

MITOCHONDRIAL MEDICINE 2007: *Riding the Wave of the Future*

In June, UMDF hosted its ninth annual symposium dedicated to mitochondrial medicine at the Catamaran Resort Hotel in Mission Bay, San Diego. The conference attracted 225 physicians, researchers and other health professionals and 200 patients and family members, all with a desire to learn more about mitochondrial disease.

SCIENTIFIC MEETINGS

The 2007 symposium covered a broad spectrum of topics that included reviews of both current knowledge and cutting edge research on mitochondrial function.

Day One – Mitochondrial Mechanisms and Disease: Topics covered included the role of mitochondrial DNA variation in age-related diseases, a mitochondrial toxin model of Parkinson's disease and molecular mechanisms of Barth syndrome. Detailed explanations of the roles of oxidative stress and ischemia in mitochondrial neuropathies and myopathies were also presented. A noteworthy research presentation was Volkmar Weissig's "Internalization of Isolated Mitochondria by Mammalian Cells," in which he demonstrated that mitochondrial uptake can restore respiration in human cells lacking functional mitochondria.

Day Two – The Role of Mitochondria in Diseases of Aging: Insights into the importance of pro-oxidant signaling to metabolism in

mitochondria and other cell organelles and the multi-faceted contribution of mitochondrial polymerase gamma to various diseases were highlights of the invited talks. Wolfgang Sperl's research presentation titled "The Relevance of Functional Investigations of Intact Mitochondria in the Diagnosis of Mitochondrial Disorders" held out the possibility of developing diagnostic tests more sensitive in recognizing mitochondria-based metabolic defects than are currently available.

Day Three – Current Options for Treatment of Mitochondrial Disease: The many obstacles to receiving approval for clinical trials of promising drugs for treatment of rare diseases were addressed by one of the faculty, while another surveyed the potential for drugs to increase respiratory function in animal models of mitochondrial disease. Jennifer Barber-Singh's research presentation, "Protective Role of NDI1 in a Mouse Parkinson's Model," examined the utility

"THIS WAS BY FAR THE BEST MITOCHONDRIAL MEETING I'VE BEEN TO. THERE SEEMED TO BE AN EFFORT TO INCLUDE NEW, YOUNG SCIENTISTS, AND SOME OF THE MOST INTERESTING TALKS CAME FROM THEM."

of an animal model for assessing the ability of gene therapy to protect against mitochondrial complex I defects in Parkinson's disease.

Day Four – Future

Treatment Prospects: The emphasis this day was on increasing the accuracy of mitochondrial disease diagnosis and of assessment of treatment efficacy through the use of technologies such as computerized or polarographic analyses and high-resolution respirometry. Another presentation detailed the roles of muscle mitochondrial function in type-2 diabetes and chronic obstructive pulmonary disease. Sarah Calvo's research presentation, "Systematic Identification of Human

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Ellie Kovalcik is pictured left at the second annual Race for Ellie at Adventure Park in Powell, Ohio. The event raised over \$41,000!

See pages 4-7 for more events and fundraisers!

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BOARD SPOTLIGHT

The day Sharon Shaw was diagnosed with mitochondrial disease in 1999 was the day she called UMDF the first time.

She called looking for support and information. What she found was kindness in the form of Chuck Mohan, who in those days referred to himself as “just a volunteer.” Sharon made a promise then that, as long as her mitochondria permit, she would be of service to UMDF in any way she could.



Per Chuck's urging, Sharon went to a Southern California support group meeting. After attending two meetings, she realized that the group would have



to become a full-fledged chapter if they were ever going to get on the map. Sharon made a passing mention of this idea, and the next thing she knew, she was nominated to be president of the new chapter.

As they say, the rest is history. Sharon served as president of the Southern California Chapter for three years, stepping down in 2003. She served as chapter liaison to the board of trustees from June 2002 to June 2003 and was appointed to the board as a full-time trustee in November 2003.

Since 2000, Sharon has also had her hand in what she loves – helping with the logistics of the UMDF symposium. Her expertise is in meeting planning, special events, conference coordination and marketing. At this year's conference, Sharon was instrumental in planning and making the Tenacious D benefit concert possible.

Sharon was first introduced to Jack on a telephone conference with Jack, his manager and a few others. They brainstormed some fundraising ideas, and one of them turned into a reality. Jack appeared as a celebrity contestant on Who Wants to Be a Millionaire in 2001, and Sharon, Chuck and Adrienne Mohan and Linda Cooper, the Southern California Chapter vice president, all flew to New York for the taping. Jack won \$125,000 for UMDF!

That night Jack invited the four of them to what would be the first of many Tenacious D concerts. None of them had ever heard the



music. They all just laughed and wondered how they were going to explain this one to the rest of the board. Then they bought Tenacious D T-shirts, the proceeds of which benefit UMDF.

Jack and bandmate Kyle Gass have now been supporting UMDF in many different ways for the last seven years. The Tenacious D benefit concert at the symposium this year brought in nearly \$50,000.

Sharon continues to expand her role with UMDF. She recently accepted the position as chair of the newly formed Adult Advisory Council. Like many adults and parents with affected children, it took more than 15 years for her to get a proper diagnosis, and she looks forward to helping to shorten that gap for others.

She has found that the best medicine is being of service to others. To have a purpose that allows her to be part of a bigger picture is what helps her stay strong.



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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.

“I owe my sanity and the peace in my heart to the UMDF,” Sharon says. “I have gotten back far more than I will ever be able to give through volunteering. The biggest lesson that has come from all of this is how I have learned to turn burden into blessing.”



**ASK THE
MITO DOCSM**

Living with mitochondrial disease presents many twists and turns and a maze of questions. UMDF is pleased to offer answers to some of those questions as taken from *Ask the Mito DocSM* at UMDF.org. Please note that information contained in *Ask the Mito DocSM* 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: Gerard Vockley, MD, PhD, of Children's Hospital of Pittsburgh; Greg Enns, MD, ChB, of the University of California, San Francisco; and Gerard T. Berry, MD, of Children's Hospital of Boston.

THE QUESTION IS...

My daughter is affected with complex IV COX. She has many other problems also, but they have only been able to diagnosis one mutation so far. Since she does not have an exact diagnosis, how do I know as her mother if I am affected and someday might become ill, or how likely is it if my next children will have it? All of her doctors I have asked cannot answer this question. I live in a constant state of worry whenever I get any ache or pain. Is there a test for me to get done?

RESPONSE FROM GERARD VOCKLEY, MD, PhD:

It is difficult to answer your question without more details. Based on your question, I assume your daughter has complex IV deficiency diagnosed by an enzyme assay on muscle. This is a specific diagnosis but can be caused by mutations in a number of nuclear genes or on the mitochondrial chromosome.

If the mutation you mention is on the mitochondrial chromosome, you could have sequencing done on DNA from several tissues to look for the same mutation. If you carry a mitochondrial mutation, all children will inherit

it but in differing amounts. But there is always the possibility of a higher or lower number of mutations present in the mitochondria of an egg cell that would in turn lead to a more or less affected baby.

If the mutation you mention is not on the mitochondrial chromosome, it is pretty good evidence that this is the gene causing the problem even though the mutation on the second copy of this gene is unknown. In this case your risk to have an affected child is 1/4 (25 percent). Prenatal diagnosis might be possible. In this case you would also not be at risk to show symptoms yourself. You should discuss these results with a medical geneticist or a genetic counselor familiar with mitochondrial disease to clarify these risks.

