

SCIENTIFIC AND PSEUDOSCIENTIFIC THERAPIES

*Steven G. Bassett, Ph.D.,
and Jean C. Bassett, R.N.*

It's an unfortunate and all-too-common story: someone has been diagnosed with a disease for which conventional medical treatments have mostly proven ineffective. No surprise if he or she then turns to any therapy that offers hope, however radical or bizarre it may seem.

Such alternative treatments are often discovered through word of mouth, media advertisements or the internet.

Unfortunately, because the average person does not have the medical background to cut through the scientific-sounding jargon, he may not be able to discern whether the treatment being touted is scientifically sound or is actually a pseudoscientific quack remedy.

Furthermore, if the patient has lost faith in the established medical community, he may actually consider it a plus that the radical therapy goes against the grain of accepted medical practice.

Because pseudoscientific therapies are widely available, this article will attempt to educate our mito families about what to look for when reading descriptions of unorthodox treatments. **No single pseudoscientific therapy has all of these characteristics, but if one or more is present, be skeptical!**

CHARACTERISTICS OF PSEUDOSCIENTIFIC THERAPIES

The following list was adapted from a classic work on this topic: *Science and Unreason* by Daisie Radner and Michael Radner.

- **"Pick-and-choose" approach to evidence.** Purveyors of alternative remedies often pick and choose only the evidence that supports their treatments. Opposing evidence is ignored or simply does not change their minds. **Scientists, however, take into account all data obtained under controlled conditions.** And they do not allow themselves to ignore contradictory evidence when reaching a conclusion.

- **Use of anecdotal evidence or testimonials.** Today's alternative medicine web sites are full of testimonials from individuals who were helped

by the treatment being promoted. While there is nothing sinister about a friend recommending a product such as a headache remedy, it is very different when a company

justifies its health products based primarily on customers' unsubstantiated testimonies, which could be fictitious. Even if such testimonies are true, they are not the results of controlled scientific studies. What other outside factors may have contributed to the positive outcome of the treatment is unknown. Also, negative testimonies from unsatisfied customers who write to say the product didn't work go unreported.

(continued on page 11)

**ONE MARK OF A TRUE SCIENTIST IS
THAT HE IS WILLING TO REJECT HIS
HYPOTHESIS IF IT PROVES WRONG
WHEN TESTED.**



***Tina Withum (right),
pictured with Dr.
Amy Goldstein of
Children's Hospital
of Pittsburgh at the
Pittsburgh UMDF
5K Run / 1-Mile
Walk June 2 at
Pittsburgh's North
Park.***

***See pages 4-8 for
more events and
fundraisers!***

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BOARD SPOTLIGHT

In this issue of *Mitochondrial News*, we are pleased to spotlight Richard W. Kubach Jr., a UMDF trustee who recently took on the role of treasurer. An extremely committed individual, Richard would never have considered getting involved with the foundation unless he saw value in its mission.



Richard has been a dynamic member of UMDF for several years, serving as chair of the planning and marketing committee for nearly two years. He was a catalyst for jump-starting this committee in 2005, and during his tenure as chair, the foundation launched into a new era, with an innovative

volunteers through several strategic planning sessions and continues to be a true asset in planning for the future.

A former president of the Pennsylvania Restaurants Association, Richard brings with him a wealth of knowledge in professional associations, management and strategic planning. He was named Restaurateur of the Year in 1994 by the Pennsylvania Restaurants Association. He is a former director of the National Restaurants Association and currently serves as the director emeritus of the organization.

His Melrose Diner in Philadelphia received the Psychologically Healthy



Workplace Award from the American Psychological Association in 2001 for his efforts to foster employee health and well-being while enhancing organizational performance and productivity. The diner was one of only 15 businesses nationwide and the only restaurant to be recognized as one of the best places for people to work.

Richard's proudest moment, though, came when he recently became a grandfather for the first time! Congratulations to the Kubach family!

From all the staff, board and volunteers, UMDF would like to thank Richard for all his hard work and his outstanding support of our mission!



logo, tag line and comprehensive identity manual to ensure the proper branding of UMDF.

He currently serves on several board committees, including the executive, finance and chapter committees, and has taken an active role with all three. He also worked diligently with the UMDF board, staff and

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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.

UNITED MITOCHONDRIAL DISEASE FOUNDATION
HOPE. ENERGY. LIFE.



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* on 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: Annette Feigenbaum, MD, FRCP, of the Hospital for Sick Children, Toronto, Ontario; Sumit Parikh, MD, of the Cleveland Clinic; Greg Enns, MD, ChB, of the University of California, San Francisco; and Michio Hirano, MD, of the Neurological Institute, New York.

THE QUESTION IS...

My daughter is 20 months old and has recently been diagnosed with mitochondrial encephalomyopathy with a complex I defect. They are not sure if she also has a pyruvate dehydrogenase defect and are still trying to sort out if her complex I is primary or secondary. We are having difficulty getting weight on her even though she seems to have a good appetite. I know some disorders respond better to certain diets. Should she be on a high carb diet, a high protein diet or a high fat diet? How about a ketogenic diet? Any suggestions you have would be great.

RESPONSE FROM ANNETTE FEIGENBAUM, MD, FRCP:

The dietary therapies in mitochondrial diseases need to be individualized. Some children respond better to high fat and others to high carb. The only good rule is that if there is PDH deficiency, a ketogenic diet does help with metabolic control. Ensuring adequate calories with all nutrients is most important as well as feeding at regular intervals without too much time between feeds,

even overnight. Arrange this with the help of a dietitian. Many children with mito diseases have a much-increased caloric requirement than would be expected, even if they are less active, as their metabolic rate may be high. This can be assessed by doing indirect calorimetry testing. For complex I deficiency, I have used higher fat diets in the range of 70 percent fat with good results regarding weight gain, even if metabolic state is unchanged. I hope this helps.

THE QUESTION IS...

I have a four-year-old son with mitochondrial encephalopathy, complex I. He was diagnosed when he was 20 months old. Since then, he was started on the mitochondrial cocktail, and it has improved his life dramatically. He is now 46.5 pounds, and at this point, his cocktail consists of CoQ10 (15 ml bid), Levocarnitine (3 ml bid), Riboflavin (5 ml a day), Vitamin C (2 1/2 ml tid) and Vitamin E (15 ml-50 units/ml). Here is my concern: I just received my Science Annual 2006 (Heritage Family Library-Southwestern), and on page 248, there is an article titled "The dangers of vitamin E." Researchers at Johns Hopkins Medical Center in Baltimore reported in November 2004 that people who routinely take high doses of vitamin E supplements may have an increased risk of dying from all causes. The researchers cautioned that most of the participants in the trials were over age 60 and had such pre-existing conditions as heart disease or cancer. Based on the study results, however, the team recommended that people avoid vitamin E supplements containing more than 400 IUs. I know that my son is a unique case in that he has mitochondrial disease, but I'm wondering if this is something we should be concerned about.

RESPONSE FROM SUMIT PARIKH, MD:

Simply put, we do not know all of the risks and benefits (if any) of anti-oxidant therapy in patients with mitochondrial disease or in unaffected individuals. While we feel that most of the supplements are 'safe,' there has been no hard scientific evidence to allow us to make this conclusion with medical certainty. Knowing that these medications are mostly safe, and not having other definitive treatments for mitochondrial disease, many physicians use the medications in the 'mito cocktail' with the hopes that they will mostly help. All of us who treat mitochondrial disease have seen remarkable gains in some patients on carnitine, coenzyme Q10 and the other cocktail drugs.

To answer your specific question, the study

you are referring to was looking at a very different population, and the results should not be extrapolated and applied to mitochondrial patients. That being said, large doses of vitamins, including Vitamin E, can have some neuro-toxic effects. The doses your son is on are not considered sufficiently large enough to be toxic, based on what we currently know. We do not have adequate medical evidence to determine if long-term use of these vitamins is potentially harmful.

THE QUESTION IS...

I don't know if this is normal or not, but here it is: my seven-year-old son constantly holds his breath. He does this several times a day. I don't know why he does this. He doesn't speak, so he cannot tell me why. Is this something I should be concerned about? Could it have something to do with a mitochondrial disease?

