

TRAVELING WITH DISABILITIES

Planes, Trains and Motorcoaches

With UMDF's ninth international symposium fast approaching, many planning to attend the conference in San Diego are likely concerned about traveling with a disability.

We have compiled some of the best advice from the Transportation Security Administration, Amtrak and Greyhound regarding traveling with wheelchairs and mobility aids, supplemental oxygen, service animals and other medical requirements.

PLANES

With all of the recent changes to security guidelines, navigating airport security with a disability can be daunting. As you plan your trip, the Transportation Security Administration recommends that you notify your airline in advance if you will need assistance at the airport. If you need someone to accompany you to your gate, your airline representative can provide a gate pass for your companion. It is recommended, but not required, that sick or disabled passengers bring documentation regarding their medical needs.

When you reach the security checkpoint, tell the Transportation Security Officer (TSO) if you are unable to walk through the metal detector. If a pat-down inspection is necessary, you should be sure to identify any special situation requiring sensitivity. You may ask to be screened in private.

HYPERBARIC OXYGEN TREATMENT

The UMDF member services department receives many requests for information on the utilization of Hyperbaric Oxygen Therapy (HBOT) for the treatment of various mitochondrial diseases.

While there is much discussion and controversy about the benefits of this treatment, unfortunately the evidence of these benefits has been largely anecdotal or issued by a biased source.

The value of HBOT therapy as a treatment for mitochondrial disorders was posed to our Scientific and Medical Advisory Board, and it was their unanimous opinion that, at this time, until there is clear, clinical evidence to support the benefits, they cannot endorse or recommend HBOT therapy as a treatment for mitochondrial disorders.

Mitochondrial disease is not as rare as once thought. It is now conservatively estimated that one in 4,000 persons will develop some form of mitochondrial disease in their lifetime, with

People with disabilities or medical conditions do not have to remove their shoes during screening. Instead, footwear is screened using a visual or physical inspection and explosive trace detection sampling while remaining on the feet.

When traveling with disabled children, parents or guardians should tell the security officer if the child has any special needs or medical devices and offer suggestions on how to best to screen the child. If your child needs to be privately screened, you should escort the child and remain with him or her throughout the process. You will not be required to be separated from the child during the screening process.

All airline passengers are now allowed to carry travel-size toiletries through security checkpoints in containers holding three ounces or less carried in a single, quart-size, sealable clear plastic bag. Beverages and other items purchased in the secure boarding area can also be brought onboard the aircraft.

Medications and other essentials permitted on the plane include prescription and over-the-counter medications; liquids, including water, juice or gels; and gels or frozen liquids needed to cool medically related items. If liquid medications are in volumes larger than three ounces, they must be carried separately of the plastic bag and declared to a security officer verbally, in writing or by a person's companion, caregiver, interpreter or family member.

Medication and related supplies are normally x-rayed, but you may ask that security officers visually inspect your medication and associated

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some researchers suggesting an occurrence rate as high as one in 2,000. Half of these will develop the disease in childhood. There is no cure or treatment for mitochondrial disease, and the impact upon the patient ranges from mild symptoms to death.

UMDF realizes that research is the key to saving the lives of those afflicted with mitochondrial disease. The disease is under-recognized and complex, affecting multiple organ systems at any age of the patient. Mitochondrial dysfunction also mimics or is the cause of other common diseases such as Parkinson's, Alzheimer's, diabetes and more. Its complex array of symptoms and multiple modes of inheritance make mitochondrial disease difficult to diagnose and currently very difficult to treat.

With this in mind, UMDF has instituted a peer review research grant program that has, to date, funded more than \$4 million of mitochondrial disease research. No research funded thus far has included or involved hyperbaric oxygen therapy, and to the best of our knowledge, there

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BOARD SPOTLIGHT

For the first 2007 issue of *Mitochondrial News*, we would like to spotlight our newest board members, Amy Goldstein, Leslie Heilman and Richard Leach. Thank you for your commitment to finding a cure for mitochondrial disease, and welcome to the board!

AMY GOLDSTEIN, M.D.

Dr. Amy Goldstein, of Pittsburgh, Pa., only recently joined the UMDF Board, but she has not been a stranger to the Foundation. Dr. Goldstein has been a faculty member for past UMDF symposia (including the *Doctor Is In* program), frequently writes articles for *Mitochondrial News* and has been extremely helpful in providing direction for UMDF marketing and development from a clinician's perspective. Dr. Goldstein is board certified in pediatrics, neurology and psychiatry. She is currently a clinical assistant professor and pediatric neurologist at the University of Pittsburgh School of Medicine and is on staff at the Children's Hospital of Pittsburgh in the division of pediatric neurology.



LESLIE HEILMAN

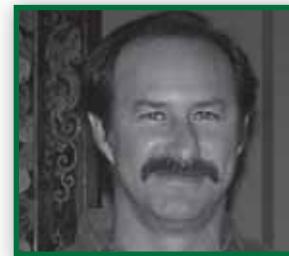
Leslie Heilman joined the UMDF board in 2007 and serves on the donor development committee. She was UMDF's first executive director from 1999 to 2001. Her fundraising and marketing experience include 10 years as the marketing director for the American Bar Association and eight years as the communications

director for the American Association of Neurological Surgeons. Ms. Heilman is currently the associate director of development and communications for the University of Pittsburgh School of Law. She earned her bachelor's degree from Penn State and her juris doctor from DePaul University School of Law.



RICHARD LEACH

For more than twenty years, Richard Leach has helped U.N. agencies, government organizations and non-profits address a wide range of issues. He has worked for organizations such as the World Health Organization, the UN World Food Program, the Alliance for Representative Democracy, the American Cancer Society, the World Wildlife Foundation, the U.S. Department of Health and Human Services and the U.S. House of Representatives, as well as being involved in various other initiatives and events. Mr. Leach practiced corporate and maritime law in California from 1986 to 1989, and he recently served as a member of the American Bar Association's



Task Force on Reform of the United Nations Commission on Human Rights. He has published articles on international human rights and microenterprise development and has served as a correspondent on Harvard Law School's Human Rights Internet Reporter.

A NEW LOOK FOR MITOCHONDRIAL NEWS!

Welcome to the new *Mitochondrial News*! As you may have noticed, our quarterly newsletter has taken on a new look in 2007.

Included in each upcoming issue of the newsletter will be a small pullout section of four to eight pages called *Partners in Progress*. This new section will include some familiar newsletter items but will also add new features, such as a researcher spotlight and a day-in-the-life article highlighting an affected individual or family member and how they overcome the obstacles mitochondrial disease brings to their lives.

Most importantly, *Partners in Progress* will focus on how we all work together toward achieving our common goal: a cure for mitochondrial disease.

UNITED MITOCHONDRIAL DISEASE FOUNDATION

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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 the UMDF web site. 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: Michio Hirano, MD, of the Neurological Institute, New York; and Andrea Gropman, MD, FAAP, of Georgetown University Medical Center, Washington, D.C.

THE QUESTION IS...

I am 51 years old and have been diagnosed with MELAS. I had a positive muscle biopsy in February 2005. I have Parkinson's symptoms, but my neurologist in Houston says it is a result of the disease. My local neurologist has me on Parkinson's medication, but it has caused some side effects such as more confusion than normal and myoclonic jerking, so we reduced the dose. My symptoms have leveled out, but I am confused about whether these drugs are helpful or if I have just had a plateau of symptoms. I have cardiac problems along with mitochondrial disease, so I am on lots of medicine. Thanks for any information. I realize you are not here to diagnose. I'm just confused!

RESPONSE FROM MICHO HIRANO, MD:

As the name implies, mitochondrial encephalomyopathy lactic acidosis

and stroke-like episodes (MELAS) is a mitochondrial disease characterized by unusual stroke-like episodes in young people (generally under age 40) and elevated lactic acid in blood. Parkinsonism (symptoms or signs resembling Parkinson's disease) is not typical of MELAS but has been reported in at least one young boy with MELAS (Ann Neurol 1999;45:130-3). In addition, mutations of the mitochondrial DNA polymerase gamma (POLG) sometimes cause Parkinsonism. Therefore, it is possible that your Parkinsonism is due to your mitochondrial disease.

Because you do not have Parkinson's disease (PD), your response to medications will be different from typical patients with PD. It is difficult to know whether the leveling out of your symptoms is due to the medications, a plateau of the disease or both. Since your Parkinsonism has not improved with medications, you should talk to your neurologist about continuing or changing therapy.

THE QUESTION IS...

Two questions regarding dental issues:

1. We have a five-year-old daughter with Complex 1 deficiency. She has developed dental caries and gum inflammation, probably due to difficulty obtaining optimal dental hygiene due to neural and GI impairment. Do you have recommendations regarding prevention and optimal dental hygiene? Secondly, she requires general anesthesia to allow therapeutic dental surgery. What are the precautions or recommendations regarding anesthesia and general perioperative care? How does mitochondrial disease affect dental health?

2. I am a middle-aged woman diagnosed two years ago with MELAS. So far this year, I've needed three root canal treatments. Now I have two more teeth that are presenting as problems, with electrical shooting sensations through them. I have had similar pains in my feet and hands. Could mito somehow cause injury or death to the nerve of the tooth? I don't look forward to an additional two root canals or the cost of the subsequent crowns on these teeth.

RESPONSE FROM ANDREA GROPMAN, MD, FAAP:

Although as clinicians, we recognize that mitochondrial dysfunction can cause multi-organ system disease, we know very little about the possible impact on dental health. Some studies have suggested that patients with significant periodontal disease have low levels of endogenous Coenzyme Q10, pointing to mitochondrial dysfunction. Additionally the generation of reactive oxygen species by the mitochondria may contribute to apoptosis and gingival inflammation. Dietary effects of mitochondrial disorders may impact the ability of the enamel and gums to remain healthy and recover from minor traumas. Future research is likely to reveal more information on this subject.