THE QUESTION IS...

As the weather gets warmer, my five-year-old son with mitochondrial myopathy is having more muscle cramps, restless sleep and generalized pain, particularly after playing outside. What is the most effective method to relieve or prevent this pain?

RESPONSE FROM GREG ENNS, MB, ChB:

Exercise intolerance, muscle cramps and muscle pain are frequently encountered in children and adults who have mitochondrial disorders. Unfortunately, there is not a specific approach that works for everyone. This is understandable given the number of different genetic changes that have been found in those individuals experiencing such symptoms.

As you certainly know, it is important to ensure that your son is well hydrated during the summer season. Children with mitochondrial disorders may be more sensitive to glucose deprivation, so it is also important to ensure that your son has adequate nutrition on board to keep on playing. Some patients have felt better eating frequent snacks or drinking fluids with dextrose during periods of exercise.

I assume that your son is also taking some form of supplements and cofactors. There have not been many convincing studies performed to date, but some reports suggest that coenzyme Q10 treatment may improve exercise performance. Creatine supplementation may also help some individuals, but again, convincing evidence for efficacy is scant.

In short, I wish I had a clear answer for you, but a common sense approach is probably best. Limit exercise if his symptoms are worsening, make sure he is taking adequate nutrition and fluids and discuss supplements with your physician.

THE QUESTION IS...

My 5½-year-old daughter, who is diagnosed with a probable mitochondrial disease, has to take six 330 mg tablets of Carnitine per day and four 60 mg tablets of Coenzyme Q10, both of which can and do cause diarrhea, and her dosages keep increasing. We have been having problems with these causing diarrhea, which keeps getting worse and more frequent because of dosage increases. It actually disrupts our lives because it can be so bad that it will go halfway up her back or out through her diaper to her pant leg and get all over her clothes, which is very difficult to deal with when we go places. Is there something we can give her to help with that? Maybe if we could give her an Immodium every day or something like that -- anything? I'm afraid it's going to get so bad, we won't even be able to go anywhere anymore. Please help!

RESPONSE FROM GERARD T. BERRY, MD:

The loose stools associated with the use of these medications is a problem that can interfere with daily living activities. This is especially so for L-carnitine as only approximately 30% of the oral dose is absorbed. Therefore, the majority is malabsorbed and can then pass from the small intestine into the colon and induce water loss. The result is loose stools or even significant diarrhea. However, most patients with metabolic diseases who are receiving L-carnitine do not suffer from massive diarrhea.

Taken together, this suggests that in some patients with chronic significant loose stools another process such as a parasitic infection of the intestinal tract may be complicating the underlying tendency toward loose stools. I suggest that the child be seen by a physician who specializes in gastroenterology (GI) for evaluation of another possible cause of the chronic diarrhea.

Lastly, this referral may be valuable for another reason as, theoretically, dysmotility of the intestinal tract due to a mitochondrial disease could induce hypermotility, which in some individuals might manifest as diarrhea. The GI consultation would be the first step in the evaluation of this uncommon expression of a dysmotility syndrome. If the loose stools do prove to be due to L-carnitine alone and/or Coenzyme Q10, then a gradual increase in dosage of either medication alone over many weeks may help the body slowly develop a tolerance and in the absence of a gastrointestinal dysfunction.

CHAPTER ACTIVITIES

CHAPTER NOTES

ATLANTA CHAPTER

• **July 26, 2007.** A special preview show of the Pumphouse Players' presentation of "The Nerd" in Cartersville, Ga., raised \$835 in honor of Sherry Mathison (pictured right, first row center).



CENTRAL OHIO CHAPTER

• **July 28, 2007.** The second annual *Race for Ellie* in honor of Ellie Kovalcik at Adventure Park in Powell, Ohio, was a great success. More than 500 participants came out to support Ellie, the Kovalcik family and UMDF. The run/walk raised over \$41,000 for the foundation! Thanks to Wendy Ivany and her race team for an outstanding job.



DELAWARE VALLEY CHAPTER

• **July 28, 2007.** The fourth annual *Delaware Valley Brew at the Zoo* at Elmwood Park Zoo in Norristown, Pa., was a great success. More than 1,400 people attended, raising more than \$30,000! Special thanks to Bob and Lisa Polsky for another great event.

INDIANA CHAPTER

• **July 30, 2007.** The third annual *Indiana Chapter Golf Outing* was held at the Hawthornes Golf & Country Club in Fischer, Ind. Thanks to Mike Hanlon and the golf committee on another successful outing!

KANSAS CITY CHAPTER

• **June 23, 2007.** The Kansas City *Mito-What? Family Fun Run* was held at Lake Waukomis' South Park in Lake Waukomis, Mo. There was lots of fun for the kids with face painting, games, music and a special kids' dash. A great time was had by all! Thanks to Therese Edwards and the race committee for organizing the event again this year.

NEW ENGLAND CHAPTER

• **May 20, 2007.** The inaugural *Bike-E-Thon* in memory of Elijah Bonney brought a great turnout for such a rainy overcast day. Dave Bonney and other event organizers helped to raise more than \$3,000!

• **July 1, 2007.** Janet Lamb of Foxboro, Mass., participated in a half-iron distance triathlon in honor of her Aunt Rose Mandill and raised \$2,350! Great job, Janet! (Team Auntie Rose pictured right.)



OHIO CHAPTER

• **July 20, 2007.** New Image Haircutters of Willowick, Ohio, held a hair cut-a-thon during the Lake County Captains' baseball game July 20 in honor of Jonathan Kucaric. Special thanks to all who helped organize this event!

UMDF WELCOMES NEW LEADERS

UMDF WELCOMES THREE NEW CHAPTERS!

At this year's symposium, UMDF welcomed three new chapters in Minneapolis/St. Paul, Central Ohio and Canada! Welcome to the new boards of directors of all three chapters.

MINNEAPOLIS/ST. PAUL:

Ryan Walther (Pres.)	Dan Russell (VP)
Jen Percy (Sec./Treas.)	Liz Beer
Chuck Parsons	Jo Parsons
Fran Russell	Anne Walther

CENTRAL OHIO:

Matthew Kovalcik (Pres.)	Paul Feeney (Sec.)
Walt Eckert (Treas.)	Dr. Barbara Marriage
Dr. Carlo DiLorenzo	

CANADA:

Keely Schellenberg (Pres.)	Erin Donovan (VP)
Doreen Booth (Treas.)	Maureen Booth (Sec.)

WELCOME NEW YORK METRO BOARD MEMBERS!

UMDF would like to welcome the newly elected New York Metro Chapter board members:

Tom Shubeck (Pres.)	Kim Zuzzolo (VP)
Gina Dudgeon (Sec.)	Bob Amato (Treas.)
Bob Brief	Caroline Shubeck

WELCOME INDIANA BOARD MEMBERS!