RESPONSE FROM GREG ENNS, MD, ChB:

Breath-holding spells are relatively common in young children and typically start between six to 12 months of age. Although these spells usually end by about three years of age, children can have them up to seven years. Such spells, especially if isolated, are not particularly concerning for mitochondrial disease. It is very important to evaluate children who have such spells, especially at a relatively late age, for other underlying problems, including seizures, central and obstructive apnea or a heart condition.

THE QUESTION IS...

I am a newly diagnosed adult with mitochondrial myopathy primarily affecting my respiratory function and fatigue. My neurologist suggested taking CoQ10 200mg per day and L-Carnitine 1000 mg per day. I am having a terrible time tolerating the side effects of carnitine, primarily nausea and headaches. I have tried hard caps, gel caps, emptying powder from gel cap, but stopped each after 3-4 days. Any suggestions? I couldn't even tolerate 250mg at a time.

RESPONSE FROM MICHIO HIRANO, MD:

L-Carnitine often causes gastrointestinal symptoms including nausea, vomiting and diarrhea. In addition, patients sometimes develop a fishy body odor. The side effects are often worse with high doses of L-Carnitine; therefore, I suggest you start taking the lowest tolerated dose. The dose can be increased gradually. In addition to pills and gel-cap preparation of L-Carnitine, there is a liquid form, which is preferred by some patients.

CHAPTER ACTIVITIES

ATLANTA AREA CHAPTER

PRESIDENT: CHRIS SWINN 770 270 5337 AtIChapter@umdf.org

• **March 12-16, 2007.** The Beta Club at Lanier Middle School hosted an awareness fundraiser in Roswell, Ga. Students sold UMDF energy bands to help create awareness of mitochondrial disease. More than \$1,700 was raised for UMDF in honor of Anna Lewis!

• **April 2007.** At the Frank H. Osborne Middle School in Hoschton, Ga., sixth grade gifted and honors students participated in a fundraiser in memory of Jake Lyons, who passed away April 7, 2007, from Leigh's disease. These incredible students (155 students in sixth grade) raised \$1,350 for UMDF. Some of these students went door to door in their neighborhoods, some raided their piggy banks and some gave up their ice cream money for a week. The class that raised the most money received a large bag of candy to share. Many thanks to all who participated!



Back Row (from left): Steven Clark, Michelle Jones, Teena Luce, Shannon McClure, Emily Lyons, Rebecca Harrington, Lori Wimmer, Jim Dew; Front Row (from left): Garnett Glaser, Rachel Blough, Karen Celis.

• **April 27, 2007.** Dare to Share, a Georgia-based charity, held their *Put a Sparkle in Their Eyes* gala at the Chattahoochee Country Club in Gainesville, Ga. Guest celebrity and Dare to Share board member Ivan Sergei attended and met with several UMDF Atlanta Chapter families. Partial proceeds from this event will benefit UMDF. Thank you to all at Dare to Share for holding this event and for supporting our mito families!



(From left) Bernard & Leslie Reynolds, Mary & Chris Swinn, Actor Ivan Sergei, Stacy & Colin Coburn at Dare to Share event.

• **April 28, 2007.** The third annual *Race for Riley* was held in Palmetto, Ga. Emily Swinn spoke to the crowd about the UMDF. Proceeds of nearly \$1,000 from the silent auction went to UMDF. Thank you to event organizers Waynette and Rodney Peek!

OHIO CHAPTER

PRESIDENT: BILL HODGES 330 929 4430 OHChapter@umdf.org

• **March 4, 2007.** The fourth annual *Guest Bartender Night* was held at Main Street Grill & Pub in North Royalton, Ohio. Guest bartenders were Diane Kobunski and Anita Ripepi. John & Diane Kobunski organized a great night filled with friends and fun that raised more than \$3,000 in honor of Kyle Kobunski.



• **May 12, 2007.** With record attendance, the Ohio Chapter raised, at last count, \$194,000 for mitochondrial disease research at their 2007 *Run Wild for a Cure 5K!* The total is expect to climb over \$200,000 as late pledges and matching corporate donations continue to come in. In the past six years, the Ohio Chapter has raised almost \$1 million to help children and adults affected with mitochondrial disease, and we couldn't have done it without YOU!



Very special thanks to KFC, the Cleveland Clinic, the Cleveland Browns and ALL the sponsors. Thanks also to the Cleveland Metroparks Zoo, Hermes Sports & Events, Cleveland Browns players and celebrity starters Ryan Pontbriand and Isaac Sowell, the terrific entertainers (all of whom donated their services), the Radio Disney Street Team and especially every amazing volunteer, without whom such a great morning would not have been possible. Finally, a special shout-out goes to our honorary chairperson Dr. Bruce Cohen, whom we just can't honor enough!



S. CALIFORNIA CHAPTER

PRESIDENT: STEVE GROSSMAN 858 202 1304 SCalChapter@umdf.org

- **March 4, 2007.** The goal — 26.2 to a Cure! Kyle DeVriendt ran the Los Angeles Marathon to raise funds for UMDF and awareness of mitochondrial disease and to honor his nephew Connor who is affected by mitochondrial disease. Thanks for all your hard work!
- **May 2, 2007.** UMDF received 25 percent of food proceeds from the Mission Valley location of Chevy's Restaurant from 5 p.m. till 8 p.m. on Wednesday, May 2! Thanks to all who helped to organize this event!
- **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 benefits UMDF, the Dystrophic Epidermolysis Bullosa Research Association of America and Camp Wonder. For more information, e-mail tami.monson@gmail.com.
- **May 30, 2007.** The Fogel family hosted a Chick-Fil-A benefit night at the Crossings in Corona, Calif.

The benefit was held from 5-8 p.m. For any customer mentioning Taryn Fogel or UMDF, Chick-Fil-A donated 20 percent of the sale to UMDF in honor of Taryn.



(From left) Heather Ilizaliturri, Taryn Fogel and Shawn York.

NOTES FROM ALL AROUND

DELAWARE VALLEY CHAPTER

- **April 21, 2007.** The annual *Cheers to You, Hope to Others* wine tasting sponsored by Chris & Sharon Kindbom was held in Medford, New Jersey, to benefit the Rachel Kindbom Angel Ray Research Fund. The Kindboms have raised close to \$100,000 for UMDF in three years.



Rachel Kindbom

INDIANA CHAPTER

- **April 20, 2007.** The inaugural *Green Gala* event in honor of Riley Henderson at the Indiana Historical Society was hosted by Tracie Wells, former FOX 59 news anchor, and featured a family film by award-winning filmmaker Dan T. Hall. A short documentary about Riley and her family was also previewed during the evening. Thanks to Sarah Mynett for making this event happen.

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!

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!

NEW YORK METRO CHAPTER

- **May 6, 2007.** The annual *Mito Run for Hope* was held at Montowese Elementary School in North Haven, Conn., in honor of Nicholas Pisani. Activities included a kids' run, a 1-mile fun run and a 5K race and fitness walk.

WELCOME NEW ATLANTA BOARD MEMBERS!

The slate of new officers was voted in unanimously as follows:

Chris Swinn (Pres.)	Mary Swinn (Sec.)
Katy Lyons (Treas.)	Richard Sheinis
Corey Williams	Nadine Mancuso
Stephanie Shapiro	Dr. Jeff Tucker
Dr. Renee Renfus	Judy Rachau
Bernard Reynolds	

Special thanks to Mark Reich, who recently stepped down from the board as he will be on sabbatical for a year.

WELCOME NEW DEL VAL BOARD MEMBERS!

UMDF would like to welcome the following twelve board members to the Delaware Valley Chapter!

Therese Garvin (Pres.)	Beth Ann Hartman (VP)
Anthony DiPietro (Treas.)	Sarah Byrne (Sec.)
Janet Blosky	Lisa Polsky
Maripat Shelly	Pat Shelly
Joanne Kratz	Michael Malavasic
Jamieson Smith	Laurie DePaolo

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For more information about a chapter, group or ambassador near you, contact the UMDf office at 412-793-8077!

MITO FACTS

- There are more than 200 inherited diseases of metabolism that are known to affect the mitochondria.
- A child with a mitochondrial disease is at highest risk for neurological and organ damage during and two weeks after an illness.
- Many children with mitochondrial disease are misdiagnosed with atypical cerebral palsy, various seizure disorders and other various childhood diseases.