In children with neurological impairment, dental hygiene may become a difficult issue to address. Additionally, certain medications given to control seizures, spasticity, etc., may cause gum hypertrophy or bleeding. The impacts of poor oral motor tone, mouth breathing and residual food in the mouth may increase risk of dental caries and poor hygiene. The control of saliva and secretions can lead to either improved care or alternatively increased caries as saliva contains important antioxidant protective effects. Often there is no choice but to perform an examination or perform dental care under anesthesia. The potential risks of anesthesia in a patient with mitochondrial disease may not be trivial. This topic is covered in much detail by an article authored by doctors Bruce Cohen and John Shoffner that appears at www.umdf.org/mitoane.pdf, and I refer you to this for more detail.

Submitting questions to *Ask the Mito DocSM* is a benefit of UMDF membership. If you are a member and would like to submit a question, please log in to the UMDF web site using your user ID and password. If you would like more information on becoming a member of UMDF, please e-mail us at info@umdf.org.

CHAPTER ACTIVITIES

ATLANTA AREA CHAPTER

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

- **September 23, 2006.** Going the Extra Mile for Josey and UMDF, a 24-hour ultra run organized by Tammy Vance, was held at Little Mulberry Park in honor of Joseph Hendley. Great job raising almost \$17,000 for the Foundation!

- **December 2006.** The Atlanta chapter was awarded a \$5,000 grant from the TJX Foundation, Southeast Region, during a luncheon at the Peachtree Club. The chapter is looking forward to working with TJX to support families through education, awareness, family events and fundraising. The chapter presented TJX with a plaque (below) featuring a group photo of the chapter from the recent holiday party (upper right). Special thanks to all who made this grant possible!



Ninety-four guests (26 families) attended the third annual Atlanta Chapter Holiday Party at the Peachtree Club.

UPCOMING EVENTS

- **March 12-16, 2007.** The Beta Club, a community service group at Lanier Middle School, will host a St. Patrick's Day awareness fundraiser in Roswell, Ga. Michele Meddin and the club will be selling UMDF energy bands in honor of Michele's niece, Anna Lewis.
- **March 25, 2007.** Marilyn Arkin has already exceeded her \$10,000 goal, raising more than \$16,000 in honor of Ross Cooper. Now she's focused on completing the 13.1 miles of the ING Atlanta Half Marathon! Good Luck Marilyn!

DELAWARE VALLEY CHAPTER

PRESIDENT: MARIPAT SHELLY 215 256 0273 DeValChapter@umdf.org

UPCOMING EVENTS

- **April 21, 2007.** The third annual Kindbom Cheers to You, Hope to Others fundraising event in honor of Rachel Kindbom will include a theme basket raffle and wine tasting. For information, contact Sharon or Chris Kindbom at chrishsharonk@comcast.net or at 609-714-1443.

- **July 28, 2007.** The fourth annual Brew at the Zoo will be held at the Elmwood Park Zoo in Norristown, Pa., in honor of all affected. Breweries and beer aficionados come together to sample the best beers in the area, eat great food, listen to music and, of course, check out the animals at the Zoo. For information, contact Bob or Lisa Polsky at 610-275-2775 or visit www.brewatthezoo.net.

INDIANA CHAPTER

PRESIDENT: SUE ANN BUBE 317 894 9099 INChapter@umdf.org



- **February 10, 2007.** Score a Goal for Mito, the fourth annual mito hockey night with the Indiana ICE, was held at Conseco Fieldhouse in Indianapolis in honor of all affected. Special thanks to Sue Ann Bube for her help raising more than \$5,000!

UPCOMING EVENTS

- **Summer 2007.** Our Miles for Mito riders won't be joining us this year at the symposium in San Diego, but plans are underway for a virtual Miles for Mito event and a ride in Indy for the 2008 symposium. For more information, or to see how you can help, contact Sue Ann Bube at 317-894-9099 or at sbube@comcast.net.
- **Fall 2007.** Join the Indiana Chapter for a Fall Walk/Run and Concert in Indianapolis. Contact John Goerges at 317-645-6142 or john.goerges@gmail.com for more information.

KANSAS CITY CHAPTER

PRESIDENT: PAM JOHNSON KCChapter@umdf.org

UPCOMING EVENTS

- **June 23, 2007.** The fourth annual Kansas City *Mito-What? Family Fun Run*, a 5K run/1-mile walk, is set to include kids' activities such as face painting, games,

music and a special kids' dash in Overland Park, Kan. Contact Theresa Edwards for more information at 816-587-1375 or e-mail kccchapter@umdf.org.

NEW ENGLAND CHAPTER

PRESIDENT: BRIDGET WILLIS NEngChapter@umdf.org

- **November 12-13, 2006.** Dr. Bruce Cohen visited Bay State Medical Center for a well-received grand rounds and dinner with area physicians. The event helped to broaden local physicians' understanding and awareness of mitochondrial diseases. As part of his visit, Dr. Cohen also had a free family symposium on November 13 in Springfield, Mass. Thanks to Dr. Cohen for helping the New England Chapter to educate and support the New England community. Education, awareness and support are priceless!
- **January 12, 2007.** The chapter celebrated its third annual holiday dinner at the East Bay Grille in Plymouth, Mass. It was a nice time for families to enjoy a relaxing dinner out. Keep an eye on the New England Chapter website for exciting family social events being planned now for this spring and summer in various local communities.

- **February 11, 2007.** The *Owen Willis Gift Recycling Silent Auction and Post-Holiday Gift Recycling Party* organized by Bridget Willis included a silent auction, refreshments and fun. A \$10 donation and a "re-give" item

for the auction was given by attendees, and more than \$1,800 was raised for the Foundation.

UPCOMING EVENTS

- **May 20, 2007.** Join the Bonney family and friends for the first *Bike-A-Thon* in memory of Elijah William Bonney at 10:00 a.m. at Haines State Park in Barrington, R.I. The ride follows the East Bay bike path in Barrington/East Providence. For more information, call Dave Bonney at 401-245-2433 or e-mail davebonney@aol.com.
- **October 6-7, 2007.** The New England Chapter's *Weekend of Hope 5K Walk and Family Fun Zone* will be held Saturday, October 6, in Plymouth, Mass., and Sunday, October 7, in Longmeadow, Mass. Your help is needed to plan the chapter's biggest event! If you have expertise in marketing, event planning, project management or just want to get involved, please contact the chapter at nengchapter@umdf.org. We need you to continue to make the *Weekend of Hope* a huge success!

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 in honor of Kyle Kobunski.

UPCOMING EVENTS

- **May 12, 2007.** The Ohio Chapter's annual race, *Run Wild for a Cure 5K Race/1-Mile Walk*, presented by KFC and sponsored by the Cleveland Clinic, will be held this year at the Cleveland Metroparks Zoo.

Organizers are hoping to draw 1,500 attendees to this year's event to raise money in honor of all affected with mitochondrial diseases. For more information, visit www.runwildforacure.org or contact the Ohio Chapter at 330-929-4430 or at OHChapter@umdf.org.



MITO GROUPSM ACTIVITIES

CAROLINA FOOTHILLS

- **August 24, 2006.** The second annual *Goobers Golf Classic* held at Boscobel Golf Course raised \$9,925 in honor of Alex Newton.
- **October 14, 2006.** The *Step Toward a Cure 5K Run/Walk* at the Clemson United Methodist Church raised \$3,579.75 for the Foundation.

Special thanks to Angie Newton,
organizer of both events!

CONTACT: ALLISON ROGERS allisonrogers@hotmail.com



ALEX NEWTON WITH
CLEMSON TIGER

CENTRAL OHIO

- **October 1, 2006.** The sixth annual *Olivia Steele Memorial Golf Outing* was held at the Royal American Links Course in Sunbury, Ohio. About 80 golfers attended the event organized by J.R. Steele. It was a beautiful day, and more than \$5,000 was raised in memory of Olivia Steele.

CONTACT: SHAWNA STEELE ssteele817@sbcglobal.net
MATT KOVALCIK mkovalci@columbus.rr.com

- **March 10, 2007.** The fourth annual *Bet on Baylee* in honor of Baylee Thompson was held at the Zanesville, Ohio, VFW. The casino night event included Texas Hold 'Em and special auctions! Special thanks to all who helped to make the night a success!

DALLAS/FORT WORTH

- **November 15, 2006.** The Sewell Family of Dealerships along with Tory Burch presented the *Tory Burch After Hours Shopping Night*, a night of shopping where 20 percent of sales at Sewell's Dallas location were donated to UMDF. Special thanks to Piper Wyatt and Tova Sido for their help in organizing this event, which brought in a total of \$12,476.50 for the Charles & Louisa Sido Research Fund.

CONTACT: TOVA SIDO ttsido@hotmail.com



CHARLES &
LOUISA SIDO



CONTACT: GRETNA COLE Glou68@aol.com
DAVID DOYLE daviddusa@hotmail.com

PACIFIC NORTHWEST

- **February 3, 2007.** Thanks to Jill Herczog, president of the Mitochondrial Research Guild of Seattle Children's Hospital, and David Doyle, UMDF's Pacific Northwest Mito GroupSM leader, for organizing a successful Northwest Mitochondrial Summit and bringing together UMDF, the Seattle Children's Hospital Mitochondrial Research Guild and Oregon Health and Science University. The professional community was well represented by such notable figures as Dr. Russell Saneto, Dr. Dave Koeller and Dr. Nancy Kennaway.

In our continuing effort to establish collaborative relationships with medical and professional organizations and to foster the formation of new UMDF chapters and groups, we visited the Pacific Northwest to see how we could work together to better address the UMDF mission.

The summit attracted more than 60 family members and professionals between the two meetings held in Seattle and Portland. It was a great opportunity to tell the UMDF story and answer questions about UMDF's strategic goals and mission.

Alone we are but a whisper, but together we become a roar!

UPCOMING EVENTS

- **May 19, 2007.** *Pole Pedal Paddle*, a six-activity event consisting of downhill and cross-country skiing, cycling, running, paddling and sprinting, will be held at Les Schwab Ampitheater in Bend, Ore. For information, contact David Doyle at 541-383-4253 or at daviddusa@hotmail.com.

ST. LOUIS AREA

CONTACT: MARSHA HOHE marshamarshamarshah@charter.net

UPCOMING EVENTS

- **April 7, 2007.** The fourth annual *Mito-What? Family Fun Day* will be hosted in Belleville, Ill. For more information or to find out how you can help, contact Marsha Hohe at 618-233-6919, e-mail marshamarshamarshah@charter.net or go to www.umdf.org/stlousrace to register.