Please join us in welcoming the new leadership team of the Indiana Chapter:

Penny Hanlon (Pres.)	Gina Boling (VP)
Jackie Parrish (Sec.)	Camille Gaughan (Treas.)
Eric Boling	Celanie Christensen
Chris Gaughan	Mike Hanlon
John Goerges	Nicole Goerges

'MITOCHONDRIAL MEDICINE 2007' (cont. from page 1)

Mitochondrial Disease Genes Through Integrative Genomics," disclosed an especially promising means of discovering currently unknown genes that contribute to mitochondrial disease. (Summaries courtesy of Steven G. Basset, PhD) Below are some reactions from scientific attendees:

I attended all of the sessions, and each one was well-programmed, well-attended and especially well-presented. Every presenter gave state-of-the art information and presented it with a passion not usually seen at scientific meetings. This is one of the hallmarks of UMDF presentations. This is a must-attend meeting for anyone interested in mitochondria and their application to clinical medicine.

~ Dr. Donald A. Fox, University of Houston

I learned a tremendous amount from the formal presentations and the informal interactions. The presentations between the community affected by mitochondrial disease and the researchers provided the clearest motivation possible for my research. In addition, the environment created many chances for interaction. A casual breakfast conversation with a stranger has already led to a successful collaboration in only two months, an afternoon walk has led to an excellent post-doc applying to our lab and dinnertime conversation has led to an international friendship and potential collaboration.

~ Sarah Calvo, Graduate Student, Broad Institute of Harvard/MIT

In my opinion, this conference is very special, firstly because scientists with and without specific medical background get together, and what is really extraordinary is that they all can meet with patients and their [families] who are, unfortunately, affected

by the disease. This "bench to bed" strategy creates an atmosphere that is very challenging and motivating because we can get an impression of where our scientific work goes and how it can be helpful. And what could be a better motivation than if the sometimes really basic research we are doing can successfully help a patient survive?

~ Susanne Arnold, PhD, Aachen, Germany

FAMILY MEETINGS

Patients and family members at the symposium had the opportunity to attend sessions relating to mitochondrial disease basics, nutritional therapies, neurological and cardiac symptoms, marriage and family stress and supportive and palliative care. Here are some reactions from family attendees:

~ The conference information and networking were great. For me, "Ask the Mito Doc" was most important. I've been trying to find a metabolic-oriented doctor who is willing to see an adult, and I was referred to one by the Mito Doc. Many thanks for all the great information.

~ Thank you very much for our scholarship to attend the symposium in San Diego, which may not have been possible otherwise. This was our first conference, and it was very valuable for us to attend. Thank you all for your hard work to make the conference such a great experience for parents.

~ I was truly excited about this meeting in terms of the amazing research breakthroughs, the great families and UMDF really working hard and effectively at putting so many things together. I left so proud to be part of this energy and so motivated to do more for the effort.

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OTHER NOTABLE EVENTS

• **May 7, 2007.** The *Fine Golf Outing* at Lake Lanier Islands Pineisle Golf Club in Georgia raised \$1,000 for UMDF in honor of Price, Spencer and Dylan Fine.

• **May 25-June 9, 2007.** *Patterns of Life*, a benefit art show featuring photographic work of Austin Monson and Miguel Garcia was held at the Santa Barbara Art Studio. This event raised \$390 for UMDF.

• **June 2, 2007.** The *Greater Mito Open Golf Outing* at Olde Highlander Golf Course in Oconomowoc, Wis., raised \$9,825 in honor of Brianna Dobke.

• **June 4-30, 2007.** The Marathas family and Longdogger's Restaurant in Indialantic, Fla., raised money for mitochondrial disease research in honor of Connor Marathas through *Connor's Energy for Life Lightbulb Campaign*. Three restaurants sold paper light bulbs to raise awareness through the month of June.

• **June 9, 2007.** The *Myles for a Cure* walk on the Cedar Valley Nature Trail in Waterloo, Iowa, was held in honor of Myles Eick. Special thanks to all who helped to organize this event!



Myles and Alexis Eick cutting the ribbon

• **June 9, 2007.** A local gardening club held a plant and garden sale in Appleton, Wis., to benefit UMDF. More than 1,000 plants, plus garden art, painted gourds, benches and more were available for sale.

• **June 23, 2007.** The second annual *Save Barnegat Bay 8K* in Lavallette, N.J., raised \$1,000 for UMDF in honor of Lauryn and Owen Boyle. Events included an 8K race and a 3.3-mile fitness walk along the shores of beautiful Barnegat Bay.

• **June 30, 2007.** Mito mom Nikki Hoekstra's company hosted a *Plants for a Purpose* fundraiser in honor of Autumn Hoekstra that raised \$1,502 for UMDF.

• **May-June 2007.** During the months of May and June, the Western Pennsylvania Mito GroupSM raised \$640 selling tickets for CleanTown USA, who donated a portion of the ticket proceeds to UMDF.

• **July 14, 2007.** *Hula Hoop for Hope*, organized by Ann Clark, raised \$3,000 in memory of Sean Clark. Ladies Workout Express volunteers participated by doing the hula for 30 minutes each.

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For more information about a chapter, group or ambassador near you, contact the UMDf office at 888-317-UMDF!

MITO FACTS

- Every fifteen minutes, a child is born who will develop a mitochondrial disease by age 10.
- Mitochondrial disease typically involves three or more organs and can occur at any age.
- Adult onset of mitochondrial disease can result in drastic changes from active lifestyle to debilitating illness in a short amount of time.



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WOMAN INTERRUPTED?

A Day in the Life of the Garvin Family

Therese Garvin had a normal life. She worked in the cardiac care unit at Albert Einstein Hospital in Philadelphia, and when she and her husband, Pete, were blessed with children, Therese quit her job at the hospital to be a stay-at-home mom for a few years. Life was good.

But, after her third child was born in 1996, Therese noticed some changes. She started falling from weakness and numbness in her legs. She



couldn't feel her hands, button clothes or hold anything weighing more than a couple of pounds.

Her doctors were baffled. She was sent to a neurologist who ran a number of tests and eventually told her it was probably Multiple Sclerosis, although they could not substantiate that diagnosis. When she experienced paralysis on the right side of her body, Therese visited her primary physician. But not realizing it was some kind of stroke, the doctor prescribed her Prozac and referred her to a psychiatrist.

When someone recommended a neurologist at Hahnemann Hospital in Philadelphia, Therese jumped at the chance for an appointment.

"I waited eight or nine months for an appointment, gathered all of my charts and went to see her," Therese recalled. "She went through the process of evaluating me and then immediately scheduled me to go out for a muscle biopsy."

Seven weeks later it was clear. The diagnosis was mitochondrial disease. After five years,

Therese finally had an answer.

At the time of the diagnosis, Therese was using a walker and a wheelchair and was experiencing seizures, fainting spells, digestive problems, much pain and weakness, terrible sleeping problems, night sweats, stroke-like symptoms and horrible fatigue.

"I was almost at my breaking point," she said. "May 22, 2001, was the best day of my life because I finally knew what was happening to me. Now I knew what was wrong and had to start the fight."

Her doctor prescribed a vitamin cocktail, and Therese began taking various other medications to treat her symptoms. Within six to eight



months, she started responding to the medication, and despite remaining difficulties, began walking without assistance.