'WHEN SHE SMILES, I SMILE' *A Day in the Life of the Pulliam Family*

Whether it's from being tickled by her daddy or hearing the delightful noises that come from strumming her fingers over a vent in the hallway of her family's home, it's a look that melts hearts.

It's those smiles that Norman Jr. and Donna Pulliam look forward to each day as they care for their four-year-old daughter, Caroline, who suffers from mitochondrial disease.

Information on the Internet largely refers to mitochondrial disease as an "invisible disease" that's often misdiagnosed and very much misunderstood. But according to the United Mitochondrial Disease Foundation, the body is made up of mitochondria, which produce 90 percent of the body's energy. When it's affected by the disease, the body is unable convert food into energy that helps sustain life.

The disease usually affects at least three organs, and typically the most affected parts are the heart, brain, muscles and lungs, which need the most energy. Unfortunately, there's no cure.

But the Pulliams prefer to focus on the positive – Caroline.

Each week, a physical therapist, occupational therapist, speech therapist and preschool teacher come to the house to work with Caroline.

A DAY IN THE LIFE

On a recent Monday morning, Caroline slept in a little later than usual.

"She's been doing her princess sleeping this morning," said Donna, as she walks into Caroline's room to wake her. She explains that, during the evening, Caroline was sick and had been up off and on during the night, so her parents decided to cancel her therapy that morning.

Donna kisses the sleepy, dark-haired girl and tells her "Good morning."

"Give her about 20 minutes and she will be laughing and smiling," Donna says, quickly changing her out of her pajamas and getting her ready for a bath.

Caroline splashes a little as her mom washes her hair.

"She usually loves bath time," Pulliam said, as

she rinses her hair. "She loves swimming pools, too."

She lifts her from the water to wrap her in a towel, then takes her to the changing table to get her ready for the day. A very patient



Caroline tugs at the cord of the hair dryer as her mother dries her hair.

"If she had all of her energy, she'd be a pistol," Donna said. "She's got spunk."

Because Caroline is hearing-impaired, she's missed most of the conversation around her and about her during the past 20 minutes, but don't think for a moment she

hasn't been watching all of what's happening in front of her. Her eyes dart around until she spots her daddy.

"Daddy's not usually home at this time in the morning, is he?" Donna says to her. "She loves daddy."

Once Caroline's dressed in her turquoise dress and matching bow, Donna connects her cochlear

implant so she can hear and again tells her "Good morning."

Donna passes Caroline off to her husband and heads off to the kitchen to get her daughter's medication. Caroline takes 10 medications through a tube each day to treat her symptoms, not the disease itself. The process takes about an hour each morning and evening, as the medicine is injected slowly into the tube by syringe. While she's taking her medication, it's also time to start feeding her. Caroline is fed through a J-tube 20 hours a day.

(continued on page P3)

FROM THE CHAIRMAN

Everything we do at the United Mitochondrial Disease Foundation is a step toward the fulfillment of our mission to promote research and education for the diagnosis, treatment and cure of mitochondrial disorders and to provide support to affected individuals and families. It is the mission that keeps us focused, and it is the focus that will bring us closer to a cure.

Since its inception, the UMDF has supported nearly \$5 million in research grants, with more than \$1 million given in each of the past four years, making the Foundation one of the leading non-governmental contributors of grants focused solely on mitochondrial disease. For the 2007 grant cycle, UMDF received 211 letters of intent, a two-fold increase in interest that illustrates how the scientific community values the work of the Foundation.

Of course, without the work of everyday philanthropists like our members and their friends and families, UMDF would not be able to support these essential research projects that give us crucial new information about mitochondria and how they work. It's the everyday philanthropists that allow us to continue to fulfill our mission by organizing events big and small to help spread the word about mitochondrial disease.

Unfortunately, it is these everyday philanthropists that can become easily discouraged or exhausted by the seemingly daunting task of raising enough money or awareness to find a cure for mitochondrial disease. But what some fail to realize is that we do not have to hit grand slams every time. UMDF can make big gains with a lot of base hits!

In 2004, the UMDF funded a grant for researcher Ramon Marti, PhD, in the amount of \$33,776 – less than 5 percent of the total amount of research funds the Foundation awarded that year – to study the restoration of thymidine phosphorylase activity in MNGIE patients through platelet infusion.



This small but very important bootstrapping grant from UMDF allowed Marti and his research team to not only develop a possible treatment for MNGIE, but also to obtain a grant for three years from the Spanish Department of Health to continue their work on gene therapy. In addition, because UMDF contributed to

the preliminary studies for gene therapy in MNGIE, the Foundation will be acknowledged in future reports to be submitted for publication.

Even a medium-sized event or a handful of modest fundraisers could have funded this grant, which made it possible for the researcher to find additional funding that has, in turn, brought us closer to a viable treatment for MNGIE! So, the next time you feel like your fundraising efforts can't make a difference, just remember that even the longest journey begins with one step. And with your help, that is one step closer to a cure!

Warmest Regards,

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

Stanley Davis, UMDF Chairman

RESEARCH SPOTLIGHT - Ramon Marti, PhD

In 2004, the United Mitochondrial Disease Foundation awarded a one-year grant of \$33,776 to Ramon Marti, PhD, to study the restoration of thymidine phosphorylase activity in MNGIE patients through platelet infusion.

MNGIE causes dysfunction in the protein thymidine phosphorylase. Due to this dysfunction, MNGIE patients accumulate the toxic substances thymidine and deoxyuridine. Marti's research project was intended to test the effects of platelet infusion on these biochemical imbalances in MNGIE patients, as it may provide valuable information on the possibilities of other permanent treatments, such as bone marrow transplantation or directed gene therapy.

The first part of the study demonstrated that platelet infusions provide a transient restoration of thymidine phosphorylase activity and reduce circulating thymidine and

deoxyuridine levels. The results supported the notion that permanent restoration of thymidine phosphorylase can be useful in MNGIE patients.

After these results, the project was readdressed to do experimental studies on gene therapy for MNGIE. The team's results demonstrate that restoration of active thymidine phosphorylase reduces the toxic accumulation of thymidine and deoxyuridine in MNGIE and provides additional support to bone marrow cell transplantation or directed gene therapy as possible treatments for MNGIE. Additionally, they developed a cellular model for the experimental study of gene therapy in MNGIE.

Because UMDF contributed to the preliminary studies for gene therapy in MNGIE, Marti and his research team were able to obtain a grant for three years from the Spanish Department of Health to continue their work on gene therapy through 2009, including a

salary for the PhD student who will work on the project over this time.

Ramon Marti graduated from Universitat de Valencia in Valencia, Spain, in 1990 with a degree in chemistry. He completed his residency in clinical biochemistry in 1995 at Hospital Universitari Vall d'Hebron in Barcelona, Spain, and then worked as a professor of biochemistry in the nurses' school. He earned a predoctoral fellowship in clinical biochemistry at the same school in 1999, the same year he finished his doctorate in biochemistry from Universitat Autònoma de Barcelona. From 2000-2002, he was employed as a postdoctoral research scientist in the department of neurology at Columbia University in New York. Since 2003, he has been working as a researcher in biochemistry and molecular biology at Hospital Universitari Vall d'Hebron in Barcelona.

UNITED MITOCHONDRIAL DISEASE FOUNDATION

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CONT. FROM PAGE ONE ~ 'WHEN SHE SMILES'

Caroline was diagnosed when she was 18 months old. Her kidneys function at about 35 percent, and she is unable to crawl, walk or talk.

But that doesn't keep Caroline from getting around on her own. Six months ago, Caroline was introduced to a mobile stander, a piece of equipment resembling a vertical wheelchair. Caroline can turn herself around in it, go anywhere in the house she likes and even pop wheelies when she really wants to show off.

"I was a little skeptical when they first brought it in for her to use as part of her physical therapy, but within 15 minutes she was zooming around," Donna said.

Caroline loves to clap for herself, her parents said, and gets what they refer to

RAJ K. CHOPRA, TISHCON CORP.

Raj K. Chopra, chairman and CEO of Tishcon Corp., has always put the UMDF families first, and he and his company have been loyal supporters of UMDF since 2000.

In 2001, Chopra donated registration bags for the UMDF symposium and specifically requested that all the families be taken care of. He has continued this generosity for every UMDF symposium and has made Tishcon one of UMDF's leading financial supporters for the symposium – donating more than \$60,000 over the past seven years.