WESTERN PENNSYLVANIA

- **February 11, 2007.** Prior to the Western Pennsylvania Mito Group meeting on February 11, a "Thank You" reception was held for all who helped with the Western Pennsylvania Wine & Spirit stores *Coins for a CureSM* campaign. During the month of December, coin boxes were placed in 240 Wine & Spirit stores across Western Pennsylvania, and \$3,839.11 has been raised to date!



FROM MITO GROUPSM TO UMDF CHAPTER

- **Houston Mito Group Becomes Chapter.** On March 29, the Houston Mito Group will hold its official ceremony signifying its transition from Mito GroupSM to UMDF Chapter status. The meeting will take place at 6:45 p.m. at Genesis BCS, 1225 N. Loop West, Suite 100 in Houston, Texas.

Festivities will include a welcome reception with food and drink, president's announcement, board introduction, review of upcoming events and fundraising opportunities, and a support group meeting on the topic of disease in the home.

In order to become a chapter, a Mito GroupSM must have been in existence for at least six months and must meet the following requirements:

WESTERN MICHIGAN

CONTACT: SUZANNE ARENDS sarends1977@charter.net

• December 31, 2006.

Benjamin (BJ) Young's Uncle Dave and Aunt Kim threw a *New Year's Eve Big Bash* to raise money for UMDF in honor of their nephew. Thanks to Dave & Kim Sprik for raising almost \$400!



CONTACT: KAREN WILSON BWilson@cvzoom.net
HEATHER PALLAS pallas092401@zoominternet.net

A very special thanks goes out to the Pallas family, who helped with 36 stores; the Yeske family, who helped with 10 stores; the Vasilich family, who helped with eight stores; the Murray and Deasy families, who each helped with four stores; the Collins family, who helped with three stores; the Kaempf and Buczynski families, who each helped with two stores; the Wilson family, who helped with one store; and the UMDF staff and their families, who helped with 31 stores. These families helped by delivering the *Coins for a CureSM* containers to each store, checked on them periodically, and collected and counted the coins at the end of the month.

UPCOMING EVENTS

- **June 2, 2007.** The fifth annual *UMDF 5K Run/1 Mile Walk One Step Closer to a Cure* will be held on Saturday, June 2, at the North Park Boat House in Pittsburgh, Pa. If you would like to volunteer for the 2007 race, contact Tania at 412-793-8077 or at taniah@umdf.org.

- Submit minutes from all meetings for past six months.
- Provide one example of publicity or public outreach.
- Submit special events forms and budgets for all events.
- Raise at least \$2000 in fundraising proceeds.
- Process all funds through the UMDF.
- Provide a meeting program or outreach to physicians that achieves a defined educational objective.
- Create a resource list of three or more doctors or agencies that are identified as working with mito patients.
- Complete all monthly reports/activity sheets.
- Have at least four individuals participating in leadership positions.

CHAPTERS, MITO GROUPS AND AMBASSADORS

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St. Louis Area Mito Group

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OREGON

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PENNSYLVANIA

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Erie Mito Group

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Pittsburgh Mito Group

Contact: Karen Wilson or Heather Pallas
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pallas092401@zoominternet.net

Ambassador – Central Pennsylvania

Contact: Kim Olanderski
E-mail: gabby244@dejazzd.com

SOUTH CAROLINA

Carolina Foothills Mito Group
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Ambassador – Chapin, S.C.

Contact: Karis Mott
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TENNESSEE

Ambassador – Crossville, Tenn.
Contact: Regina Norrod
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Ambassador – Dayton, Tenn.

Contact: Kristie Goodwin
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TEXAS

★Houston Chapter
President: Deb Schindler
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Dallas Mito Group

Contact: Tova Sido
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Ambassador – Wichita Falls, Texas

Contact: Shamayn Kennedy
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UTAH

Ambassador – Utah/North Dakota
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VERMONT

Ambassador – Vermont
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WASHINGTON

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WISCONSIN

Ambassador – Kimberly, Wis.
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Ambassador – Waukesha, Wis.

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INTERNATIONAL

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Ambassador – Ontario, Canada
Contact: Robert Sealey
E-mail: sealey@sympatico.ca

UMDF YOUTH AMBASSADOR

California
Contact: Brittany Wilkinson
E-mail: dotoheven@aol.com

New Jersey

Contact: Jamieson Smith
E-mail: Jamster1221@aol.com

For information on starting
a chapter or group, or to
become an ambassador in
your area, contact the UMDF
member services department
at 412-793-8077.

MITO FACTS

- Mitochondria are responsible for creating more than 90 percent of the energy needed by the body to sustain life and support growth.
- When mitochondria fail, less and less energy is generated within the cell, and cellular injury and even cellular death follow.
- Diseases of the mitochondria appear to cause the most damage to cells of the brain, heart, liver, skeletal muscles and kidneys and cells of the endocrine and respiratory systems.

ENERGY FOR LIFE

*A Day in the Life of Brittany Wilkinson,
UMDF Youth Ambassador*

Brittany Wilkinson, a 15-year-old high school sophomore at Clovis East High School in central California, has been called “the most courageous and caring teenager you could ever know.”

She inspires everyone she meets, from fellow students to complete strangers, and if you are lucky enough to meet Brittany, you will easily see why. Her energy is contagious.

Brittany has three confirmed life-threatening mutations of her mitochondrial DNA that leave her with no energy and pain that often lands her in the hospital for extended periods. Her disorder was found to be maternally inherited, and the rest of her family has tested positive also, though their symptoms are much milder.

Although she wasn't diagnosed until age seven, Brittany's hospital stays began at eight months old. She has had three surgeries to correct her ongoing reflux,



though none have fixed the problem, and last year she

underwent brain surgery to implant a shunt to remove excess fluid from her brain. Fatigue and severe muscle pain are constant, and she also suffers from a low heart rate, central apnea and migraine headaches that can last for days. A daily IV infusion of carnitine helps her cells process energy.

To help with Brittany's more basic needs, the family added one more member about two years ago: a service dog appropriately named Freedom. The four-year-old yellow Labrador goes everywhere with Brittany, including the hospital and her school. Freedom can bring Brittany items she needs, can find help and can even turn on light switches, but best of all, she provides constant love and companionship.

Despite the obvious physical drain her disorder causes, Brittany has managed to be among the most active students her age. She participated in the school play at her elementary school and was an extra in two independent films. She even competed in a world tap-dancing competition at age seven, although it was the last time she could dance unaided.



Brittany began using a power wheelchair at age eight, but she continued to perform from her wheelchair as a two-year member of her school's dance team.

“It shows that when something you love is taken away because of this disease, there are other ways or things to replace them,” says Linda Wilkinson, Brittany's mother.

After spending seven weeks in the hospital and missing countless days of school, Brittany graduated from Fairmont Elementary School as an eighth grade valedictorian but was too weak to read her speech at graduation. Instead, her sister, Ashley, and brother, Derron, had to help.

During one recent hospital stay, Brittany decided she had to either give up or do *something* to help. She chose the latter and organized her first golf tournament and dinner/dance weekend from her hospital bed, sending more than 400 letters and e-mails soliciting donations and visiting dozens of businesses in person. Brittany and her energy for life have been featured in stories in such newspapers as *CUSD Today*, the *Sanger Herald*, the *Clovis Independent* and the *Fresno Bee*, and she was recently interviewed for KMPH's *Great Day* morning show.

Brittany was recently named the first UMDF Youth Ambassador, and she is very excited to be able to help others affected by mitochondrial disease in new ways. She is currently being schooled from home because of the amount of time she spends in the hospital, but she still works hard to organize fundraisers to raise awareness and money for research and, someday, a cure. Although she continues to fight a difficult battle, Brittany all the while uses what little energy she does have to improve the lives of affected individuals.

To honor Brittany and her continuing fight with mitochondrial disease, the Wilkinson family established the Brittany Wilkinson Research Fund through UMDF. Money donated to this fund goes to research in Brittany's name.

For more information about Brittany, visit www.brittanywilkinson.org or see page P7 for upcoming events!

SOME OF BRITTANY'S EVENTS:

- Dinner/Dance & Auction at Break the Barriers, Fresno, Calif.**
- Golf Outing at Brighton Crest Golf and Country Club, Friant, Calif.**
- Indoor Soccer Tournament at Hoover High School, Fresno, Calif.**
- Walk-A-Thon at Woodward Park, Fresno, Calif.**
- President's Day Matinee with Fresno Falcons hockey team**
- Neighborhood coin drives**

FROM THE CHAIRMAN

On behalf of the staff and the board of trustees of the United Mitochondrial Disease Foundation, I would like to wish everyone a happy and healthy new year!

The staff especially wanted to thank everyone for their holiday cards, letters and pictures. It was wonderful to see everyone and hear what has been going on in their lives.

The past year has brought many successes, including increased membership, greater participation in the research grant program and heightened public awareness of mitochondrial disease, not to mention a ten-year foundation anniversary. And we are sure that, with your help, the year to come will bring even greater accomplishments for our cause!

January 1, 2007, marked a changing of the guard in the UMDF executive board, and I am pleased to step into the role of chairman after working as vice-chairman for the past four years. I would also like to welcome my new executive board: Vice Chairman W. Dan Wright, Secretary Sharon Shaw and Treasurer Richard W. Kubach Jr.

In this first issue of 2007, I would like to take the opportunity to thank John DiCecco, our previous board chairman, for his time and commitment to UMDF. Even though he did not have any family members afflicted with a mitochondrial problem, John volunteered his time to further our efforts toward a cure. His work on behalf of UMDF was greatly appreciated by all, and his will surely be a tough act to follow.

Another long-time board member, Dr. Bruce Cohen, has also stepped down as a UMDF trustee. Dr. Cohen has worked tirelessly for UMDF throughout the years as a symposium faculty member and two-time chairperson, a committee member, a newsletter contributor and a key medical reference. Despite his continually busy schedule, Dr. Cohen has already pledged his time to several UMDF Grand Rounds events to come in 2007 and beyond.

