply for Medical Assistance for your child, call or visit your Public Assistance Office or call (717) 236-6310 to receive an application by mail. Request the Application for Health Care Coverage for Children (Form PA600 CH-7-00).

Documentation that will be necessary to make the application are the child's birth certificate, Social Security number, proof of any other type of health insurance, proof of all family income, proof of any income your child earns (the income limit for your child is approximately \$600.00 per month), and proof of your child's disability. Proof of disability can be in the form of medical records or a letter from your child's physician. Additionally, an explanation from the parent as to how the disability affects the child at home will be necessary. You will also need

to have the names, addresses, and telephone numbers of the physicians who care for your child. If you bring all this information with you to your meeting with the caseworker, you may go home with a Medical Assistance card for your child that same day.

After receiving the card, you may have one more decision to make. Depending on what county you live in, you may need to choose a state subsidized HMO through which to activate your Medical Assistance benefit. In southwestern Pennsylvania the three MA-HMOs are: UPMC for You, Gateway, and MedPlus. Before deciding on your child's HMO, make certain that your pediatrician or primary care physician, medical specialists such as your child's neurologist, pharmacy, and the hospital you would most likely use accept that HMO's insurance. Likewise, if your child uses equipment from a durable medical equipment supply company, check to make certain that they accept the new insurance.

This program provides a valuable insurance safety net for many of our most medically needy youngsters in the state of Pennsylvania. Most states have similar programs. One way to find out if your state has such a program would be to contact the agency in your state that oversees programs for children with special health care needs. This information can be found at the National Information Center for Children and youth with Disabilities (NICHCY) website- [www.nichcy.org](http://www.nichcy.org). At the website, select your state and then look for *Programs for Children with Special Health Care Needs*.



**United Mitochondrial Disease Foundation  
Mitochondrial Medicine 2004**

**Streams of  
Energy**

Brochures Available! Call 412-793-8077 or email [kara@umdf.org](mailto:kara@umdf.org) if you have NOT received your registration brochure! Or visit [www.umdf.org/conferences](http://www.umdf.org/conferences) to download.

## Miles for Mito



Bob Thomas, Vice President of the Indiana Chapter, is not a seasoned cyclist. As a matter of fact, he's not a cyclist at all. But for the love of his son, Gabe, and his dedication to finding a cure, he (and a couple of his friends) are going to bike ride 500 miles in August.

Bob and his friends plan to begin their journey on August 3rd and arrive in Pittsburgh on Friday, August 6th just in time for the family program of the conference. The *Miles for Mito* route will run from Mt. Pleasant, IN (south of Indianapolis), continue through Ohio (north of I 70), and end south of Pittsburgh.

If you live within a two hour radius of I 70, please contact [kara@umdf.org](mailto:kara@umdf.org) or [INchapter@umdf.org](mailto:INchapter@umdf.org) to find out how you can promote this heroic effort. You can help by collecting pledges, assisting the UMDF office in soliciting sponsorships, or participating by riding a few miles with Bob as he passes through your area. The UMDF office may also set up several "gatherings" at key points in the ride to cheer them on as they bike *Miles for Mito*.

*Pledge forms and more information will be available soon via the UMDF web site or by calling the office at 412-793-8077.*

## Mitochondrial Medicine 2004 OUTREACH

Please help us spread the word about the Mitochondrial Medicine 2004 Conference in August. If you are willing to distribute the Scientific Meeting brochures to physicians and other allied health professionals in your area, please contact [kara@umdf.org](mailto:kara@umdf.org) or call 412-793-8077.

### Conference Highlights for Family Program

- As a "lighter" side of the conference, the program committee has added the following sessions for Friday morning: Organizing the Perfect Walk/Run, How to Start a Group, Getting Good Publicity, Meaningful Membership, UMDF Present and Future, and 25 Easy Fundraising Ideas. Friday afternoon will include the Mito Basics, Behavioral Issues, and Art Therapy for Siblings and Patients.
- Anthony Linnane, PhD, will present *Mitochondrial Disease: A Way Forward* to families and physicians during the Friday night banquet.
- And please check out the brochure for all the dynamic topics in line for Saturday, such as Genetics of Mitochondrial Disease, Palliative Care, Muscle Biopsy - What to Expect, and much more.
- Additional activities on Saturday will include the *Doctor is In*, the *Genetic Counselor is In*, the *Counselor is In* and possibly a massage therapist to help you relax after a long day of sessions!
- Family sessions run Friday morning through Saturday afternoon. Meals include two continental breakfasts, two lunches, and the Friday night banquet.

## Ask the Mito Doc

Continued from page 2

take care of your child.

Support the physicians and researchers who are interested in mitochondrial disease, such as UMDF or local interest groups. Develop parent support groups. The task is endless, and in the end one can only do his/her best. As you take care of your child, others will notice your care and love. That will be the most attractive ingredient to gain support for this disease.

### The Question Is:

Can you please address some issues in regards to behavioral problems related to mito disease?