The UMDF symposium is vital in continuing the mission of the foundation – promoting research and education for the diagnosis, treatment and cure of mitochondrial disorders and providing support to affected individuals and families. For many patients and families, the symposium represents a life line, and because of supporters like Tishcon, we can continue to cast that line.

Tishcon is also a supporter of many regional events throughout the year that are held to benefit UMDF. In 2002, the company made it possible to reprint the UMDF Cookbook so it could be used to raise more funds.

Chopra is a recipient of Vitamin Relief USA's Guardian Angel Award, and Tishcon has received recognition and praise in the United States Congressional Record for their support of humanitarian programs.



"Donations to these organizations are the least Tishcon – and others in our industry – can do," said Chopra. "You can't just look for payback, but every grain of gold you part with comes back to you ten-fold."

Chopra is a leading authority on health foods and vitamin supplements in the United States. He is acknowledged to be an expert in chewable

multivitamin formulations, timed release formulations and bioenhanced supplements. He is a member of the American Pharmaceutical Association, the American Academy of Pharmaceutical Scientists and the Institute of Food Technologists. Tishcon is a corporate member of the National Nutritional Foods Association and the

American Herbal Products Association.

Raj Chopra graduated with a bachelor's degree in pharmacy from Gujarat University in India in 1965. He received his master's degree in industrial pharmaceuticals from Columbia University in 1968. He served as a teaching assistant during his stay at Columbia and was a research fellow in 1967 and 1968. He worked as the technical director at Pharmaceutical Formulations Inc. in Edison, N.J., from 1968-1977 and then went on to help found Tishcon Corp. in 1977. He served as the president and chief scientific officer from 1977-2004 and became the chairman and CEO in 1995.

as "happy hands" when she's excited. She waves her hands in the air and then turns the apparatus to head off to her room.

When she returns, Norman entertains her by helping her make music with a pillow. The repetitive slapping of the pillow makes her laugh but also wears her out.

He leans toward her. "Caroline, say mama." "Dada," she replies, before she rolls away.

Donna says most of the time, Caroline is very content, but that she does have definite opinions and can respond to things in her own way.

The Pulliams adopted a son last year and said that Caroline and he have the same sibling rivalry seen in most families. But Donna said that Andy, who's 10 months old and very active, has forced Caroline to be more active.

"She likes him sometimes, but other times she will push him away," Norman said. "I took them for a walk yesterday, and she kept her hand on his leg and patted his leg while we were walking."

Donna says it's like raising two first children, as each has different needs and different milestones to reach.

Norman laughs. "Parents of a four-year-old shouldn't have to call other people for parenting advice," he says.

But when they see Caroline smile, the sleepless night before seems forgotten.

"When she smiles," Donna said, "I smile."

Carolyn Farr Smith is the features editor at the Herald-Journal, Spartanburg, S.C. Reprinted with permission.

RESEARCH GRANTS

2007 UMDF RESEARCH GRANT RECIPIENTS

• **\$157,450** Mindong Ren, PhD, New York University School of Medicine. *Project title: Genotype-phenotype correlation and genetic modifiers in Barth Syndrome.*



• **\$118,648** Michael King, PhD, Thomas Jefferson University, Philadelphia, Pa. *Project title: Development of high throughput assays for mitochondrial respiratory chain function.*

• **\$114,189** Patrice Hamel, PhD, Ohio State University. *Project title: Molecular genetic dissection of mitochondrial complex I assembly.*



• **\$111,779** Brett H. Graham, MD, PhD, Baylor College of Medicine, Houston, Texas. *Project title: Mutant complex I in drosophila melanogaster: A novel genetic model for mitochondrial disease.*

• **\$110,000** Konstantin Khrapko, PhD, Beth Israel Deaconess Medical Center/Harvard Medical School. *Project title: Development of high throughput mtDNA sequencing for mutation detection and heteroplasmy assessment.*



• **\$100,000** Ludivine Walter, PhD, Cornell University. *Project title: Determination of the Nuclear Transcriptional Responses that Affect*



Animal Physiopathology upon Impaired Mitochondrial Respiratory Chain Function.



• **\$99,000** Paul Cobine, PhD, University of Utah. *Project title: Defining copper homeostasis in the mitochondria: Recruitment and distribution of copper for the assembly of cuproenzymes.*

• **\$98,340** Ann Saada (Reisch), PhD, Hadassah Hebrew University Medical Center, Israel. *Project title: Mitochondrial DNA synthesis and Krebs (tricarboxylic acid) cycle: The succinyl-CoA synthase.*



• **\$94,481** Tina Wenz, PhD, University of Miami. *Project title: Increased mitochondrial biogenesis as therapy to mitochondrial myopathies.*



• **\$86,250** Paolo Pinton, PhD, University of Ferrara, Italy. *Project title: Mitochondrial calcium signaling and organelle dysfunction in mitochondrial diseases: Molecular determinants and regulatory mechanisms.*

• **\$60,500** Orly Elpeleg, MD, Hadassah Hebrew University Medical Center, Israel. *Project title: Identification of novel genes associated with isolated complex I deficiency using whole genome mapping in small consanguineous families.*



ABOUT THE UMDF GRANT REVIEW PROCESS

Because new, aggressive research for rare disorders is often not underwritten by federal grants, the UMDF is committed to funding such grants and others that will forward the cause of research into mitochondrial diseases.

Letters of intent from research applicants worldwide are reviewed and ranked by the UMDF's scientific and medical advisory board. Investigators providing applications of greatest interest and scientific value are then invited to present a formal proposal. Formal proposals are reviewed three times. Primary and secondary reviewers each submit a full-page summary and score the proposal based on significance or impact, approach and feasibility. These scores are then averaged with a third score from the proposal reader.

The UMDF 2007 grant review session in Dallas included evening and morning sessions at which the

review board discussed and ranked the proposals. Starting with the worst scores, proposals were discussed and the lowest-scoring group of applicants eliminated in the first session. All remaining proposals were covered at the second review session, with each board member submitting a final score for each proposal.

After all scores were averaged, members of the UMDF scientific and medical advisory board convened for an allocations meeting to vote on which projects should be recommended to the board of trustees for funding and how much to offer each researcher based on the requested amount and covered services. The UMDF board of trustees then voted based on the review committee's recommendations. Each award is disbursed over one, two or three years according to the terms of the grant.

MITO MOTHERS ATTEND GRANT ALLOCATION MEETING

Two Dallas mothers who have spent years campaigning to improve the lives of those affected by mitochondrial diseases had the rare opportunity April 27 to see the fruits of their labors. Tova Sido and Kathryn Parsons attended the allocation session of UMDF's grant review and selection meeting in Dallas as observers to see how the Foundation distributes research funds, much of which are raised by parents just like them.

Parsons set out on her quest for a cure for mitochondrial disease after her daughter, Quincy, was diagnosed in April 1995 at just 14 months old. In June of that year, she attended what would be a pivotal conference on mitochondrial disease, where she joined the founders of several other volunteer parent groups to create the UMDF.

Tova Sido was referred to UMDF in August 2003 when her eight-month-old son, Charles, died from complications of mitochondrial disease. By the end of 2003, the Sidos had founded the UMDF's Dallas/Fort Worth mitochondrial disease support group. In June 2005, the unthinkable happened – the Sidos' seven-month-old daughter, Louisa, suddenly succumbed to mitochondrial disease as well.

These dedicated parents hope that one day the hard work will pay off and the lives of children like theirs will be saved, but in the meantime, it is rewarding just to see the kinds of cutting-edge research that their events can fund.



Louisa (above) and Charlie Sido (right)



Quincy Parsons



Quincy Parsons and Charlie Sido represent the full range of mitochondrial disease. Though they shared the same birthday, their lives could not have been more

different, but why one child responds to treatments and another does not illustrates the huge variance in how the disease affects different individuals.

Quincy is now 13, and thanks to a coenzyme Q10 treatment, vigorous relentless therapies and strong teachers, she is a thriving teenager who almost never gets sick anymore. Quincy is a miracle, Parsons says. But that's the mystery of mitochondrial disease – we know so much more and yet still so little.

I had the distinct honor to witness the UMDF Grant Allocation Meeting in Dallas this year. Any observer can easily see that the time, energy and concern these physicians and scientists give to this volunteer position is astounding.