Joining our board of trustees this year are Amy Goldstein, MD, Leslie Heilman and Richard Leach. Amy Goldstein has long been a UMDF ally in Pittsburgh, serving as faculty for past symposia and writing articles for the newsletter. Leslie Heilman is also no stranger to UMDF, serving as the first executive director from 1999-2001. Richard Leach is a fairly new friend to UMDF, and we are looking forward to applying his expertise in successful non-profit and governmental organizations to further the UMDF mission. You can read more about these newest board members and others at www.umdf.org/about_umdf/trustees.aspx.

We would also like to thank our outgoing Scientific Advisory Board members for their outstanding service and welcome all members of our newly restructured



Scientific and Medical Advisory Board, which will be announced officially in our next issue of *Mitochondrial News*.

And last, but certainly not least, we cannot forget to thank our chapters, Mito GroupsSM

and Mito AmbassadorsSM for their time and effort, and of course for the substantial funds and awareness they have raised. Your work is priceless!

We are beginning to move into "fundraising season," when the weather starts getting warmer, and everyone wants to get outside – and help a great cause, of course. Our volunteers will soon be out in full force organizing walk/runs, family fun days, golf outings and other outdoor sporting events, all with an aim to tell others about mitochondrial disease and make a difference in the lives of affected individuals and their families by raising important funds for research.

Mitochondrial Medicine 2007: Riding the Wave of the Future, UMDF's ninth annual international symposium, is also fast approaching, and plans are underway to make this the best conference yet. Families, patients and scientific and medical professionals from fields such as biochemistry, genetics, neuroscience, cardiology, nephrology, hematology and pediatrics will converge in San Diego, Calif., June 13-16 (June 15-16 for families) to share knowledge and cultivate personal and professional relationships. Join us for the symposium, and stay for a special UMDF benefit concert featuring Jack Black and Kyle Gass of Tenacious D!

With such exciting events coming up, we're sure you'll have a role to play. Until then, stay happy, stay healthy, and stay tuned to the UMDF website for up-to-date information!

Warmest Regards,

A handwritten signature in black ink, appearing to read "Stanley Davis".

Stanley Davis
UMDF Chairman

VAMSI MOOTHA, MD

In 2004, the United Mitochondrial Disease Foundation awarded a research grant of \$90,200 to Vamsi Mootha, MD, of the Broad Institute of MIT and Harvard in Cambridge, Mass., to study genomic approaches to human cytochrome c oxidase deficiency (COX).

Cytochrome c oxidase deficiency is caused by a defect in Complex IV of the respiratory chain. It is a very rare inherited metabolic disorder characterized by a deficiency of an essential enzyme in the mitochondria. COX deficiency can affect the tissues of the skeletal muscles, heart, kidney, liver, brain and/or connective tissue.

Mootha's research group consists of computer scientists, biologists and clinicians who are attempting to understand the role of mitochondria in both rare and common human diseases. They are using a multidisciplinary approach including biochemistry, computer science, genetics and mathematics to identify the genes and networks underlying mitochondrial function in health and disease.

The group's comprehensive computational strategy will identify genes that code for assembly factors responsible for cytochrome



c oxidase. Candidate sequences are validated through the use of RNA interference in cultured cells with subsequent biochemical assay of potential changes in respiratory function.

Using the new tools of genomics, Mootha's group is compiling a protein parts-list for this complex organelle and then using computational strategies to reverse-engineer the cell's instructions for properly assembling these structures. With this information in hand, his group is systematically identifying the genes underlying rare but devastating diseases, such as mitochondrial respiratory chain disorders and maternally inherited encephalomyopathies.

"By integrating the results from our in vitro experiments with those from our human studies, we hope to uncover the biological networks that are operative in human disease," said Mootha.

The longer-term goal of the group is to develop a predictive understanding of mitochondrial function that can be exploited in the development of novel therapies for disorders stemming from dysfunction of this organelle.

A 2004 recipient of the MacArthur "Genius" award for his research on mitochondrial biology and integrative genomics, Mootha is an assistant professor of systems biology at Harvard Medical School and an assistant professor of medicine at the Center for Human Genetic Research at Massachusetts General Hospital.

Mootha received his undergraduate degrees in mathematical and computational science from Stanford University. He received his medical degree in 1998 from the Harvard-MIT Division of Health Sciences and Technology at Harvard Medical School, where his thesis work was focused on mitochondrial physiology. After completing his internship and residency in internal medicine at Brigham and Women's Hospital in 2001, he worked as a visiting scientist at MDS Proteomics in Denmark. He then completed a postdoctoral fellowship at the Whitehead Institute/MIT Center for Genome Research.

Dr. Mootha will be speaking to the scientific attendees at the symposium in June. See UMDF.org for details!

SYMPTOMS OF CYTOCHROME C OXIDASE DEFICIENCY

- ***Encephalomyopathy.***

Typically normal for the first six to 12 months of life and then show developmental regression, ataxia, lactic acidosis, optic atrophy, ophthalmoplegia, nystagmus, dystonia, pyramidal signs and respiratory problems. Frequent seizures. May cause Leigh Syndrome.

- ***Myopathy.***

Main variants:

- ***Fatal infantile myopathy.***

May begin soon after birth and is accompanied by hypotonia, weakness, lactic acidosis, ragged-red fibers, respiratory failure and kidney problems.

- ***Benign infantile myopathy.***

May begin soon after birth and is accompanied by hypotonia, weakness, lactic acidosis, ragged-red fibers, respiratory problems. Can be followed by spontaneous improvement.

DEVELOPMENT

SUPPORTING OUR CAUSE

COINS FOR A CURESM IS EXPANDING

UMDF now has attractive, lockable acrylic coin boxes for you to place in stores and businesses around town. The boxes measure six inches by four inches by three inches and have a six-inch by five-inch backdrop with information about UMDF and mitochondrial disease. We can send you one or 100!

Contact Tania today at 412-793-8077 ext. 102 or at taniah@umdf.org to get your Coins for a CureSM campaign started or to reserve your Home Collection Box (see below)!

TEA FOR MITOSM

Tea for MitoSM, UMDF's new fundraiser, is a "virtual" tea party that will be one of the easiest fundraisers you can do!

UMDF will provide you with the Tea for MitoSM host or hostess kit that includes invitation cards, response cards, envelopes and tea bags. All you have to do is "invite" your family, friends, acquaintances and co-workers to enjoy a cup of tea in the comfort of their own homes while thinking of you and supporting your cause with a donation to UMDF!

If you would like more information about Tea for MitoSM, contact Tania at 412-793-8077 ext. 102 or e-mail taniah@umdf.org.



SPECIAL THANKS TO CIBC

UMDF would like to send a special "Thank You!" to CIBC World Markets for their support of UMDF through Miracle Day on December 6.

On Miracle Day, 95 percent of CIBC World Markets' net commissions from trades made through the firm that day are donated to more than 350 participating Miracle Day charities located throughout the United States. This December, UMDF was one of those chosen charities.

We truly appreciate the help of brothers Lee and Skip Trachtman, who contacted UMDF volunteer and donor Michael Friedberg, whom they had heard on the radio promoting his walk and golf tournament in New Jersey. Michael introduced them to UMDF, and after applying, we were accepted. This year we received \$5,000!

If you trade in the stock market and can trade through CIBC, please contact the development department so you can be added to the list to be notified of our participation in Miracle Day next year.

'FIVE PERCENT DAY' AT WHOLE FOODS

Do you have a Whole Foods Market in your area? If so, ask them about their "Five Percent Day." Charities may apply to this program and, if accepted, will receive five percent of the store's sales from that day. Stop by the Whole Foods customer service desk to pick up an application. If you need assistance in completing the application, do not hesitate to contact the development department.

COINS FOR A CURESM HOME COLLECTION BOXES

We are pleased to introduce our Coins for a CureSM Home Collection Boxes! These boxes are made of cardboard and can be easily unfolded for mailing and assembled for your use. The boxes can be used anywhere in your home where you might have extra change, such as your laundry room, kitchen or bedroom. Home Collection Boxes are available today!

Thank you to the Zucker/Uhrman Philanthropic Fund for their support of the Home Collection Boxes!

Their ongoing support over the years has been invaluable. Their gift has made this important fundraising and awareness project possible.



CIBC
World Markets

APPRECIATING THOSE ALONG THE WAY!

While we would like to list ALL of our donors individually, please understand that it would be very difficult to do so, with 3,613 names that donated \$1-\$99 (**THANK YOU!**), 1,278 names that donated \$100-\$249 (**THANK YOU!**) and 337 names that donated \$250-\$499 (**THANK YOU!**).

Please know that we have not forgotten and deeply appreciate each and every individual, organization and corporation that has generously donated money to support our mission. We know who you are, and you are appreciated! Your contributions continue to make a difference in the lives of those affected with mitochondrial disease.

The following acknowledgements include donations of \$500 or more entered into the system between July 1, 2006, and Dec. 31, 2006. We continue to move through a database transition, so we need to know if our information is not accurate! If your name or company's name is incorrect or not listed, please contact kara@umdf.org.

BENEFATOR \$10,000+**Corporations, Organizations and Foundations:**

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			Lee-Jun Wong

MARK YOUR CALENDARS!