Through all of her hospital stays and everyday care, Therese's family was there to support her. Her husband, who works as an officer in the Philadelphia Fire Department, took on a second job when she fell ill. With their mother's illness and their father's 90-hour work week, the Garvins' children, Heather, 18, Scott, 13, and Jacqueline, 11, sometimes

"MY MOM HAS ALWAYS TOLD ME THAT HARD WORK AND PERSEVERANCE WILL GET YOU THROUGH ANYTHING. SHE IS THE EPITOME OF PERSEVERANCE." ~ HEATHER, 18

"LOVING, STRONG AND BRAVE ARE JUST THREE OF THE MANY REMARKABLE CHARACTERISTICS OF MY MOM." ~ SCOTT, 13

"MY MOM INSPIRES ME. SHE STRUGGLES ALL THE TIME TO WALK AND DO ALL THE THINGS A MOM HAS TO DO, SHE NEVER COMPLAINS." ~ JACQUELINE, 11

had to be more independent than they were before, but they took the new challenges in stride.

"I couldn't have been so strong had it not been for my family," Therese said. "They are my support system."

But Therese recognized that she needed outside support as well, so she contacted the Delaware Valley Chapter of the United Mitochondrial Disease Foundation and attended one of their walk fundraisers.

(continued on page P4)

FROM THE CHAIRMAN

At UMDF, we want to be able to answer the questions “What is Mitochondrial Disease?” and “What does UMDF do?” The following five messages have been developed so that *YOU* can help friends, family, school officials and members of the media to better understand mitochondrial disease and why finding a cure is so important.



The mitochondria, powerhouses of the human cell, hold the key to many diseases.

- Mitochondrial diseases are under-diagnosed, and their rarity is questionable (not as rare as once thought).
- The research benefiting children and adults with mitochondrial disease may have more positive far-reaching impact for everyone.

“The Little Engine that Could” and *does* make a difference in the lives of thousands!

- Many of us have read “The Little Engine that Could,” but we didn’t know that, within their own bodies, there were little engines that need to function properly to meet our bodies’ needs.
- Defects in the mitochondria trigger a host of illnesses characterized by widely varying symptoms, and for many, the disease can be fatal.

Living with mitochondrial disease requires building a medical home.

- Mitochondrial disease involves coordinating many different doctors, specialists and therapists. The family has no choice but to become experts in home health care.

- Typically, more than one child, and possibly a parent, will be affected with mitochondrial disease in the same household. Care-giving is both physically and financially exhausting for the entire family.

Mitochondrial disease is a notorious masquerader and a diagnostic nightmare.

- Diagnosing mitochondrial disease can be a nightmare -- many experts refer to it as a “notorious masquerader” because it wears the mask of many different illnesses.
- Right now there is no known cure, so supporting research that slows the progression of the disease is a top priority for the UMDF.

Mitochondrial disease and disabilities in the classroom and in the workplace.

- Many children and adults with mitochondrial disease are excluded by classmates or coworkers because of their disabilities. Some adults lose their jobs.
- The United Mitochondrial Disease Foundation is reaching out to educate the public about mitochondrial disease and to encourage compassion and understanding.

We hope these talking points will help you be a better advocate for mitochondrial disease awareness and research. From all affected by mitochondrial disease, thank you for your continued support!

Warmest Regards,

A handwritten signature in cursive that reads "Stanley Davis".

Stanley Davis,
UMDF Chairman

MITOCHONDRIAL DISEASE
*The body's inability to turn
food into the energy needed
to sustain life.*

RESEARCH SPOTLIGHT - Patrick Chinnery, PhD

In 2005, the UMDF awarded a grant of \$162,878 to Patrick F. Chinnery, PhD, of the University of Newcastle upon Tyne in the United Kingdom to study the prevalence of ten mtDNA mutations.

Each of us depends upon our own mitochondria to derive energy, in the form of ATP, from the food that we eat. Because ATP has to be readily available for use by our cells, the mitochondrial enzyme systems responsible for its production are constantly working.

Unfortunately, this complicated machinery can malfunction, sometimes because the mitochondrial enzyme complexes were improperly assembled. One possible cause of mitochondrial malfunction is that the mitochondrial DNA (mtDNA) contains a mutated faulty genetic code.

Dr. Chinnery and his team at the University of Newcastle Upon Tyne set out to determine how common these mutations are in the

general population. They compared their findings with the number of mutations identified in mitochondria from individuals living in the same region of the United Kingdom who are affected with mitochondrial disease. Because it is suspected that mtDNA mutations are more common than is currently understood, Dr. Chinnery’s study should lay the groundwork for developing a more accurate assessment on their incidence in the population at large.

Dr. Chinnery received his bachelor of medical science (BMedSci) and his bachelor of medicine and surgery (MBBS) from the University of Newcastle upon Tyne in 1989 and 1992, respectively. He earned his Membership in the Royal College of Physicians (MRCP) in 1995, completed his PhD in 2000 at the University of Newcastle and received his CCST in neurology from the Specialist Training Authority in 2002. He was the recipient of the 1997 and 2000 Charles Symmonds Prize from

the Association of British Neurologists, the 1997 Liversedge Prize from the North of England Neurological Association and the 1997 Foreign Scholarship Award from the American Academy of Neurology.

Chinnery worked at Newcastle as a Wellcome Trust Clinical Research Training Fellow from 1995 to 1998 and as a Wellcome Trust Advanced Clinical Research Fellow from 1998 to 2000. He was an honorary clinical assistant in neurology from 1998 to 2001 at the Institute of Neurology, Queen Square, London, and a clinical lecturer in neurology from 2000 to 2002 at Newcastle. From 2002 to 2004 he was honorary consultant neurologist at Newcastle Hospitals NHS Trust and a senior lecturer in neurogenetics at Newcastle. Chinnery has been a Wellcome Trust Senior Fellow in Clinical Science since 2003, and has been an associate editor of *Brain*, a journal of neurology, and a professor of neurogenetics since 2004.

UNITED MITOCHONDRIAL DISEASE FOUNDATION

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SUPPORTING OUR CAUSE

CHARITABLE GIVING

Only *you* can make the choice to help others and your family at the same time!

Have you ever considered a charitable gift, but hesitated because of financial concerns? When done properly, charitable giving can help you further the mission of your favorite charity without negatively impacting your own finances.

QUESTIONS TO GET YOU STARTED

- Do you have adequate retirement income?
- Do you have unneeded assets?
- Do you have a favorite charity?

Thanks to hard work and prudent money management, some people find that they do not need assets from a particular retirement account to support their lifestyle. This opens the door to legacy planning and charitable giving.

The charitable optimization strategy offers an alternative to giving IRA assets, which are subject to hefty taxes. Using wealth enhancement or wealth replacement, you can magnify the assets that you want to give to your family and favorite charity. Choosing an appropriate method depends on your financial situation, needs and legacy intentions.

As the owner of a traditional IRA or qualified retirement plan, you are required to start taking annual distributions soon after you reach age 70½ even if you do not need them, and generally, you must pay income tax on them. If this money is not needed to meet living expenses, it can provide for a larger-than-expected gift to your family *and* your favorite charity.

Using life insurance is one way that offers instant magnification of your gift starting with the first premium payment. The beneficiary of the life insurance is guaranteed to receive the full death benefit tax-free regardless of the number of premium payments made up to the time of death.

HOW DOES THIS WORK?