No one could ignore the heavy weight of responsibility of granting \$1.2 million to research projects around the world, and yet there was an air of grateful confidence because of the diligence of each member and the history of the process that is followed.

Watching this process at work was especially poignant to me. More than ten years ago, we handed out our first small grant, which at the time was still a huge accomplishment. Even then, upholding strict scientific standards was the highest priority; seeing the process evolved to this level was beyond gratifying. The 2007 Grant Allocation Meeting is proof to each and every one of us and to thousands of our friends and family that our humble tasks UNITED together in the name of UMDF are, in fact, great and noble.

Before I drove home from the meeting, I called a few special friends who have supported UMDF from the very beginning. With tears streaming down my face, I told them what I had just witnessed. "I am calling you because you need to know what a great thing you have done. This is the result of your support. This is what your money has done. From the bottom of my heart, thank you."

~ Kathryn Parsons

The experience at the review session was truly amazing. I think the most remarkable thing was knowing that each one of these scientists had donated his time to be there.

Dr. Copeland was such a wonderful host and explained the process so well. It was interesting, educational and rewarding. Taking part in fundraising efforts and being a donor myself, it really was wonderful to see the time, effort, sincerity and care with which each one of these board members took this grant process.

UMDF continues to amaze me, and I am truly grateful for the "open door" that they always seem to have for their members.

I have worked for nonprofits, and honestly, I have never seen such a remarkable institution. The staff at UMDF continues to amaze me. And the scientific and medical advisory board is second to none.

My husband and I were truly grateful to be a part of the grant process. Thank you so much for including us.

~Tova Sido

DEVELOPMENT

SUPPORTING OUR CAUSE

YOU CAN HELP UMDF WIN \$5 MILLION FOR RESEARCH!

American Express has kicked off The Members Project – a program that will award up to \$5 million to a deserving nonprofit organization. The United Mitochondrial Disease Foundation has entered a project called **PROJECT MITOCHONDRIA: Research for a Cure**, and we need YOU to log on to www.membersproject.com to give the project a high rating!

Out of all of the projects submitted around the country, those with the highest rating will make it to the Top 50. But, you have to log on and rate our project by July 3!

If we make it to the Top 50, we will ask you to log on again to vote for **PROJECT MITOCHONDRIA**. From there, a celebrity panel of judges will choose the winner. You have to be an American Express cardholder to rate and to vote, but you can always sign up for a card on the site.

Please pass this incredible opportunity on to everyone you know – the more people who rate our project the better!



PLANNED GIVING CAN WORK FOR ANYONE

There is an old adage that charity begins at home. Probably no charitable instrument can illustrate the potential of that premise as easily as the Charitable Gift Annuity. It is truly the gift that keeps on giving – to UMDF and back to the donor.

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

For many older individuals who are past the higher risk investment accumulation phase and more concerned with ensuring income than building additional wealth, a charitable gift annuity may provide the answer. In addition, those persons of more modest means who are concerned with the extreme swings of the financial markets over the past few years may benefit from a CGA. By definition, a CGA is a contract, part gift (not investment) and part annuity, an arrangement by which the charity agrees to provide the specified annuitant or beneficiary with a fixed payment monthly, quarterly, semi-annually or annually...for life! It's an income stream you can't outlive and a way to support UMDF without financial sacrifice.

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

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

Please call UMDF if you are interested in any type of planned giving tool. You may visit our web site and click on "Make a Donation" to learn more. The UMDF development department can also provide you with a list of financial planners around the country who may be able to help you.

WHAT THE SPECIAL EVENTS DEPARTMENT CAN DO TO HELP WITH YOUR EVENT

- General fundraising and special event troubleshooting and guidance
- Budgeting guidance for your event
- Establishment of event timelines
- Connections with local families
- Letters of endorsement for approaching donors and soliciting auction and donation items
- Assistance with writing grants and gathering necessary attachments
- Information about navigating local raffle laws
- Ready-to-use sponsor materials
- Protocol for state regulation disclosures



WHAT YOU CAN DO TO HELP UMDF FUNDRAISING

- Inquire at your workplace about matching gifts or programs that match volunteer hours
- Write UMDF in on your workplace giving pledge card (i.e. United Way or Community Health Charities)

ATLANTA CHAPTER

- **July 26, 2007.** A special preview show of the Pumphouse Players' presentation of "The Nerd" at 8:00 p.m. in Cartersville, Ga., to benefit UMDF. Tickets are \$10. Contact Sherry Mathison at 770-386-1165 or heyralph@bellsouth.net.
- **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.

CHICAGO CHAPTER

- **September 16, 2007.** Inaugural *Chicago Area Chapter 5K Run/Walk* along scenic Lake Michigan near Montrose Beach. Contact Marybeth Kelley at 847-441-8261 or mbkelley@kelleymanagement.com.

DELAWARE VALLEY CHAPTER

- **July 28, 2007.** Fourth annual *Delaware Valley Brew at the Zoo* at Elmwood Park Zoo in Norristown, Pa. For more information, visit www.brewatthezoo.net.
- **September 8, 2007.** Eighth annual *Go for Mito! 5K Run 1 Mile Walk* will begin at 9:00 a.m. at the Philadelphia Museum of Art. For more information or to register online, go to www.umdf.org/goformito.

INDIANA CHAPTER

- **July 30, 2007.** Annual Indiana Chapter UMDF golf outing at The Hawthornes Golf & Country Club in Fischer, Ind. Contact Mike Hanlon at mh4j@sbcglobal.net or 317-858-6356, or visit www.umdfgolfouting.golfreg.com.

NEW ENGLAND CHAPTER

- **July 1, 2007.** Janet Lamb of Foxboro, Mass., will participate in a half-iron distance triathlon in honor of her Aunt Rose Mandill. For more information, please visit www.umdf.org/teamauntierose or e-mail janet@universalmedicalinc.com.
- **August 26, 2007.** An afternoon of food, friendship and fun in honor of Cameron Genie beginning at 1 p.m. at the Chicopee Falls Moose Family Center in Chicopee, Mass. Proceeds will benefit UMDF. For information, call Dan or Becky at 413-746-8171.
- **October 6-7, 2007.** New England Chapter's *Weekend of Hope 5K Walk and Family Fun Zone* in Plymouth, Mass., and Longmeadow, Mass. Contact the chapter at NEngChapter@umdf.org for information.

OHIO CHAPTER

- **July 20, 2007 & August 24, 2007.** New Image Haircutters of Willowick, Ohio, hair cut-a-thon during Lake County Captains' baseball games July 20 and August 24 in honor of Jonathan Kucaric. For more information, contact Donna at 440-944-7073 or amerikooch@adelphia.net.
- **August 4, 2007.** The Ohio Chapter's second annual *Shadow Woodstock 2007*, the Family "fun-raising" event in honor of Kyle Kobunski in Auburn, Ohio. Festivities begin at 8 a.m. and will include music, food and kids activities. For information, visit www.atocharities.org.

CENTRAL OHIO MITO GROUP

- **July 28, 2007.** The second annual *Race for Ellie* in honor of Ellie Kovalcik at Adventure Park in Powell, Ohio. 5K run, 1-mile walk and kids' fun run start at 9:00 a.m. Online registrations are available at www.umdf.org/raceforellie.
- **October 4, 2007.** Second annual KGWP Golf Outing in honor of Ellie Kovalcik held in Columbus, Ohio. For information, call 614-222-4888.
- **October 7, 2007.** Seventh annual Olivia Lauren Steele Memorial Golf Outing will be at Clover Valley Golf Club in Columbus, Ohio. For information, contact J.R. Steele at 614-846-4149.

WESTERN PA MITO GROUP

- **August 11, 2007.** Inaugural Pittsburgh *Brew at the Zoo* at the Pittsburgh Zoo & PPG Aquarium, starting at 7 p.m. For more information, visit www.umdf.org/pghbrewatthezoo or call UMDF at 412-793-8077.
- **September 15, 2007.** *Sip and Savor the Moment for a Cure* at 7 p.m. at the LaCasa Narcisi Winery in Gibsonia, Pa., in honor of Hannah Pallas. For information, call Heather at 412-389-2081 or hpallas@parentenet.com.
- **September 30, 2007.** UMDF is *Cruisin' Toward a Cure* in Monroeville, Pa. Contact Tania at 412-793-8077 or taniah@umdf.org.