- **March 12-16, 2007.** The Beta Club, a community service group at Lanier Middle School, will host a St. Patrick's Day awareness fundraiser in Roswell, Ga. Organizer Michele Meddin and the club will be selling UMDF energy bands to help create awareness of mito in honor of Michele's niece, Anna Lewis.
- **March 16-18, 2007.** The third annual *Writers at the Beach: Pure Sea Glass*, a three-day writers conference, will be held in Rehoboth Beach, Del., in honor of Sam and Zachary Juhlman. For more information, contact Maribeth Fischer at info@writersatthebeach.com or visit www.writersatthebeach.com.
- **March 17-18, 2007.** *Preston's March for Energy* in honor of Preston Buenaga will be held March 17 during the Shamrock Sportsfest in Virginia Beach, Va. The Shamrock Marathon will be held the following day. Contact Deb Buenaga at dsb6891@earthlink.net or visit www.shamrockmarathon.com for more information.
- **March 23-24, 2007.** The *Caroline's On My Mind Weekend* events will benefit the Caroline Virginia Pulliam Mitochondrial Disease Fund. The event, held in Spartanburg, S.C., will consist of a golf tournament Friday and a 5K walk/run and BBQ/band party Saturday. For more information, contact Matthew Myers at 864-596-5022 or e-mail matthew.myers@firstcitizenonline.com.
- **March 25, 2007.** Marilyn Arkin has already exceeded her \$10,000 goal, raising over \$16,000 in honor of Ross Cooper. Now she's focused on completing the 13.1 miles of the ING Atlanta Half Marathon! Good Luck Marilyn!
- **April 7, 2007.** The fourth annual *Mito-What? Family Fun Day* will be hosted in Belleville, Ill., in honor of all affected. For more information or to find out how you can help, contact Marsha Hohe at 618-233-6919 or e-mail marshamarshamarshah@charter.net.
- **April 21, 2007.** The third annual *Kindbom Cheers to You, Hope to Others* fundraising event will be held in Medford, N.J., in honor of Rachel Kindbom. The event will include a theme basket raffle and wine tasting. For more information, contact Sharon or Chris Kindbom at chrisnsharonk@comcast.net or 609-714-1443.
- **May 12, 2007.** The Ohio Chapter's annual race, *Run Wild for a Cure 5K Race/1-Mile Walk*, presented by KFC and sponsored by the Cleveland Clinic, will be held this year at the Cleveland Metroparks Zoo. Organizers are hoping to draw 1,500 attendees this year to raise money in honor of all affected with mitochondrial diseases. For more information, visit www.runwildforacure.org or contact the Ohio Chapter at 330-929-4430.
- **May 13-19, 2007.** The seventh annual *Kites for Kristen* will be held in Chicago, Ill., in honor of Kristen Charleston. Activities include kite decorating, a jeans day, a silent auction and a raffle. For more information, contact Pat Charleston at 773-229-0605 or e-mail Russ_Pat@sbcglobal.net.
- **May 19, 2007.** *Pole Pedal Paddle*, a six-activity event consisting of downhill and cross-country skiing, cycling, running, paddling and sprinting, will be held at the Les Schwab Ampitheater in Bend, Ore. For information, contact David Doyle of the Pacific Northwest Mito GroupSM at 541-383-4253 or daviddusa@hotmail.com.

- **May 20, 2007.** The Bonney family and friends are pleased to present the first *Bike-A-Thon* in memory of Elijah William Bonney at Haines State Park in Barrington, R.I. The ride starts at 10:00 a.m. and will follow the East Bay bike path in Barrington/East Providence. For more information, call Dave Bonney at 401-215-5844 or e-mail davebonney@aol.com.
- **May 20, 2007.** Join Linda and Brittany Wilkinson for a golf outing in honor of Brittany at Brighton Crest Golf Course in Friant, Calif. For information, call 559-299-1767 or visit www.brittanywilkinson.org.
- **June 2, 2007.** The fifth annual *UMDF Pittsburgh 5K Run/1 Mile Walk 'One Step Closer to a Cure'* will be held on Saturday, June 2, at the North Park Boat House in Pittsburgh, Pa. If you would like to volunteer for the 2007 race, contact Tania at 412-793-8077 or taniah@umdf.org.
- **June 2, 2007.** Join the Dobke family of Waukesha, Wis., for a golf outing at Old Highlander Golf Course in honor of Brianna Dobke. Golf fees are \$100 per person. There are multiple prize holes and challenge holes throughout the course. A variety of sponsorship opportunities are available. For more information, call David Dobke at 262-853-4045 or e-mail RedefineHope@Hotmail.com.
- **June 9, 2007.** The *Ally Brunk Memorial 5K Walk/Run* will be held in Potterville, Mich. For more information or to find out how you can help, contact Dan or Julie Brunk at 517-627-3715 or e-mail brunkfam06@aol.com.
- **June 16, 2007.** Come for the symposium in San Diego, stay for the UMDF Benefit Concert with Jack Black and Kyle Gass of Tenacious D. Venue and additional information to be announced. Visit www.umdf.org for updates.
- **June 23, 2007.** The fourth annual Kansas City Chapter's *Mito-What? One Step Closer to a Cure 5K Run/1 Mile Walk* is set to include kids' activities such as with face painting, games, music and a special kids' dash in Overland Park, Kans. Contact Theresa Edwards for more information at 816-587-1375 or e-mail kccchapter@umdf.org.
- **July 28, 2007.** The Delaware Valley Chapter's fourth annual *Brew at the Zoo* will be held at the Elmwood Park Zoo in Norristown, Pa. Breweries and more than a thousand beer aficionados come together to sample the best beers in the area, eat great food, listen to music and, of course, check out the animals at the Zoo. For more information, contact Bob or Lisa Polsky at 610-275-2775 or visit www.brewatthezoo.net.
- **Summer 2007.** Our *Miles for Mito* riders won't be joining us this year at the symposium in San Diego, but plans are underway for a virtual *Miles for Mito* event and a ride in Indy for the 2008 symposium. For more information, or to see how you can help, contact Sue Ann Bube at 317-894-9099 or at sbube@comcast.net.
- **October 6-7, 2007.** The New England Chapter's *Weekend of Hope 5K Walk and Family Fun Zone* will be held Saturday, October 6, in Plymouth, Mass., and Sunday, October 7, in Longmeadow, Mass. Your help is needed to plan the chapter's biggest event! If you have expertise in marketing, event planning or project management, or if you just want to get involved, please contact the chapter at NEngChapter@umdf.org. We need you to continue to make the *Weekend of Hope* a huge success.
- **Fall 2007.** Join the Indiana Chapter for a Fall walk/run and concert in Indianapolis. Contact John Goerges at 317-645-6142 or John.Goerges@gmail.com for more information.

JOIN US IN SAN DIEGO!

MITOCHONDRIAL MEDICINE 2007: RIDING THE WAVE OF THE FUTURE

CATAMARAN RESORT HOTEL AND SPA, SAN DIEGO, CALIFORNIA
SCIENTIFIC MEETINGS JUNE 13-16, 2007 • FAMILY MEETINGS JUNE 15-16, 2007

THANKS TO OUR KEY SPONSORS

Office of Rare Diseases, NIH



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Registration brochures are being mailed, and online registration is available at www.umdf.org!

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PARTNERS IN PROGRESS

A Day in the Life

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Research Spotlight

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Donors

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Upcoming Events

P7-P8

As the perfect finale to the UMDF Symposium, please join **Jack Black** and **Kyle Gass**, the certified Platinum duo **Tenacious D**, for a special concert as they **rock your socks off!**



Kyle Gass and Jack Black

Concert will be held in San Diego on Saturday evening. Discount tickets will be available to conference attendees and UMDF members. More details to follow. Visit www.umdf.org for updates.

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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.

FUNDRAISING HIGHLIGHTS

• **June 17, 2006.** The third annual *Ally Brunk Memorial 5K Run/Walk* was held in Potterville, Mich. Dan & Julie Brunk raised \$2,700 in memory of Allyce Danielle Brunk.

• **October 7, 2006.** Kelly Pierce and the Beta Tau Chapter of Delta Gamma at the University of Miami held a walk/run, raising more than \$1,500.

• **October 22, 2006.** The third annual 5K run/1-mile walk in Marlboro, N.J., organized by Michael and Rhonda Friedberg, raised money for the Zachary Friedberg Research Fund. The \$25,000 donation to UMDF also included proceeds from a golf fundraiser on Sept. 26.

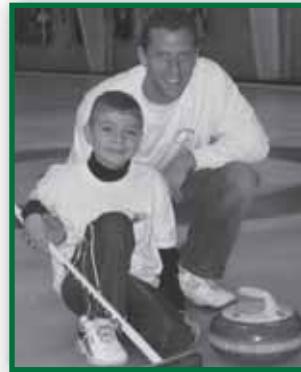
• **November 5, 2006.** The First United Methodist Church of Franklin, Tenn., held an alternative gift market in honor of Andrew Garrison. A contribution of more than \$460 was made to UMDF, and a Christmas card was sent to each donor with UMDF information.

• **January 12, 2007.** The fourth annual *Mito-What? Post-Holiday Gift Recycling Party* was held in McLean, Va., in honor of David Hefferon. The party, organized by Elizabeth Hefferon, included a silent auction of re-gives and raised a total of \$7,113.

• **February 5-17, 2006.** The fourth annual *National Honor Society Basket Raffle* was held at Minnechaug Regional High School in Wilbraham, Mass. Sara Martin and NHS members raffled theme baskets for UMDF.

• **February 17, 2006.** The fourth annual *Curl-O-Rama*, sponsored by Chesapeake Physical & Aquatic Therapy, was held at the National Capital Curling Center in Laurel, Md.

The Bowie Baysox Curling Team beat Team Trinity 6-1 in five ends. Silent and live auction events benefited the Lustgarten Foundation for Pancreatic Cancer Research and UMDF in honor of Peter Lubelczyk (above).



• **February 19, 2006.** The Fresno, Calif., Falcons hockey team hosted a matinee and donated 200 tickets to the Wilkinson family. \$1,000 was raised to benefit UMDF through the Brittany Wilkinson Research Fund.

• **February 23, 2006.** The first *Cards for a Cure* casino night event was held at the Plantation Clubhouse in Destin, Fla. Proceeds from the event will be donated to UMDF in honor of Robert Tucker.

• **March 9, 2006.** At *Ramsey's 8th Annual Charity Basketball Game*, teachers played against local VIPs, and Ramsey cheerleaders provided entertainment. Proceeds from the event organized by Brian Werner will be sent to UMDF and Autism.

• **March 10, 2006.** A dinner/auction to benefit the Brittany Wilkinson Research Fund was held at Break the Barriers in California. Thanks to Linda & Brittany Wilkinson for their tireless fundraising and awareness efforts!

• **March 12, 2006.** To kick off *Preston's March for Energy*, students in the walking club at Forwood Elementary School in Wilmington, De., walked in honor of Preston Buenaga and received club points for their efforts!

We do our best to include all events. To help ensure your event is included, send all necessary information to info@umdf.org.