### Response From:

**Amy Goldstein, MD**

I have a broad response to this issue which is this: mitochondrial disorders can affect the brain, which can cause anything from headaches to encephalopathy to seizures to dementia to learning disabilities to behavior problems to

sleep disturbances, etc. The problem that some psychiatrists have in treating these children and adults is that they do not neatly fit into a DSM-IV criteria (Psych Diagnostic Manual), and the drugs have been designed with these criteria in mind (i.e. major depression, anxiety disorder, etc.). In neurologic disorders though, it is important to treat the symptoms even if they do not neatly fit into a psychiatric category of diagnosis. These symptoms include aggression, self-stimulatory behavior, insomnia, hyperactivity, and inattention. These not only occur in mito disorders, but commonly in epilepsy, tuberous sclerosis, Rett's syndrome, and many other disorders that affect the brain.

It is going to be hard to recommend certain drugs because each case is so individual. For aggression, I have used tricyclics which also treat sleep problems,

neuropathic pain, GI symptoms and headaches; alpha-agonists, such as clonidine and tenex, which also treat hyperactivity and sleep but can cause rebound hypertension; SSRIs such as Prozac; antipsychotics such as Risperdal or Zyprexa which can help with comorbid movement disorders and sleep but can cause weight gain. For sleep I try melatonin, chloral hydrate, Tranxene, or Ambien.

If a patient has a seizure disorder that is not well controlled, I try to see if an anti-epileptic drug can be used for the problem first; Neurontin is a good example because it can be used for sleep, mood stabilization, neuropathic pain, GI symptoms. Tranxene is another good example. I continue to avoid Depakote for seizures and behavior. If the behavior problems are really severe, I try to refer the patient to a child psychiatrist rather than sub-optimally treat him/her myself.



### Tomato Face Foods Still Needs YOU!

**YOU can help Tomato Face Foods** continue reaching thousands across the U.S. Do you know someone in your local supermarket or grocery chain? If so, please contact [kara@umdf.org](mailto:kara@umdf.org) or 412-793-8077, ext. 106.

Hats off to Barbara Bruck, Allen Segal and their daughter Dana for their wonderful interview with Monica Robbins, Health News anchor for WKYC Channel 3 in the Cleveland area. Awareness is the KEY!!!

Ann Eide is currently asking persons to step forward and share their experiences living with Mitochondrial Disease.

The stories will be compiled in a book entitled *Mito Memoirs: A Journey into Our Lives*. The book will be sold at the Heartbeats For Mito Fundraiser in Tuscaloosa, AL (Fall 2004). All proceeds will benefit the UMDF. For more

information, please contact Ann at:

[memoir@HeartbeatsForMito.org](mailto:memoir@HeartbeatsForMito.org).

Thank you.

## THANK YOU

### Mitochondrial Medicine 2004 Sponsors and Exhibitors

*(Please note: the following are Sponsorships and Exhibitors received as of 5-5-04)*

#### Sponsors

- ☆ Eberly Foundation
- ☆ Commonwealth of PA
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#### Exhibitors

- ☆ Sigma-Tau Pharmaceuticals
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## UMDF Chapters & Groups

### ARIZONA

#### ★Arizona Chapter

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### CALIFORNIA

#### ★Southern California Chapter

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### INDIANA

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## Power Up Pittsburgh



*Kelly and Dan Deasy share their experiences as a "mito family" with Kathy and Bill Bell, of Aqua Filter Fresh, Inc.*

On April 22, State Senator Sean Logan hosted a reception to benefit the Mitochondrial Medicine 2004 conference and has offered to continue this event annually.

The reception raised more than \$15,000 for the conference and provided the foundation a superb opportunity to network with local politicians, businesses, and philanthropists. Thanks Senator Logan!

Special thanks to G. Kidd, Inc. and Holiday International Travel for helping spread the word and for donating a wonderful door prize.



*Senator Logan (far left) pictured with door prize winner Laurie Saxon (holding prize), the Petrulli Family (Holiday International Travel) and UMDF Chairman, Chuck Mohan.*

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We're Here to Help You! 412-793-8077**

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**★ Mark your Calendars ★**

**See pages 4 and 5 for Upcoming Chapter Events**

- June 5, 2004 - 2nd Annual Pittsburgh UMDF 5K Run and 1 Mile Walk at North Park.
- June 5, 2004 - 1st Annual Mito-What? Trap Shoot, Brighton, Colorado at Colorado Clays
- June 24, 2004 - 7th Annual Pittsburgh UMDF Golf Outing at Churchill Valley Country Club.
- July 19, 2004 - 5th Annual Ohio UMDF Golf Outing at Chagrin Valley Country Club.
- September 18, 2004 - 5K Run/Walk - Birmingham, AL
- September 18, 2004 - 1st Annual You Go Girl Golf Outing in Pittsburgh (Monroeville, PA)



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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 for cures and treatments of mitochondrial disorders and to provide support to affected individuals and families.

Deadline for next issue is 06/30/04