AROUND THE COUNTRY

- **August 2, 2007.** Bike night at J&J's Smokin Café in Green, Ohio, in honor of Joey Ricci. Contact John Emanuele at 330-603-8109 or johnpemeanuele@yahoo.com.
- **August 6, 2007.** The Fischer Wine Tasting in Milwaukee, Wis., in honor of Sam & Zach Juhlmann. For information, contact Emily Fischer at 414-526-2653 or efischer@vonbriesen.com.
- **September 8, 2007.** A charity softball tournament will be held in Severn, Md., in honor of Ally Yates. For information, contact Bonnie at 410-768-2075 mito_cure@yahoo.com.
- **September 9, 2007.** *Ride for Energy, Ride for Life* in Allenberry, Pa. Contact UMDF at info@umdf.org for more information.
- **September 15, 2007.** The *Lohr Pumpkin Patch Walk* in Broadway, Va., will be held in honor of Owen Hollar. For more information, contact gwynnharrison@earthlink.net.
- **September 28, 2007.** *Elena's Hope Research Fund Dinner* in Kimberly, Wis. Contact Mindy Welhouse at 920-427-8924 or visit www.elenashope.org for more information.
- **September 28, 2007.** *David Hamm Research Fund Golf Outing* at Compass Pointe Golf Course in Pasadena, Md. Contact Danette at 410-439-5804 for more information.
- **October 7, 2007.** Emily Fischer will run the Chicago Marathon in memory of Sam and in honor of Zach Juhlmann. For information, contact Emily at 414-526-2653 or efischer@vonbriesen.com, or go to www.umdf.org/raceforresearch to make a donation.

UMDF Youth in Action: Spreading the Word about Mitochondrial Disease!



UMDF Youth Ambassador Brittany Wilkinson is pictured above with her mother and singer Josh Groban (and, of course, her service dog, Freedom). Brittany gave Josh a packet of information about mitochondrial disease and UMDF.



UMDF Youth Ambassador Jamieson Smith had the pleasure of meeting New Jersey Governor John Corzine while promoting current NJ legislation marking the third week of September as Mitochondrial Disease Awareness Week. The bill was passed June 11.



Above is Emily Swinn posing with actor Ivan Sergei after lunch together at the Peachtree Club in Atlanta April 30. Ivan was wonderful to Emily and promised to keep in touch and to see her whenever he is in town visiting his family!

PARTNERS IN PROGRESS

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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.

MITO GROUP ACTIVITIES

PACIFIC NORTHWEST MITO GROUP

• **May 19, 2007.** The *Pole, Pedal, Paddle* event was held at the Les Schwab Amphitheater in Bend, Ore. The event, organized by Dave Doyle, included six activities: downhill and cross country skiing, cycling, running, paddling and a sprint.



LEFT: Hazel (back), Hunter, Eoin, Grant and Cathal paddle for mito!

BELOW: A relay race heats up!



ST. LOUIS MITO GROUP

• **April 7, 2007.** It was just 20 degrees with gusting winds, but there were still more than 100 runners at the fourth annual *Mito-What? Family Fun Day* at the Shrine of Our Lady of the Snows in Belleville, Ill. Marsha Hohe & Joni Schnitzler organized the event that raised more than \$16,800. Activities included a 5K run, a 1-mile fun walk and a 1/2 mile kids' run and family fun like face painting, crafts, clowns, a climbing wall and much more.

WESTERN PA MITO GROUP

• **June 2, 2007.** The fourth annual Pittsburgh 'One Step Closer to a Cure' 5K Run / 1-Mile Walk raised more than \$35,000. There were lots of fun activities for the kids, including larger than lifesize puppets from Puppets for Pittsburgh.



OTHER NOTABLE EVENTS

- **March 17-18, 2007.** *Preston's March for Energy* raised more than \$21,000 in honor of Preston Buenaga. The event included activities at the Shamrock Sportsfest in Virginia Beach and a walk at Forwood Elementary School. Special thanks to Deb, Steve, Amy and Jerry again this year!
- **March 23-24, 2007.** *Caroline's on My Mind Weekend* in Spartanburg, S.C., raised \$40,000 in honor of Caroline Pulliam. Thanks to Donna and Norman Pulliam for their support!
- **April 16, 2007.** Mike O'Hanlon of Milton, Mass., ran the Boston Marathon in honor of Alexandra Danner, his good friend's daughter. Mike raised more than \$6,000 for UMDF! You can still donate at www.firstgiving.com/MikeForUMDF.
- **May 10, 2007.** The *Josie Mazzo Children's Charities Golf Outing* in memory of Josie Mazzo was held in Burns, Tenn. Proceeds went to

UMDF, Ronald McDonald Children's Charities and Vanderbilt Children's Hospital.

- **May 13, 2007.** Mindy Welhouse held a Mother's Day Flower Sale to benefit the Elena's Hope Research Fund in honor of her daughter, Elena.
- **May 13-19, 2007.** The seventh annual *Kites for Kristen* raised more than \$16,000 for the Kristen Charleston Research Fund. Students at St. Daniel the Prophet School in Chicago had a dress down day, made donations and decorated kites. A raffle was also held during the week with lots of great prizes.
- **June 4-30, 2007.** The Marathas family and Longdogger's Restaurant in Indialantic, Fla., are raising funds for mitochondrial disease research in honor of Connor Marathas through *Connor's Energy for Life Lightbulb Campaign*. The restaurant will sell paper light bulbs to raise awareness through the month of June.

- **June 9, 2007.** A local gardening club held a plant and garden sale at the Prince of Peace Lutheran Church in Appleton, Wis. More than 1,000 plants, plus garden art, painted gourds, benches and much more were available for sale. Proceeds benefit UMDF, and the North Outgamie Chapter of Thrivent will supplement funds raised.
- **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!
- **June 23, 2007.** The second annual *Save Barnegat Bay 8K* in Lavallette, N.J., raised money for Save Barnegat Bay, Lavallette Emergency Services and the UMDF in honor of Lauryn & Owen Boyle. Events included an 8K race and a 3.3 mile fitness walk along the shores of beautiful Barnegat Bay.

FUNDRAISING HIGHLIGHTS

GIFTS FROM THE HEART

- Ilyssa Resnick, Cooper Adelstein's cousin, had her Bat Mitzvah and donated \$150 to UMDF.
- In lieu of wedding gifts, Carolyn Tuttle and Michael Hodges donated \$500 to UMDF in honor of Caleb Krug.
- Lococco birthday party donations of \$350 were sent to UMDF in honor of Danielle Lococco of Illinois.
- Thomas Lyons' Seventh Birthday letter writing campaign raised \$80 for UMDF in honor of Thomas.
- Great River Medical Center in Iowa held a casual day and donated \$440 to UMDF in honor of Kristen McGuire.

- The Center Ice Skating Club in Canton, Ohio, donated \$182 in proceeds from their Spring Ice Skating Show in honor of Hannah Roberts.
- A Home and Garden Party held in Minnesota raised \$115 in honor of Caleb Schuster.



Hannah Pallas

- Patricia Shuker's surprise birthday party donations totalled \$1,485 for UMDF in honor of Hannah Pallas.
- Kelsey Wright of Texas held a bracelet sale and raised \$150 for UMDF.

On May 12, the Corvette Club of Western Pennsylvania donated \$1,000 to UMDF. Thank you to everyone in the Corvette Club for their continued support of UMDF!

ONGOING FUNDRAISERS

COINS FOR A CURESM

So far, UMDF's *Coins for a CureSM* campaign has raised more than \$20,500! There are a total of 395 canisters (134 classrooms, 11 districts and 211 stores) and 32 campaigns still active. There have been 266 canisters sent back as completed (256 classrooms, 12 districts and 10 stores), representing 17 completed campaigns. That's a total of 49 *Coins for a CureSM* campaigns across the country! Thank you to everyone who has participated!

TEA FOR MITOSM

UMDF currently has 31 families participating in the *Tea for MitoSM* fundraiser. The campaigns have brought in \$9,360 to date with an additional \$1,295 coming in from flat donations to the fundraiser (by people not participating in the campaign) for a total of \$10,655.

For information about how you can become involved, contact Tania at 412-793-8077 or at taniah@umdf.org.

THE UMDF GRAND ROUNDS PROGRAM

The United Mitochondrial Disease Foundation has made it a top priority to reach out to physicians through grand rounds – introducing and/or broadening the knowledge base on mitochondrial diseases.