GIFTS FROM THE HEART

- In honor of Connor Clifton's second birthday October 7, donations were accepted in lieu of toys, and \$200 was donated to UMDF.
- Joan Daly and the 2A second-grade class at St. Jude Elementary School in Chalfont, Pa., donated \$200 in honor of Juliet Belcher.
- Deb's Threads in Pittsburgh sent a holiday donation of \$50 in honor of all employees and volunteers of UMDF.
- As a Christmas gift to boss Ed Feeney, the staff of Emerson Network Power donated \$525 to UMDF in honor of his granddaughter, Ellie Kovalcik.
- In Boston, the Grantham, Mayo, Van Otterloo & Co. (GMO) legal department chose UMDF as their annual charity, and funds were matched by GMO. A total of \$4000

was raised in honor of Sean Munzer.

- Sister Clara Mohan of New York held a full dress day induction for the National Honor Society. Fifty dollars was raised in memory of Gina Mohan.
- Propel East Charter School of Turtle Creek, Pa., held a jeans day and raised \$70 in honor of all affected.
- UMDF Trustee Joseph Rice and his wife, Patricia, along with his daughter and son-in-law, Sandy and Richie Bruns, organized a letter writing campaign in memory of Sandy's mom, Linda Rice. Linda celebrated



her 10th anniversary in Heaven March 7, and the family hopes this campaign helps to celebrate her life.

- St. Margaret of Scotland School in Western Pennsylvania held a jeans day in honor of Thomas and Danielle Deasy, raising \$174 for UMDF.
- Sterling Images Photography Studio at the Dulles Town Center in Dulles, Va., donated \$1 for each Halloween photo taken. Allison Fischer-Stasiowski arranged this event, which raised \$128 in honor of Michael DiLorenzo.
- Nine-year-old Michael Watts of Georgia donated birthday money in the amount of \$140 in honor of Ty Seldes.
- Eugenia Zyga of Garfield Heights, Ohio, made and sold scarves and donated \$70 to UMDF in honor of her great granddaughter, Melanie Kraig.

FUNDRAISING HIGHLIGHTS

COINS FOR A CURESM

- Hope Eacrett of Lowell, Mass., raised \$2,538.73 in memory of Natalie Jean Eacrett at Kids on Track Preschool and Wang Middle School.
- Rita Grosso of Indiana collected \$100 outside of the Walmart in Monticello, Ind., in honor of Riley Henderson.
- Megan and Stephanie Fonagy of Cecil, Pa., raised \$1092.50 at Canonsburg Middle School in honor of Austin Manz, Megan's cousin.
- Beth Hartman of the Delaware Valley area collected \$44 in just one month at Sylvestris Restaurant in honor of Haley Hartman. The campaign is set to continue through the rest of the year!
- Marion Hunsberger of the Delaware Valley area raised \$1,080 at Carversville General Store and Philip's Wine & Spirit in memory of Jeffery & Heather Hunsberger.
- Donna Mohan of the New York Metro area has collected \$325 to date from various locations. She has six friends and family members in New York and New Jersey helping to raise money in honor of Michelle Mohan.

- Angie Newton raised \$969.60 in honor of Alex Newton at Central Elem. School.
- Debra & Emilee Pace of St. Harrison, Ark., raised \$52.54 at the Bank of the Ozark in honor of Emilee Pace.
- Mike and Kristen Quarles of the Atlanta area raised \$7,437.95 in memory of Palmer Quarles at Macedonia Elementary School, where Palmer's brothers, Preston and Parker, attend school. Ms. Eckard's class came in first place raising \$1,714.62, Ms. Ferrante's class came in second raising \$663.21 and Mr. Arnett's was third raising \$367.21.



- The Roberts family of Ohio raised \$370 in honor of Hannah Roberts at Orchard

- Hill Elementary School, where Hannah's sister Jamie (right) attends school.
- The Sharon School near Atlanta raised \$42.80 in honor of Rebecca Paul.
- St. Bernadette's Catholic School in Monroeville, Pa., raised \$1238.06 in memory of Gina Mohan. This is the sixth year for this campaign run by Sister Carol Arch (below, with coins)!



CURRENT 'COINS' CAMPAIGNS

- Sherri Breslow of the Delaware Valley area will campaign at Rosa International Middle School in honor of Sydney Breslow.
- Amanda Brose of Williston, N.D., will collect at Little Tetons Daycare in honor of Logan Palmer.
- Paul and Maura Buckley of New England will campaign at Lexington Center Retailers in honor of Neil and Tyler Buckley.
- Jennifer Bukovac of Virginia will place canisters at Starbucks and restaurants in honor of Stephen and Samuel Bukovac.
- Jennifer Clifton of Southern Florida will collect from various stores in her area in honor of Connor Clifton.
- Dustin & Kelly Ann Conover of Concord, Calif., will collect coins for the Brandon Leach Research Fund.
- Nicole Goerges of Noblesville, Ind., will place canisters at Sandy Creek

- Elementary School in honor of Abigail Goerges.
- Mary Hamilton and the Boys and Girls Club's Keystone Club of Rice Lake, Wis., will be placing containers in 11 schools and 10 stores as their service project in honor of Jake Hamilton.
- GinaMarie Hammer of the Delaware Valley area will place canisters in stores in honor of GinaMarie, Anthony and Kathryn Hammer.
- John, Nora and Nick Hodgson and Mary and Michael Brunelli, all of New York, will be collecting coins at their school in honor of their cousin, Stephen Bukovac.
- Norma Kohnen of Western Pennsylvania will be placing boxes in various stores throughout the area in honor of John Kohnen.
- Jennifer Kokora of Clifton, N.J., will campaign at schools #8 and #17 in honor of Andrew Pisarczyk.

- Susie Leach of Chevy Chase, Md., will collect at various locations for the Brandon Leach Research Fund.
- Diana Nieves of the New York Metro area will collect coins from Quality Building Construction and Touch of Class Hair Salon in honor of Nicole Kelli Nieves-Roberts.
- Jessica Savasta of Eighty Four, Pa., will collect coins in memory of Lukas Friend.
- Kim Stover of South Elgin, Ill., will campaign in honor of Andrew Stover.
- Leigh Ann Tucker of Ohio will place canisters in stores in Ohio and Florida in honor of Robert M. Tucker II.
- Melissa and Diane Weiner of the Pacific Northwest will collect coins at Bethel High School in honor of Melissa Weiner.
- Linda Wilkinson of Clovis, Calif., will collect coins at Clovis East H.S. and Golden Valley H.S. in honor of Brittany Wilkinson.

Anew chapter in the story of David Hamm's life began on, of all days, April Fool's Day in 2005.

It was then that he was given the diagnosis of a rare, non-curable and eventually fatal genetic disorder. He asked his doctor about the possibility of a misdiagnosis. Perhaps it would later be determined that he simply had a common cold.

To his disappointment, the doctor replied, "I am so sorry, but you do not have the common cold."

The diagnosis was MELAS Syndrome, a progressive neurodegenerative disorder that David had never heard of. Neither had his primary physician nor his neurologist, who had been treating him since May 2003 when he suffered a stroke that left him temporarily paralyzed in his left side.

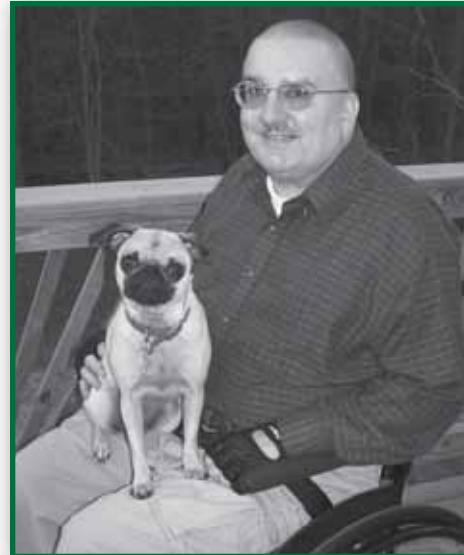
"I still respect both doctors very much because they did not make any mistakes," he says. "They simply did not know. With the complexity of illnesses and treatments and the many types of specialists that are available to us, it is easy to see how a single doctor could not put all of the puzzle pieces together."

It was a major lifestyle change for David to learn that he would be permanently disabled and unable to return to work, as his disorder is neurologically degenerative and things will likely get worse over time. It was a blessing in disguise, though, to finally have a possible explanation for some of the symptoms he experienced over the years, such as sweating "profusely" when getting dressed in the morning or tiring quickly while performing the simplest tasks.

If you could only do 5 percent of your normal activities, what changes would you make in your lifestyle? As David quickly found out, how he spends his limited energy became more important than how he manages his time. He no longer has a full day to do things and, depending on the activity, might only have enough energy to stay active for a fraction of the day.

"With the time that I have left on this earth, I plan to make a difference by educating anyone that wants to learn about the mitochondrial family of disorders," David pledges.

To help him spread awareness, David has an unusual ally – an 18-month-old female Pug named Mito. Now, Mito may sound



like an odd name for David's sidekick, but her name serves two purposes. First, it "breaks the ice" when David explains to new acquaintances that her name is an acronym for "More Intelligent Than Owner." It also opens the door for a more serious discussion on mitochondrial disease. David says Mito is an inspiration for him to fight his life-compromising

mitochondrial disorder. She gives him encouragement and inspiration to press onward against her namesake.

"You see, as mito with a lowercase 'm' tries to steal my life, Mito with an uppercase 'M' keeps me active and hopeful," Dave says. "She is a great conversation tool."

Even though David suffers from the effects of having MELAS, requiring a wheelchair and, now, going deaf, he and his wife have refocused their energy to expand their DAT Ministries (short for David and Theresa Ministries) to thousands of new people that are fellow "Wheelies" and "Deafies."

"It is just another assignment for us where we can better understand what others are faced with on a daily basis," he says. "In ministry, the better you can relate to somebody, the better probability that they will truly listen to what you have to say. The 'been there, done that' badge on the shirt opens many doors."

David continues to raise awareness about mitochondrial disease as the leader of the D.C. Area Mito GroupSM of UMDF. To see how you can become involved in Mito GroupSM activities in the Washington, D.C., area, contact David at admin@datm.org.