Let's assume that you have a \$250,000 IRA, but you have adequate retirement income and do not need the distribution from this asset for living expenses. If your required minimum distribution is \$20,000 a year, you would need \$6,000 to pay income tax, and the remaining \$14,000 could be used to purchase a life insurance policy with a \$350,000 death benefit. Then, make your family the beneficiary of your life insurance and your favorite charity the beneficiary of your IRA.

Upon your death, your family will receive the death benefit of \$350,000 tax-free, and the

charity will receive \$250,000 from your IRA tax-free. Without this planning, your family would have received \$250,000 from your IRA less taxes of approximately \$75,000, leaving a total net inheritance of \$175,000.

Please do not underestimate the value of estate planning. The above strategy may not work for everyone, depending on insurability. Each financial situation is unique and should be looked at on an individual basis.

For more information or to contact a financial specialist to review your personal situation, please contact UMDF at 412-793-8077 or toll-free at 888-317-UMDF.

NEW MACY'S FUNDRAISING OPPORTUNITY

Macy's department store has just announced a "ready-made" fundraiser for all non-profit organizations.

"Shop for a Cause" will be held October 13 at all Macy's stores across the country. You can apply to your local Macy's to sell \$5 shopping discount passes in your community.

All proceeds from selling the passes go to UMDF. Simply send us the funds you raise by selling the passes. Please let us know if you are going to participate with your local store!

For details and an application, visit www.macys.com/campaign/shopforacause.jsp.

WHAT THE DEVELOPMENT DEPARTMENT CAN DO FOR YOU

- Help write requests and gather any necessary attachments for organizations that might donate to your event
- Help approach potential donors and prepare sponsor materials
- Assist in putting together requests for workplace giving programs
- Follow up on a lead to a charitable foundation that might donate to UMDF

WHAT YOU CAN DO FOR THE DEVELOPMENT DEPARTMENT

- Inquire at your workplace about programs that match gifts or volunteer hours
- Write UMDF on your workplace giving pledge card (i.e. United Way or Community Health Charities)
- Let us know if you hear of any grant opportunities in your area



WOMAN INTERRUPTED?

(cont. from page one)

"I found the people so inviting, and it was just so nice to talk to people who understood the challenges of everyday life," Therese said. "I understand this disease seems to be more common in children, so to meet affected adults was comforting."

Therese found that involving herself in the chapter and being positive about the disease gave her hope for the future and made a big difference in her mental and physical well-being. After deciding to be more involved, Therese was elected chapter president in May 2007.

"I couldn't be more honored," she said. "It's like a full-time job. I seem to be on the phone many hours a day, and I receive at least 10 e-mails a day from people who need assistance, and I am so happy to help all of them. I have met such wonderful people since I was elected."

Since then, Therese has been able to travel across the country to attend events and meet other affected individuals and families. Her new responsibilities as chapter president have required her family to adapt again, but they recognize how important UMDF is to her.

"It is not an easy journey," she said, "but it is my journey to accept. I was once this active person who worked full time, and then one day I felt like I'd lost my identity. With the help and support of my family, the UMDF and my doctor, I will do my best. We are all given our crosses to bear in life, and I think it's about how we go about carrying that cross that makes us better people."

ATLANTA CHAPTER

- **October 1, 2007.** Fourth annual *Atlanta Chapter Golf Tournament* at The Standard Club in Duluth, Ga. Contact Chris Swinn at 404-817-0999 for details, or go to www.foreacuremito.org.

CENTRAL OHIO CHAPTER

- **October 4, 2007.** Second annual *KGWP Golf Outing* in honor of Ellie Kovalcik in Columbus, Ohio. For information, call 614-222-4888.
- **October 7, 2007.** Seventh annual *Olivia Lauren Steele Memorial Golf Outing* at Clover Valley Golf Club in Johnstown, Ohio. For information, contact J.R. Steele at 614-492-8425.

HOUSTON CHAPTER

- **October 14, 2007.** Playitstore Productions presents a special matinee production of *YOU-GO-GIRL the Musical* at 2:00 p.m. Tickets are \$40 and include a champagne and chocolate reception after the performance. For information, contact Patricia Barry Rumble at 713-784-9400 or playitstore@sbcglobal.net or visit www.you-go-girl-themusical.com.
- **October 18, 2007.** The *2007 Christopher Schindler Memorial Celebration* at The Briscoe Manor in Richmond, Texas, starting at 6:00 p.m. Activities include dinner, auctions and entertainment. For more information, contact Tanya or Joe Schindler at 281-450-5333 or e-mail cutterjoe@sbcglobal.net or tanya.campbell@sbcglobal.net.

NEW ENGLAND CHAPTER

- **October 6-7, 2007.** New England Chapter's *Weekend of Hope 5K Walk and Family Fun Zone* in Plymouth, Mass., and Longmeadow, Mass. Visit www.mitowhat.org or e-mail NEngChapter@umdf.org for information.

AROUND THE COUNTRY

- **October 6, 2007.** Seventh annual *Brayden C. Suman Mito-What? Golf Classic* at the Oaks Golf Course in Kentucky. For more information, contact Jason McGuire at jmcguire@rivercitiescourier.com or 606-324-0656.
- **October 7, 2007.** The *2007 Emily's Race for Research* at the Chicago Marathon. Emily Fischer will run in memory of Sam Juhlmann and in honor of his brother, Zach. For information, contact Emily at 414-526-2653 or efischer@vonbriesen.com, or go to www.umdf.org/raceforresearch to make a donation.
- **October 13, 2007.** Inaugural *Kure for Kat 5K Run/1-Mile Walk* at South Lakes Park in Denton, Texas, in honor of Katherine Dickens. For registration or more information, go to www.umdf.org/kureforkat, or contact Maggie Dickens at 940-382-2434 or kureforkat@yahoo.com.
- **October 20, 2007.** Inaugural *Martinis at the Mendelson* event 5:30-7:30 p.m. at the Mendelson Gallery in Pittsburgh's Shadyside neighborhood. Activities include a martini bar and diamond raffle, plus 25 percent of proceeds from artwork sold that evening will benefit UMDF. For more information, call 412-793-8077 or e-mail info@umdf.org.



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.

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GIFTS FROM THE HEART

- Thanks to Jan Litvene and Chuck Lederman of Chicago for a July donation of \$540 in wedding favors in honor of Barbara Bruck and her family.
- Our Lady of the Lake in Michigan held a fundraiser in memory of Sean Clark, raising \$353.87. Thanks to all who participated!
- Pembroke Pines Charter Elementary School in Florida held a student dress down day May 10 and raised \$145 in honor of Connor Clifton, little brother of students Donny and Mason Clifton.
- Ackerman, Link & Sartory of West Palm Beach, Fla., donated \$100 in proceeds from a weekly dress down day in honor of Michael Link of Palm Beach Gardens, Fla.
- McLaurin Elementary School in Mississippi raised \$202.85 with a *Stop Mito in Genes* casual day in honor of Jude Manley.
- Mohan's annual *4th of July Party* raised \$799 in memory of Gina Marie Mohan.
- Cloverdale Elementary School Student Council in Cloverdale, Ind., raised \$519 for UMDF in honor of Andrew Nees.
- Pat Shuker organized a *Jeans Day* at Northwood Realty in Allison Park, Pa., on May 18, raising \$80 in honor of Hannah Pallas.
- *Bonnie Klein's Traveling Craft Sale* journeyed from Wyoming to North Dakota, raising \$335 in honor of Logan Palmer. The craft sale featured handmade washcloths, pot holders, slippers and scarves.