The primary purpose of grand rounds is to provide continuing education to health care providers on topics specific to mitochondrial disorders, the practice of which furthers the 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.

With generous support from various funders, the UMDF hopes to schedule up to eight grand rounds per year. Grand rounds will also be coupled with a special family meeting to help educate patients and families about mitochondrial disease – and many times, the family meetings are suitable for outreach to nurses, therapists, educators and various allied health professionals.

The Foundation has hosted a handful of these meetings and has received positive feedback from the medical community *and* the families.

If you would like to see the UMDF bring a grand rounds program to your area, please contact Kara Strittmatter at kara@umdf.org.

Special thanks to Transgenomic Labs for financially supporting the 2007 UMDF Grand Rounds program!

2007 GRAND ROUNDS SCHEDULE AS OF MAY 16, 2007

- August 21, 2007: Children's Healthcare at Scottish Rite, Atlanta, Ga.
Speaker: Bruce H. Cohen, MD
- August 22, 2007: Children's Healthcare of Atlanta at Egleston.
Speaker: Mark Korson, MD
- August 23, 2007: Des Moines, Iowa
Speaker: Sumit Parikh, MD (to be confirmed)
- August 28-30, 2007: University of Minnesota, Minneapolis, Minn.
Speaker: Bruce H. Cohen, MD
- September 17-18, 2007: Arnold Palmer Hospital, Orlando, Fla.
Speaker: Bruce H. Cohen, MD
- September 27, 2007: Children's Healthcare, Columbus, Ohio.
Speaker: Bruce H. Cohen, MD
- October 18, 2007: Special Physician Outreach Dinner, Denver, Colo.
Speaker: Bruce H. Cohen, MD (to be confirmed)
- November 13-15, 2007: Kansas City, Mo.
Speaker: Amy Goldstein, MD
- December 12-13, 2007: Oregon Health & Science University, Portland, Ore.
Speaker: Bruce H. Cohen, MD

ADULT ADVISORY COUNCIL

The Adult Advisory Council was formed in April 2007 to be a resource to the UMDF board of trustees as well as a “think-tank” to develop better ways for the Foundation to address the needs of the adult-affected membership.

The main purpose of the council will be to speak for the adult affected community by assisting UMDF in representing this population with equity. The council will provide input on collateral and marketing, give advice on issues that affect the adult population and evaluate whether UMDF is conducting appropriate outreach. It will examine



what steps are already in place to meet the demands of the affected population, such as the symposium. The Council will also develop awareness and a voice to represent the adult community, as well as develop equity between adults and children who are affected.

UMDF Trustee Sharon Shaw has graciously agreed to co-chair the Council. Affected with mito herself, she has an intimate understanding of the issues that pertain to adults and the difficulties of negotiating health-care systems, as well as insight into the need to be more inclusive of all affected by this disease.

A diverse and experienced group of affected adults were asked to participate in the Council. Confirmed members are Robert Brief, Barbara Bruck, Marge Calabrese, David Hamm, Michael Malavasic, Melissa Matheny, Allen Segal, Jean Shepard, Gail Wehling and Gregory Yellen. The first official meeting of the Adult Advisory Council took place May 15, 2007, via conference call.

CALLING ALL MITO ADULTS!

Mitochondrial News Needs YOU! Please consider submitting an article on your experiences with a specific topic of interest. If you want to contribute, please contact Amy Campbell at amyc@umdf.org or at 412-793-8077, ext. 112. We look forward to hearing from you!

MOM AUDITIONS FOR PHILANTHROPIC REALITY SHOW

UMDF member and Mito Mom Julie Manley traveled to New York City to audition for Oprah’s “Big Give” reality show. The show planned to follow contestants for about eight weeks as they travel around the country and are challenged to think of and carry out innovative ways to help others and give back. The goal of the show was to promote philanthropy—the contestants’ goal is to stay in the competition by “out giving” each other.

Although Julie didn’t make it to the finals, she had a great time transforming into “Mighty Ms. Mitochondrion” to help spread the word about mito! Julie plans to make mitochondria costumes available for sale in the near future, so stay tuned for updates!

After a faulty valve, loss of pressurization in the cabin, fire trucks on the runway, missing a connecting flight and losing our luggage, we are back home from Oprah! It was 16 degrees and snowing from 5 a.m. to 9 a.m. I had a good friend with me, friends who shared their home with us, family members who watched my kids and a husband with a stomach virus... what a group effort!

Although I made it to the 2nd round (the “Maybe” group), I wasn’t chosen as a finalist. I look forward to seeing who makes it, and I think you would enjoy the show.

It was refreshing to stand in line with people who cared for others and were trying to do great things. The best part is that most of these contestants’ goals are already in motion, and I enjoyed hearing their stories.

Thanks for your support and for all you do.

~ Julie Manley, a.k.a. “MIGHTY MS. MITOCHONDRION”



Julie (above) in character for Oprah. Jett and Jude Manley (right) pose in mom’s costume.



MEMBER RESOURCES

SPECIAL THANKS

This year, representatives of FOD Support, the Organic Acidemia Association and the Barth's Foundation attended the UMDF symposium in San Diego. FOD and OAA were investigating how our symposium can benefit their membership with an eye for joining us in Indianapolis in 2008. We look forward to collaborating with all of these organizations in the future!

NEW LOOK FOR THE MITO PIN!

The Mito Pin, a green ribbon with the letters UMDF previously printed in the center, has been changed to have the letters MITO in the center.

UMDF has made this change to create a universal symbol for mitochondrial disease. This pin will be made available to the UMDF membership as well as the Foundation's partners in collaboration. It is hoped that the ribbon will eventually receive the same recognition as the pink ribbon for breast cancer awareness.



MITO TREATMENT RESOURCES

As part of the UMDF mission, we are happy to make available some special UMDF member resources for the treatment of mito patients. Acquiring prescribed levels of recommended vitamins and co-factors can often cause financial stress for families affected by mitochondrial disease. Epic4Health, Tiscon Corp and Vitaline have generously offered discounts on CoQ10, L-Carnitine, Vitamin E and other mitochondrial disease treatments for UMDF members.

To view all available offers, log in to the UMDF website using your Member ID and password, and follow the link for Member Resources. If you do not have your Member ID and password contact the UMDF office at info@umdf.org or at

412-793-8077, and we will be happy to provide them to you.

Please note that the use of supplemental vitamins and co-factors is largely unproven and therefore controversial in patients with mitochondrial diseases. Please check with your doctor before making any changes in your treatment.

OLEY FOUNDATION ANNUAL CONFERENCE

The Oley Foundation will hold its 22nd annual consumer/clinician conference, *Safe and Sound on HomePEN*, June 27-July 1, 2007, in Hyannis, Mass.

Experience has shown that the adjustment to living with home tube or IV feeding can be eased through contact with and support of others in the same or similar situations.

This conference focuses on the medical and emotional challenges of patients on home intravenous nutrition and tube feedings. Information

is shared in large and small groups led by well-known clinicians from across the country and attended by people who depend on tube or IV feeding.

All Oley services, including the conference registration, are FREE for consumers and family. Lodging and meals are the responsibility of individuals. A limited number of travel grants are available for first time conference goers.

Founded in 1983, Oley is a national non-profit education, self-help and research organization for patients and consumers on home IV and tube feeding (homePEN). Through this conference and other activities, Oley offers members of the homePEN community opportunities to learn and share experiences.

For more information, visit www.oley.org, call 800-776-6539 or 518-262-5079 or write bishopj@mail.amc.edu.

FLASHES OF HOPE

Flashes of Hope is a non-profit organization dedicated to creating uplifting portraits of children fighting life threatening illnesses. The portraits, taken by award-winning photographers, help children feel better about their changing appearance by celebrating it. For families of terminally ill children, it's especially important to have a portrait that preserves forever the beauty, grace and dignity of their child. For more information, visit the Flashes of Hope website at www.flashesofhope.org.

GINA PASSES IN THE HOUSE

The Coalition for Genetic Fairness is an alliance of advocacy organizations, health professionals and industry leaders working to educate Congressional policymakers and staff about the importance of legal protections for genetic information and ensure passage of meaningful genetic information non-discrimination legislation. The Coalition has worked for twelve years toward the passage of legislation to eliminate the misuse of genetic information.