RAISING AWARENESS

On February 1, Norma Gibson, a UMDF Ambassador, spent about an hour educating Jane Enloe's class at Sequoia Middle School in Pleasant Hill, Calif., about mitochondrial cells, how they work in the body and how things can go wrong, using her daughter, Heidi, as an example of how things can progress.

Thirty 11- and 12-year-old students sat totally quiet and listened intently to Norma's speech, and they had really terrific questions following the presentation. Students were given a handout illustrating a drained battery as a comparison to mitochondrial disease, and each received a UMDF bookmark.

"It was a fun day and the class seemed very appreciative," said Norma. "It was a wonderful class."

Two of the girls from the class, Kayla Hasson and Britney McClanahan, were doing a report on mitochondrial disorders because Britney's five-year-old sister has been diagnosed with



a mitochondrial disease.

The picture of Norma and Kayla above was taken outside of the classroom. Unfortunately, Britney was unable to attend school that day due to illness.

FROM PAGE ONE

TRAVELING WITH DISABILITIES (CONT.)

supplies before the screening process begins. If this is your preference, please have these materials separated from your other property when you approach the security officer at the metal detector. To prevent medication, medical supplies or fragile medical materials from becoming contaminated or damaged, passengers are required to display, handle and repack their own medication and associated supplies during visual inspection. Any medication and/or supplies that cannot be cleared visually will be x-rayed.

Supplemental personal medical oxygen and other respiratory-related equipment can be taken through the security checkpoint, but only after it has been screened. Passengers are required to disconnect their oxygen for the canister and system to be x-rayed. Be sure to check with your doctor before departure to make sure you can disconnect your oxygen safely. If your doctor says that you cannot safely disconnect your oxygen, or if you are concerned, ask the security officer to use an alternative process to inspect your oxygen source while you stay connected to it.

Please note that federal regulations prohibit airlines from allowing passengers to bring their own oxygen canisters onboard to use during the flight, so passengers are responsible for making arrangements with the airline, friends, relatives or a local supplier to remove the canister from the gate area immediately after they board the aircraft. Passengers are also responsible for contacting the airline to arrange for supplemental oxygen onboard the aircraft and for arranging for a local provider during layover stops and at the final destination.

If you employ the use of a service animal, you should inform the safety officer that the animal is a service animal and not a pet. This will provide you with an opportunity to move to the front of the screening line since the officer may need to spend more time with you. Appropriate documentation and the presence of a harness or markings on the harness will help to assure the officer that you use the animal for a disability.

Passengers must assist with the inspection process by controlling the service animal while the officer conducts the search. At no time during the screening process will you be required to be separated from your service animal. Security officers have been trained not to distract,

interact with, feed or pet service animals and should ask permission before touching your animal or its belongings.

Air carriers are required to allow passengers to stow wheelchairs or component parts of a mobility device under seats or in overhead compartments. They must permit one folding wheelchair to be stowed in a cabin closet or other approved priority storage area. If the passenger using the device pre-boards the airplane, stowage of the wheelchair takes priority over the carry-on items brought on by other passengers boarding at the same airport.

When stowed in the cargo compartment, wheelchairs and other assistive devices must be given priority over other cargo and baggage and must be among the first items unloaded. Mobility aids will be returned to the owner as close as possible to the door of the aircraft or at the baggage claim area, depending on the passenger's request made before boarding.

On certain aircraft, electric wheelchairs or other devices too large to fit in the cabin or in the cargo hold in one piece will have to be disassembled in order to be transported. When assistive devices are disassembled, carriers are obligated to return them to passengers in the condition that the carrier received them.

Carriers must allow the transport of battery-powered wheelchairs, except where cargo compartment size or aircraft airworthiness considerations prohibit. If the chair is powered by a spillable battery, the battery must be removed if the wheelchair cannot be loaded, stored, secured and unloaded always in an upright position. Batteries that are nonspillable do not need to be removed under DOT regulations, but rules require nonspillable batteries to be clearly marked. The carrier may remove a battery that is not marked as nonspillable if the wheelchair cannot be loaded, stored, secured and unloaded always in an upright position.

The airline carrier cannot make passengers sign a waiver of liability for damage or loss of wheelchairs or other assistive devices, but they can make note of any pre-existing defect to the device. On domestic trips, the airline's liability for checked baggage is limited to \$2,500 per passenger, but this limit does not apply to wheelchairs or mobility devices. When such a device is lost or destroyed on a domestic trip, compensation is calculated using the original purchase price of the

(continued on page 13)

HYPERBARIC OXYGEN TREATMENT (CONT.)

has never been a controlled trial for the use of hyperbaric oxygen in the treatment of mitochondrial disorders with human subjects.

The issue with patients who have electron transport chain disorders is an inability to reduce molecular oxygen, which we breathe, into water, which we excrete, because of a block in complex IV or proximal and distal subunits. For the purpose of energy production, it is counterintuitive to believe that putting more oxygen into this system would be helpful. Hence, hyperbaric oxygen would not push energy production, unless the problem with the mitochondrial disorder was caused by an oxygen binding issue with complex IV, which has not been described.

Excessive oxygen results in free radical production, and because there is adequate proof that excessive free radical production results in further damage to the mitochondria in many mitochondrial disorders and mitochondrial models, the use of hyperbaric oxygen poses a relative risk.

There is an inherent danger in any single case report demonstrating a treatment benefit in a patient. Please consider the following:

- There are hundreds of mitochondrial disorders, and successful treatment of one disorder will not translate into successful treatment of others.
- With case reports, especially those where the report is based on retrospective views of function without objective measurements,

there is potential bias on both the parents' and physicians' parts.

- If there is a conflict of interest, especially a financial conflict of interest, it should be mentioned one way or another in a report. In the case of hyperbaric therapies, the physician that makes the report may be an owner or part owner of the hyperbaric facility or benefit in some other financial way. If a conflict exists, it should be stated. If a conflict does not exist, it should be stated.
- The issues we have seen are based on newspaper reports, not reports in peer-reviewed journals.
- There is a problem with proof of principle. The science of mitochondrial disorders, as we understand them, is that patients would worsen with extra oxygen.
- If the single patient does have a mitochondrial disorder AND truly gets better with hyperbaric oxygen, there may be other factors that could explain the improvement.

UMDF strongly suggests that you seek the advice of a physician with clinical experience in the treatments of mitochondrial disease and who is familiar with your affected family member's medical history before considering any treatment regime.

UMDF, with the limited scientific information available for review, cannot at this time endorse the use of hyperbaric oxygen therapy (HBOT) for the treatment of mitochondrial disease.

TRAVELING WITH DISABILITIES (CONT.)

(continued from page 12)

device. However, this expanded liability for assistive devices does not extend to international trips, so check with your airline before your international departure.

Disability and medically related items permitted beyond the checkpoint include: wheelchairs and other mobility aids, support braces and appliances, service animals, baby apnea monitors, exterior medical devices, assistive/adaptive equipment, CPAP machine respirators, tools for equipment disassembly/reassembly, personal supplemental oxygen, medications and any other disability-related equipment or supplies.

The limit of one carry-on and one personal item does not apply to medical supplies, equipment, mobility aids or assistive devices carried or used by a person with a disability. As always, make sure to have an identification tag on all your carry-on items, mobility aids and other equipment.

OTHER PROVISIONS CONCERNING ELECTRIC WHEELCHAIRS:

- *The battery of a wheelchair may not be drained.*
- *Carriers cannot charge for packaging wheelchair batteries.*
- *Carriers may require passengers with electric wheelchairs to check in one hour before flight time.*
- *Passengers must be allowed to provide written instructions regarding the disassembly and assembly of their wheelchairs.*

TRAINS

If you are planning a trip by train, Amtrak suggests that you make reservations to hold the space and accommodations needed for wheelchair space, transfer seats (to travel in a seat and stow wheelchair) or accessible sleeper accommodations. Because accessible space is limited, reservations should be made as far in advance as possible.

Discounts are available to passengers with disabilities when reservations are made by phone or at a ticket counter. Written documentation of the disability must be provided at the ticket counter and when boarding. Acceptable documents include a transit system ID card, a membership card from a disabilities organization or a letter from your physician.

Most Amtrak stations in major cities and across the country are handicapped accessible, and all stations are expected to be fully accessible by 2010. Information about station accessibility is available by contacting Amtrak at 1-800-USA-RAIL.

Passengers should arrive at the station at least one hour prior to departure, in case there are others needing assistance also. Courtesy wheelchairs and wheelchair lifts are available at most staffed stations, and Amtrak staff can assist you in boarding and detraining at both high- and low-level platforms and on bi-level trains. Amtrak also offers meal service options that include service in your room or at your seat or service in the lounge car, when possible.

If you use a wheelchair designated by the ADA as "common," including battery-operated chairs, you can choose to remain in your chair throughout the trip. Otherwise, many train cars also have accessible seating, where you can sit while storing your chair nearby. Wheelchairs or mobility aids should not exceed 30 inches wide, 48 inches long and two inches of ground clearance and should weigh less than 600 pounds when occupied.

Should your disability require you to bring oxygen on the train, you

will need to notify Amtrak when making your reservations or within 12 hours of your departure. Oxygen is prohibited on trains except for passengers with a medical necessity.

Your portable oxygen container must be able to operate for a minimum of four hours without available onboard electrical power, and equipment must be UL or FM listed. Each tank and its equipment must weigh 50 pounds or less per unit. Oxygen systems must be either a two-tank system (max. 50 pounds per tank) or a six-tank system (max. 20 pounds per tank) that allows tanks to be separated and handled individually.

Trained service animals accompanying passengers with disabilities are allowed in all customer areas in stations, on trains and on Amtrak Thruway motorcoaches. You are required to keep your service animal under control at all times; the animal should always be on a leash or in a carrier, except as needed for boarding and detraining. If schedules permit, you may walk your animal at station stops, but you must notify the conductor when you first board the train.

MOTORCOACHES

When traveling by bus with Greyhound, it is suggested that you contact the customer disability hotline at 1-800-752-4841 at least 48 hours before your departure and provide the operator with your specific travel needs and schedule. You should also inform Greyhound employees of any special needs you may have during your trip.