- Jennifer Cook, stepmother to Logan Palmer, raised \$604 with a coins drive and two jeans weeks at the JCPenney Store and Salon at the White Mountain Mall in Rock Springs, Wy.



(L to R) JCPenney participants Brittany Rasmussen, Kria Morrison, Jennifer Cook and Sue Stackey with Logan Palmer (front)

- Jerry & Marleen Davis celebrated their wedding by donating \$825 to UMDF in honor of Carly Platt. Thanks, and congratulations!
- Guests of Carly Platt's Bat Mitzvah in July donated \$250 to UMDF in lieu of gifts.
- The *Rosenthal Birthday Party* in July raised \$300 in honor of Jake Rosenthal of Indiana.
- The *Silpada Jewelry Party* held May 1 in Arizona raised \$925 in honor of Derek Swanson.
- Chad & Maria Inman donated \$75 in proceeds from the "dollar dance" at their wedding in honor of Baylee Thompson.
- The *Wojciechowski 10th Birthday Party* May 21 in West Kingston, R.I., raised \$420 in honor of Haley Wojciechowski.
- Upon the passing of John Lennon Sr., a beloved family member of Josephine Wells, his children asked that family and friends donate to the UMDF in lieu of flowers. Special thanks to the family for this kind gift.
- A Michigan Valueland store raised \$50 selling energy for life bracelets in honor of BJ Young.
- A *Fine Arts Night & Bake Sale* in Oswego, Ill., organized by Cali D. Bonie raised \$1,240 in honor of Abigail Kasuba.
- St. Matthew's Church raised \$70 with a *Penny Lineup*.



Klein's Traveling Craft Sale

ONGOING FUNDRAISERS

COINS FOR A CURESM

The following families participated in the Coins for a CureSM campaign and sent in funds raised in the month of July:

- The Davis Family
in honor of Carly Platt
- The Mohan Family
in honor of Michelle Mohan
- The Mott Family
in honor of Alyssa Mott
- The Rivera Family
in honor of Rosendo Robles
- The Ursiny Family
in honor of Scott, Brittain, Caleb, Jessy & Nikolas Ursiny

TEA FOR MITOSM

The following families participated in Tea for MitoSM and sent in funds raised in the month of July.

- The Dunn Family
in honor of Charlie Dunn
- The Goetzinger Family
in honor of Stephen and Samuel Bukovac
- The Armfield Family
in memory of Michelle Armfield
- The Lubelczyk Family
in honor of Peter Lubelczyk and in memory of Andrew Lubelczyk

A special thank you to all of these families and to the families who are still participating in Coins for a CureSM and Tea for MitoSM!

For information about how you can become involved, contact Tania at 888-317-UMDF or taniah@umdf.org.

FROM PAGE ONE

'MITOCHONDRIAL MEDICINE 2007' (cont. from page 5)

~ I arrived home with the information to move forward in my daughter's care. I feel like I understand the disease a lot more, and I am encouraged that we are not alone. I love knowing there is a network to navigate this journey, as different as it is for all of us.

~ I attended the symposium in San Diego, and I learned so much and met terrific, devoted doctors and researchers. It was amazing. The families are incredibly strong, and I think we all encourage each other. I felt such a warmth being there, and seeing how we all just accept it, live with it, fight it and continue to live our lives.

FRIDAY NIGHT LUAU AND AWARD PRESENTATIONS

On Friday night, scientific and family attendees alike gathered for a luau celebration complete with island-themed food and entertainment. After the banquet was complete, awards were presented to the 2007 grant recipients and the winners of the *Heartstrings* and *LEAP* awards. At the conclusion of the awards ceremony, guests were treated to Polynesian music, drumming and dancing, with songs and dances from Tahiti, Hawaii, Samoa and New Zealand. The performers had many costumes to reflect the different cultures of Polynesia, and there were even some audience participation numbers!



LEAP AWARD

Living, Encouraging, Achieving & Persisting

This award was created to recognize an individual age 14 years or older living positively with mitochondrial disease, highlighting the person's accomplishments and volunteer service. The individual should demonstrate a positive attitude, hope for a brighter future and an enthusiasm that inspires others.

This year's recipient is Jamieson Smith (*below*), a sophomore at Shawnee High School in Medford, N.J. Jamie was diagnosed with a mitochondrial disease in 1999 and has had many health struggles since his diagnosis, but each time he overcomes them with a positive attitude and a unique energy for life.



Despite being hospitalized every 21 days for IVIG therapy, Jamie is living life to the fullest. He is involved in UMDF not only as a youth ambassador, but also as a member of the Delaware Valley Chapter board. He recently testified in support of the New

Jersey Mitochondrial Disease Awareness Week legislation, which was passed in June. Jamie is also active in several school and church activities, is an honor student and was February 2007 Student of the Month.

Above all, Jamie cares deeply about finding a cure for mitochondrial disease, not only for himself but for his friends who are also affected.

HEARTSTRINGS AWARD

Recognizing a youth commitment that tugs on the heartstrings

This award was created to recognize a child or teen who has donated or raised funds for UMDF, enabling UMDF to continue its mission. The winner is chosen based on related criteria of age, time invested, talents demonstrated, effectiveness and generosity.

This year we have two honorees -- sisters Ashley and Brittany Wilkinson (*right*). Brittany, UMDF's first youth ambassador, is a courageous young lady who doesn't let the weeks or months she spends in the hospital keep her from working on her fundraising events, making calls, dictating letters and talking to everyone who comes into her room about what she is doing and why. After raising more than

\$16,000 in one year, Brittany is working hard to go nationwide this year!

Her older sister Ashley is also living with mitochondrial disease, but she doesn't let that stop her from walking door-to-door to pass out flyers for her sister's events. She even sings at the dinners, performs with her sister and gives speeches to classrooms, despite trips to the hospital three times a week for four-hour infusions. These young ladies are an inspiration and are very deserving of this award!



JACK BLACK VISIT AND CONCERT

As a perfect finish to the 2007 symposium, UMDF hosted a benefit concert at the San Diego House of Blues featuring Tenacious D.

A couple of hours before the concert, Jack Black made a surprise visit to the hotel to meet some of our mito families. Dozens of children and adults waited patiently as Jack met each family, autographed photos



from his movies and posed for pictures (*left, with Jude Manley*). The autographs, each on different pictures, were all personalized with names and individual messages.

After the concert, Jack and bandmate Kyle Gass hosted an art auction in the VIP room and surprised everyone at the end of the night when they auctioned themselves for dinner! The evening raised nearly \$50,000 for UMDF! Thanks to Jack and Sharon Shaw for making this event possible.

ADULTS MEET IN SAN DIEGO

A welcome addition to this year's symposium was the first Mito Adults Gathering, which was held Saturday morning.

Adults from all over the country took this opportunity to get to know each other and share their concerns. With more than 32 attendees, it was obvious that mito adults are not alone!

The meeting was ably hosted by Gail Wehling, a member of the Chicago Chapter board and Pam Johnson, president of the Kansas



Pam Johnson, above with Dr. Howard Zucker at the symposium

City Chapter and chapter liaison to the UMDF board of trustees. Both Gail and Pam are also affected adults and understand the challenges faced by adult mito patients.