The Genetic Information Nondiscrimination Act (GINA, H.R.493) passed the House of Representatives April 25, 2007. Representative Slaughter (D-NY) and Representative Biggert (R-IL), GINA's lead sponsors, spoke to the need for protections against genetic discrimination and thanked the House chairs of the committees of jurisdiction for their work to move the bill. Members of the House from both sides of the aisle stood in support of GINA and called for a favorable vote on the legislation. The bill was passed with a 420-3 vote under the suspension of the rules.

Fear of misuse of genetic information causes many individuals to not avail themselves of genetic testing, information that can be used to manage their health proactively. The potential for discrimination continues to grow as the number of tests available increases and electronic health information proliferates.

For more information about the coalition, please visit www.geneticfairness.org.

DOES YOUR FAMILY HAVE A PERSONAL WEB SITE?

UMDF is interested in creating a page on UMDF.org that lists mito families' personal web sites (such as CaringBridge). If you have a personal web site you would like to share with the rest of the Mito community, please e-mail the link to info@umdf.org with "Personal Web Site" in the subject line.

CONT. FROM PAGE ONE ~ 'SCIENTIFIC AND PSEUDOSCIENTIFIC THERAPIES'

- **Irrefutable hypothesis.** One mark of a true scientist is that he is willing to reject his hypothesis if it proves wrong when tested. The pseudoscientist's hypothesis may include cherished beliefs that he is unwilling to reject under any circumstances. If he cannot imagine a set of results that would falsify or refute his hypothesis, then it is not a real hypothesis. It's useless for someone to conduct investigations to determine whether or not an irrefutable hypothesis is correct when his belief in it will not be altered by the outcome.
- **Incorrect use of the scientific literature.** By its very nature, true scientific research is often tentative and indefinite. Scientists know that experimental designs can be flawed and that confirmed hypotheses are not absolute truths. Their research reports, which make up the literature of science, often contain phrases such as "our study suggests" or "it is therefore possible." The pseudoscientist treats research papers as the final word on a given topic — as long as they agree with his preconceived ideas. Just as he picks and chooses his data, he also uses a selective approach to the scientific literature. A common practice is to cite research performed in a lab owned by the company selling the product. The pseudoscientist may even cite a legitimate peer-reviewed article from a recognized medical journal but ignore the reality that no scientific paper stands in isolation from others in the field.
- **Misuse of scientific terms.** Pseudoscientific literature often misuses scientific terms and concepts. Knowing that the general public may not understand such jargon, the writer can manipulate the language of science to present a plausible scenario for how his remedy works. What he says may make no sense scientifically but will nevertheless convince many to buy his product.
- **Outdated thinking.** A pseudoscientific article may refer back to a method of treatment or way of thinking about an illness that has been scientifically invalidated. **Medicine is a progressive field that replaces outdated or less effective treatments with new ones.** In contrast, it is a common pseudoscientific approach to make reference to obscure research conducted many years prior. The implication is that this research was suppressed by the medical establishment, when it is much more likely to have been abandoned as ineffective or even harmful.
- **False similarities.** The pseudoscientist tends to see similarities between his own unproven therapies and those that have been scientifically substantiated. For example, without providing any evidence, he may claim that, just as certain accepted medical therapies "boost the immune system," his product does the same thing. This sounds scientifically similar to conventional treatments but is likely a false comparison.
- **Use of conspiracy theories.** The inventor of a pseudoscientific therapy may claim that his product has been kept from public knowledge by



the government, the medical community or the pharmaceutical industry because its disclosure would prove economically disastrous. Countless healthcare jobs would be lost if the treatment or cure were made available. This, of course, presupposes that not even one physician is completely committed to the health and welfare of his/her patients, that every person "in the know" can keep a secret of that magnitude and that none of those countless conspirators might also have a medical need for such a product themselves.

- **Refusing to revise.** Because the pseudoscientist operates under an irrefutable hypothesis, he refuses to revise or reject his assertions despite evidence to the contrary. He already "knows" that he is right and cannot be convinced otherwise. Further, he does not take it well if his own "research" is questioned. Rather than evaluating the merits of the criticism, he derides the critics as being narrow-minded conspirators who are blinded to the "truth."

LET THE BUYER BEWARE

With the above characteristics of a pseudoscientific approach in mind, the informed patient/consumer will want to consider the following suggestions when making decisions regarding unorthodox or unusual therapies.

- Read the vendor's literature or web site carefully, looking for examples of pseudoscientific reasoning.
- Determine if any supporting research or clinical trials were performed in an independent lab, particularly a recognized research facility such as a large university.
- Conduct an online search for articles that objectively discuss the treatment. Note whether these articles are in respected mainstream journals or only in alternative medical literature. Include such web sites as **quackwatch.org**. Beware if you can find no mention of the treatment in the scientific literature.
- Locate and read any research reports cited by the vendor. These should be available online, although only the abstract may be available free-of-charge. Then, using key words, do a Medscape or PubMed search for other scientific abstracts and papers that might refute the cited articles.
- Conduct an online search for other articles written by the scientist/author of a treatment article. Were these published in recognized scientific journals or only in alternative medicine publications?
- Trust your physician. Consult him/her if you are considering an unorthodox therapy. If he/she has objections, ask for specifics. Don't become your own doctor and leave the professionals out of the picture.

None of this is meant to preclude the possibility that a previously untested treatment or supplement really could prove effective once it is tested. **Never give up hope. Keep an open mind, but always ask for evidence.**

ANNOUNCEMENTS

MITOCHONDRIAL DISEASE AWARENESS WEEK

The United Mitochondrial Disease Foundation is proud to announce a collaborative effort with the Mitochondrial Disease Action Committee to declare and implement awareness of mitochondrial disease nationwide during the third week of September.

Why the third week? New Jersey started the ball rolling for this week more than two years ago. UMDF volunteers diligently campaigned New Jersey legislators and their dream became a reality June 11 when the bill was passed. Ohio is following suit, and it is our hope to continue this effort throughout the United States.

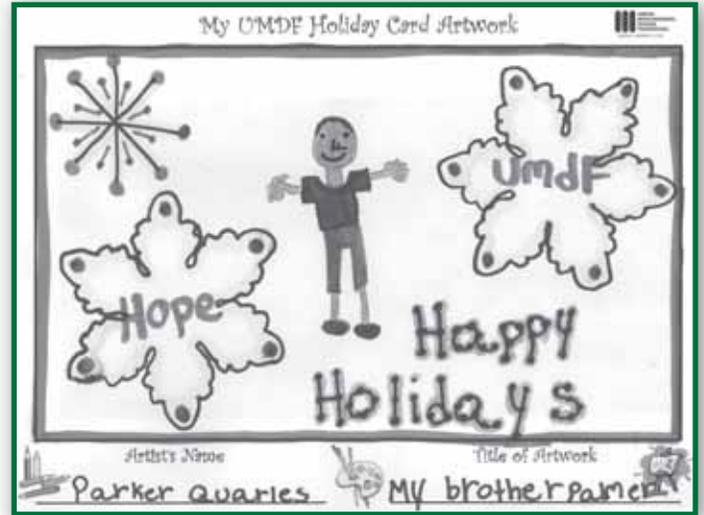
Join the effort for mitochondrial disease awareness! Together, we can allow mitochondrial disease patients to have a voice. Contact John Eliyas, UMDF director of member services, at JohnE@umdf.org or at 412-793-8077 for information on how to reach out to your local legislators in establishing these dates for mitochondrial disease awareness.

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 will soon be open for business. This online store will be selling 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.

UMDF HOLIDAY CARD ART CONTEST WINNER

The winner of the new UMDF Holiday Card Kids Art Contest is Parker Quarles from Canton, Ga. Parker is 8 years old and was inspired to design the card by his younger brother, Palmer, who died from a mitochondrial disease. The title of his card is 'My brother, Palmer,' and it will be the design for UMDF's 2007 holiday card. Parker will also receive a Toys 'R Us gift card for being chosen.



SUBMISSION DEADLINE FOR ISSUE 3 IS JULY 31, 2007!



IN THIS ISSUE:

What is pseudoscience?
Read page 1!

Are breath-holding spells normal?
See page 3!

What is UMDF doing in my area?
Check out pages 4-8!

New Adult Advisory Council...
Find out more on page 9!

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