Many members shared their experiences, tips and ideas for managing life with mitochondrial disease. The group also took the opportunity to share their needs and offer suggestions on how they may be better addressed by the medical community. A member of the UMDF staff was also available to answer members' questions. Plans are underway to make this type of meeting a permanent addition to the annual symposium.

The Adult Advisory Council Team (AACT) also had a meeting at the symposium. The AACT's purpose is to represent and serve the affected mito adult community and to work hand-in-hand with UMDF on all adult-related issues of interest. This committee will consider feed back from the Mito Adult Gathering as it provides input for UMDF plans.

CALLING ALL MITO ADULTS!

Mitochondrial News Needs YOU! Please consider submitting an article on your experiences with a specific topic that would be of interest to other mito adults. If you want to contribute, please contact UMDF at info@umdf.org or 888-317-UMDF. We look forward to hearing from you!

'TY'S STORY' PRODUCER WINS EMMY AWARD

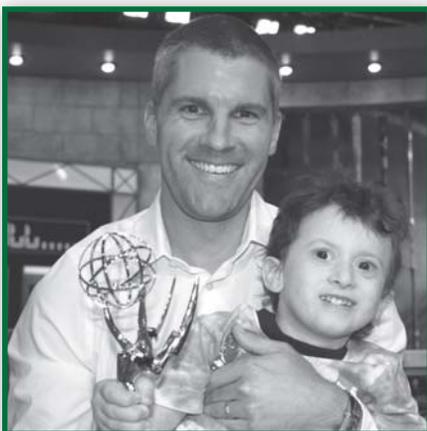
When television producer Brian Parker learned about Ty Seldes' struggle with mitochondrial disease, he agreed to produce a segment for his show TBS STORYline, a venue for dynamic, in-depth stories that address relevant issues in the Atlanta market.

The segment, which originally aired in April 2006, highlighted the need for mitochondrial disease awareness by including interviews with Ty's family and Dr. John Shoffner of Horizon Molecular Medicine in Atlanta.

"Ty's Story" was awarded the 2007 Southeast Regional EMMY Award for outstanding achievement in the health and science category. When Brian accepted his award for the production, he stressed the importance of spreading the word about the disease and supporting mitochondrial disease research.

Ty will receive his very own personalized EMMY Award for his outstanding performance and contribution in creating awareness for mitochondrial disease.

The award-winning story can be viewed at www.tystrot.com by clicking on the NEWS menu.



Ty Seldes is pictured above with Brian Parker, who won an EMMY Award for 'Ty's Story.'

2007 DRESSED FOR MITO AWARENESS

"What are YOU?"

That's the question we're hoping to hear around the country this Halloween during the *Dressed for MITO Awareness* campaign.

Join other mito-affected families who are donning mitochondria costumes and T-shirts this October for Halloween parties, harvest activities or trick-or-treating. If you wonder what your answer might be to a "What are YOU?" question, we can provide brochures with your child's photo to explain mitochondrial disease.

Several pre-ordered mitochondria costumes include John Deere (green or pink), Spiderman (red with blue matrix) and college sports teams (LSU purple with yellow matrix). Be creative and ask for a personal touch to your costume!



To order mitochondria costumes online, visit www.umdf.org/dressedformitoawareness. Proceeds will benefit the United Mitochondrial Disease Foundation. For more information, contact Julie Manley at 601-824-1541 or go to www.savejude.com. Volunteers are needed to sew costumes. Please let us know if you are able to help!

In conjunction with this campaign, consider participating in a Halloween casual day! UMDF will provide simple instructions, posters, stickers and handouts for mito awareness. Ask your boss, principal or administration if you can dress down for mito awareness. Call 888-317-UMDF or e-mail info@umdf.org for more information.

MEMBER RESOURCES

LOOKING FORWARD TO SERVING YOU...IN A NEW ROLE

Dear Members,

Since 1997, the United Mitochondrial Disease Foundation has been an integral part of my life and continues to be a passion for me. From marketing to member services to fundraising, I have had the privilege to work with many of our UMDF patients, families and physicians over the past 10 years – and enjoyed every moment.

On July 30, 2007, Chuck Mohan made an official announcement to the board of trustees that the UMDF had selected a new director of chapter and membership services. That “new” person will be me – Kara Strittmatter.

It is with great pleasure that I accept this position and join the UMDF member services team. I am looking forward to serving our chapters, groups, ambassadors and members from around the world, and I hope to prove myself in this new position by continuing the great work of our membership services staff and volunteers.

This move will also have an extremely positive impact on raising awareness and marketing our cause. Since I will be taking the symposium planning with me to the member services department, the new director of communications and marketing can remain focused on reaching out to the media and the public.

In the coming months, our entire staff will continue to reach out to our membership through a new-and-improved web site, e-mail blasts, chapter events and other UMDF activities occurring across the United States.

NEVER FORGET: The UMDF mission includes providing support to affected individuals and families and, with the help of our staff and volunteers, I intend to do my very best to uphold that part of our mission!
Sincerely, Kara Strittmatter

SONGS OF LOVE FOUNDATION

Looking for a personal gift for a mito kid in your life? The Songs of Love Foundation takes personal information you provide about a child you know that has had a long hospitalization and creates a CD just for him or her at no charge.

UMDF member Hilma Dragon describes her experience with Songs of Love as a great “pick-me-up” for both her and her son. “When Evan left [the hospital], the playroom volunteer filled out the paperwork that I provided, and sent it to [Songs of Love]. Evan’s song touches on family members, school teacher, therapists and favorite things he likes, or silly things he does, like spit raspberries.”

For more information, please visit www.songslove.org, or you can contact the Songs of Love Foundation by mail at P.O. Box 750809, Forest Hills, NY 11375, by telephone at 718 441-4588 or by e-mail at info@songslove.org.

ABLEPLAY

For families with disabled children, gift buying can be complicated when trying to find the right toy for the special needs child in their lives. With winter holidays fast approaching, a reliable new resource was recently introduced by AblePlay to help parents, relatives and family friends find the right toy match.

Each toy is rated in four disability categories -- cognitive, communicative, physical and sensory. Ratings are awarded in each category on a scale of zero to five stars, with the number of stars representing the depth of accessibility, appropriateness and overall use of a particular item, from exceptional to not suitable.

Lekotek toy and play experts put each product through a rigorous evaluation process before calculating a rating and posting it on the AblePlay website. AblePlay evaluators assess each toy with five to eight children of varying abilities during at least five to eight play experiences. In addition to quantifiable data, both parent and child observations and evaluator comments are taken into account. All data is tallied and the AblePlay Rating™ is calculated.

Since so many more people are trying to streamline their holiday shopping by purchasing online, visitors to www.ableplay.org can purchase toys online directly from manufacturers after reading the Comprehensive Product Reviews. Happy holidays!

VACATION TOWARD A CURESM

A special thanks to our mito families and friends for their support of the 2007 Vacation Toward a CureSM raffle to raise funds for mitochondrial disease research. In 2007, more than \$25,000 was raised through this national fundraising event. Congratulations to the winners!

- **1st Prize:** Patrick Kelly, Chicago, Ill. Round trip air transportation for two to New York City and two-night accommodations in Midtown. Trip includes a midweek tour of the Fox News Studio, admission to a taping of “The O’Reilly Factor” and a meet and greet with Bill O’Reilly.
- **2nd Prize:** Charles Modispacher, Pittsburgh, Pa. \$500 in Visa Gift Cards and a travel kit.
- **3rd Prize:** Mary Ann West, Sulphur, La. A \$100 gift card to Darden Restaurants (valid at Olive Garden, Red Lobster, Smokey Bones or Bahama Breeze).

MARK YOUR CALENDARS NOW FOR

INDY 2008



Setting the Pace In Mitochondrial Medicine

Hyatt Regency • Indianapolis, IN
June 25-28, 2008

Course Co-chairs: Salvatore DiMauro, MD, and Bruce H. Cohen, MD.
Call 888-317-UMDF or visit www.umdff.org for more information!

WE'D LIKE YOUR FEEDBACK!

At UMDF, we strive to deliver a newsletter that is useful and informative for our membership.

In order to better serve *you*, we ask that you please take a few moments to fill out the following survey and return it to us by October 31, 2007.

Feel free to return the completed survey in the enclosed postage-paid envelope or mail to: UMDF, 8085 Saltsburg Road, Suite 201, Pittsburgh, PA 15239. The survey can also be completed online. Visit www.umdff.org for the link!

Thank you in advance for your help!

-
- Gender: Male Female
 - Relationship to mitochondrial disease (check all that apply):
 Parent of Mito child Dx Date: _____ Patient Age: _____
 Mito Adult Dx Date: _____ Patient Age: _____
 Relative/friend of affected member? Dx Date: _____
 - What is your level of interest in the foundation's newsletter?
 High Medium Low
 None Undecided
 - The newsletter is my main source of medical information about mito.
 True False
 - I find the main articles relevant to my particular situation.
 Always Usually Occasionally
 Rarely Never Undecided
 - What is your level of interest in the "Chapter Activities" section of the newsletter?
 High Medium Low
 None Undecided
 - How important to you is receiving the newsletter on a regular basis?
 Very Important Somewhat Important
 Somewhat Unimportant Very Unimportant
 Undecided
 - How satisfied are you with the layout of the newsletter?
 Very Satisfied Somewhat Satisfied
 Somewhat Dissatisfied Very Dissatisfied
 Undecided
 - How satisfied are you with the quality of the articles?
 Very Satisfied Somewhat Satisfied
 Somewhat Dissatisfied Very Dissatisfied
 Undecided
 - How satisfied are you with the overall content?
 Very Satisfied Somewhat Satisfied
 Somewhat Dissatisfied Very Dissatisfied
 Undecided
 - How satisfied are you with the timeliness of the information presented in the newsletter?
 Very Satisfied Somewhat Satisfied
 Somewhat Dissatisfied Very Dissatisfied
 Undecided
 - How satisfied are you with the practicality and helpfulness of the information presented in the newsletter?
 Very Satisfied Somewhat Satisfied
 Somewhat Dissatisfied Very Dissatisfied
 Undecided
 - How satisfied are you with your ability to submit information or articles for inclusion in the newsletter?
 Very Satisfied Somewhat Satisfied
 Somewhat Dissatisfied Very Dissatisfied
 Undecided
 - How much do you agree or disagree that the issues covered are important to UMDF members?
 Strongly Agree Somewhat Agree
 Somewhat Disagree Strongly Disagree
 Undecided
 - What information or sections, if any, would you like to see included in the newsletter in the future?

 - What sections, if any, do you think should be removed from the newsletter?
 Adult Corner Ask the Mito DocSM
 Board Spotlight Chapter Activities
 Fundraising Highlights Member Resources
 News & Announcements Other: _____
 - I would like to read more about:
 How to live, work and play with mitochondrial disease
 Mito education Mito research
 More medical articles School related topics
 - I feel the newsletter effectively provides information important to the overall needs of the members.
 True False
 - When I'm finished reading the newsletter, I save it for future reference.
 True False
 - Overall, how satisfied are you with the regular newsletter?
 Very Satisfied Somewhat Satisfied
 Somewhat Dissatisfied Very Dissatisfied
 Undecided

ANNOUNCEMENTS

NEW TOLL-FREE NUMBER FOR UMDF

The UMDF National Office now has a toll-free number available to all U.S. residents. The headquarters can now be reached at 1-888-317-UMDF (8633) or at 412-793-8077.

MITOCHONDRIAL DISEASE AWARENESS WEEK

Are you interested in raising awareness in your state about mitochondrial disease? One of the ways you can help is to lobby for a Mitochondrial Disease Awareness Week in your state.

In most states, this can be done by proclamation for one year, with the potential for annual renewal, but the **best possible option** is to have the third week of September permanently designated as Mitochondrial Disease Awareness Week through legislation.

Several UMDF members have been successful in their efforts to have the third full week of September permanently designated Mitochondrial Disease Awareness Week in the state of New Jersey. Highlighting the week are Coins for a CureSM campaigns, information tables at local malls and hospitals and various fundraisers. There are efforts underway in several other states to pass a law permanently establishing the third week of September as Mitochondrial Disease Awareness Week. In addition, UMDF members have been successful in securing one-time proclamations from governors in Georgia, Washington and Massachusetts.

You can join the effort! Contact UMDF at 888-317-UMDF or e-mail info@umdf.org to request a packet of information. Wouldn't it be wonderful to see every state designate the third week of September as Mitochondrial Disease Awareness Week?

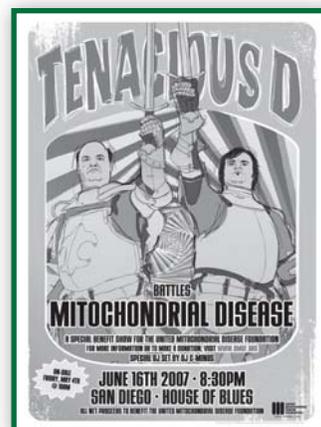
UMDF MERCHANDISE

UMDF merchandise is a great way to raise awareness and to support UMDF and all those affected with mitochondrial diseases. The UMDF LogoShop is now open for business! This online store will sell UMDF logo merchandise, all to benefit the work of the Foundation. Branding Solutions, the business of UMDF member Rob Platt, whose daughter is affected, is our partner in this project. Please visit the shop at www.umdf.bsilogoshop.com. Many new products as well as some old favorites will be offered.

TENACIOUS D BATTLES MITOCHONDRIAL DISEASE

If you didn't get your t-shirt and poster from the Tenacious D benefit concert at the San Diego House of Blues, this is your **LAST CHANCE!** UMDF snatched the remaining inventory, and now *you* can take advantage of this limited opportunity!

T-shirts are black with vibrant-colored imagery (*pictured right*) and are available in Youth, Adult and Girls' sizes. At \$20 each, they are a steal! The event poster featuring the same image is just \$15 and looks great framed! Contact the UMDF LogoShop to place your order while supplies last!



SUBMISSION DEADLINE FOR ISSUE 4 IS OCTOBER 31, 2007!



UNITED
MITOCHONDRIAL
DISEASE
FOUNDATION®

HOPE. ENERGY. LIFE.

IN THIS ISSUE:

Miss this year's symposium?
Read page 1!

Trouble with muscle pain?
See page 3!

What's new in my area?
Check out pages 4-7!

UMDF is dressed for success!
Find out more on page 9!

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