There are three assistance options to help disabled passengers to board a Greyhound bus: a lift-equipped bus, alternative lift equipment and manual lifting. When using a lift-equipped bus, the total weight of the passenger and wheelchair or mobility aid cannot exceed 600 pounds, and the wheelchair itself must be less than 30 inches wide and 48 inches tall. If you can transfer independently to and from a wheelchair to the alternative lift equipment (Scalamobil), your weight must be 265 pounds or less. If manual lifting is required, your weight may not exceed 200 pounds.

Your wheelchair may travel inside the bus if it can be safely stowed in the overhead compartment. Chairs or scooters that cannot be safely stowed inside the bus will be placed in the baggage compartment, if possible. The dimension of the baggage compartment is 33 inches x 33 inches x 48 inches, and the maximum weight limit for mobility aids is 200 pounds. If your mobility aid is stowed in the baggage compartment, ask a customer service agent for a claim check in case of damage or loss; a maximum reimbursement of \$250 is allowed per adult ticket purchased.

Portable oxygen and respirators are permitted on the bus with a maximum of two canisters aboard the bus and two in the baggage compartment. Oxygen canisters to be stored in the baggage compartment must be in protective cases with safety caps on the valves, and each container may not exceed 4.5 inches in diameter or 26 inches in length. Customers are responsible for ensuring that they have enough oxygen to complete their travel and are responsible for making arrangements for refills en route.

Customers with disabilities who use a service animal are welcome on Greyhound buses with the understanding that the service animal is the responsibility of its owner and must be under control at all times.

If you require assistance that Greyhound cannot provide, consider including a personal care attendant (PCA) in your travel plans. Requests for a half-price PCA ticket must be made at least 24-48 hours prior to departure. PCAs must be capable of providing assistance, travel the entire trip with the customer and be at least 12 years of age. Picture identification is required for ticket to be issued, and the half-price PCA ticket cannot be combined with any other reduced fare.

For more information about traveling with a disability, visit www.tsa.gov, www.amtrak.com, www.greyhound.com or contact UMDF at info@umdf.org.

MEMBER RESOURCES

BRAIN AND TISSUE BANK FOR DEVELOPMENTAL DISORDERS

The Brain and Tissue Bank for Developmental Disorders at the University of Maryland in Baltimore is a tissue resource established to further research aimed at improving the understanding, care and treatment of developmental disorders.

The Brain and Tissue Bank is funded by the National Institute of Child Health and Human Development to serve as an intermediary for people who wish to donate tissue for research at the time of their surgery or death.

If you are interested in becoming a registered donor, or if you have any questions or concerns regarding the donation process, please contact Christine Wade-Mariani or Melissa Larkins, project coordinators, at 800-847-1539 from 9 a.m. to 5 p.m. EST, Monday through Friday, or visit www.btbankfamily.org. Thank you for taking the time to consider the great gift of tissue donation!

MITO TREATMENT RESOURCES

As part of UMDF's mission, we are happy to introduce some special UMDF member resources for the treatment of mito patients.

Vitamins and co-factors are often the first line of defense for mitochondrial disease patients. However, please note that

the use of supplemental vitamins and co-factors is largely unproven, and their use is therefore controversial in patients with mitochondrial diseases. Clinical trials of some of these treatments are underway, and UMDF will make every attempt to keep you informed regarding progress and results of such trials. The first step toward getting treatment for your mitochondrial disease is, of course, to see a doctor!

See page 15 for sample offers from Epic4Health and Vitaline Formulas. To view all available offers, log in to the UMDF web site using your Member ID and password, and follow the link for Member Resources.

GET THREE FOR FREE!

Try *Exceptional Parent Magazine* for 3 Months---FREE! As a UMDF member, you are invited to preview 3 free issues of *Exceptional Parent* without any obligation.

If you decide to subscribe, simply remit the introductory rate of \$24.95 for 15 issues in total (additional charges for Canadian and overseas addresses), and EP will donate \$5 to UMDF from your paid subscription. If you decide that EP does not suit your needs simply write cancel on your invoice and the first 3 issues of EP are yours to keep without any further obligation. For details, follow the link for Member Services when you log in to your UMDF member account.

NEW UMDF STAFF MEMBERS

Since September 2006, UMDF has added four new employees to its professional staff at the national office. It is our pleasure to introduce Amy Campbell, our communications assistant; Leo Constantino, our financial and data entry assistant; John Elias, our director of member services; and Stephanie Ritenbaugh, our development assistant.

Amy Campbell came to UMDF in September 2006 as the communications assistant. She works mostly on compiling and laying out the quarterly newsletters, annual reports, web updates and other communications and development projects.

Amy previously worked for nearly three years as a production coordinator for a book publisher in the Pittsburgh area and also worked as a graphic designer at a local advertising newspaper. She received her bachelor's degree in journalism from Indiana University of Pennsylvania in 2003.

Leo Constantino started working for UMDF as an intern in September 2006. After graduating from the University of Pittsburgh with a bachelor's in public service and a certificate in non-profit management, he joined the UMDF staff as a full-time employee.

Leo works in the finance department and is the assistant to Mark Campbell, the UMDF chief financial officer. He is also an assistant in the data entry department, head of the United Way giving campaigns and the staff liaison to the IT committee.

Leo previously worked as an intern for a financial firm in downtown Pittsburgh. He was born and raised in Monroeville and is a 2002 graduate of Gateway High School.

John J. Elias joined UMDF as the director of chapter and membership services in September 2006. He and the member services staff support current UMDF chapters, groups and ambassadors and develop new ones. John is currently working to develop a board training manual for chapter leaders that will be highlighted at the symposium.

John worked in the non-profit behavioral health sector for more than fifteen years, most recently as the director of mental health services for Family Services of Western PA. He holds a bachelor's in organizational psychology and a master's in sociology from Bowling Green State University, as well as a certificate in government relations from the Government Relations Institute.

Stephanie Ritenbaugh joined the UMDF staff as a development assistant in November 2006. She helps research corporations, foundations and other organizations for potential funding, writes grant requests and assists in record-keeping as grants are executed. She also helps to recruit potential exhibitors and sponsors for the annual symposium and develops research fund brochures.

Before coming to UMDF, Stephanie spent two years as a full-time reporter for a local newspaper. She graduated from Shenandoah University in 2004 with a bachelor's degree in mass communication.

SPECIAL OFFERS FROM EPIC4HEALTH AND VITALINE

Epic4Health Q-Gel, L-Carnitine Discount

Epic4Health and Tishcon Corp. have teamed up with UMDF to offer special supplement pricing on Q-Gel, L-Carnitine and other mitochondrial disease treatments.

Epic4Health.com is the web site of Equivalent Pharmaceutical Industries Corp., which gets all of its Q-Gel products directly from Tishcon, an FDA regulated facility and one of the United States' most respected manufacturers of dietary supplements, vitamins and over-the-counter products

-- not to mention a regular UMDF symposium sponsor and exhibitor!

Vitaline Formulas Exclusive CoQ10 Discount

In support of sufferers of mitochondrial disorders, Vitaline® Formulas has partnered with UMDF to provide an exclusive discount on Vitaline CoQ10 and other frequently prescribed products for UMDF members.

As America's leading developer and marketer of proprietary, specialty dietary supplements to medical professionals and their patients, Vitaline is proud to provide their expertise in support of the efforts of UMDF. Vitaline

SUPPORTING RESEARCH

On Thursday, Feb. 8, UMDF Trustee and former New York Metro Chapter President Joseph Rice presented Dr. Zaza Khuchua, a research associate professor in pediatrics at the Vanderbilt University Medical Center in Nashville, Tenn., with a grant check in the amount of \$110,000 for developing animal models for research on Barth syndrome.



Dr. Khuchua's grant, which is to be distributed over two years, was one of 10 selected from a field of 120 submissions in the 2006 UMDF grant cycle. Khuchua and his colleagues will study a previously

developed fish model of Barth syndrome, a mitochondrial cardiolipin disorder and will complete development of a mouse model of the same disease, allowing extensive research on the syndrome's basic pathology without having to rely upon human subjects.

manufactures the most clinically studied CoQ10 on the market. It has been the subject of studies at prestigious medical institutions such as Harvard and the National Institutes of Health (NIH).

Vitaline/Integrative Therapeutics Inc.'s top 50 products have been the subject of more than 2,500 independent, peer-review-published, double-blind, placebo-controlled clinical trials/studies, and the products are produced in an FDA-registered drug facility. For more information, visit www.VitalineFormulas.com.

The following products are just a sample of what is available online at a 60 percent discount through this special partnership:

Vitaline® CoQ10 300 mg Maple Nut Flavor (56186)

Vitaline® CoQ10 400 mg Orange Flavor (56239)

L-Carnitine from Integrative Therapeutics Inc. (224004)

Vitamin E 400 IU (16756)

Log into your UMDF Member Account for more information!



Barth syndrome is a rare mitochondrial disease that causes severe muscle weakness in humans, affecting the muscles of both the heart and the musculoskeletal system. The disease prevents normal function of a specific population of immune system cells and has a high rate of infant mortality. Previous studies have shown that the muscle mitochondria in Barth patients are deficient in cardiolipin, a compound that is an essential component of the mitochondrial inner membrane. Production of the energy needed for cell activity is impaired in the absence of normal cardiolipin levels.

From left: Sharon Barker, Theresa Shalaby, Leah Heyman, Kim Roberts, UMDF Trustee Joseph Rice, research grant recipient Zaza Khuchua, Ph.D., and Julie Smith.



ANNOUNCEMENTS AND MERCHANDISE

HEARTSTRINGSSM AND LEAPSM AWARDS

UMDF wants to recognize our champions and heroes, and we need your help! Nominations are open for the 2007 UMDF HeartstringsSM and LEAPSM awards. You can download and print the appropriate forms from the UMDF web site, or you can request forms by mail or fax by contacting us at info@umdf.org or at 412-793-8077. Submissions must be received or postmarked by April 27, 2007.

IT/DATABASE TRANSITIONS

As we continue to transition our database to new technology, we ask that members please be patient with any glitches that may continue to occur. Please notify us of any problems that you encounter, and let us know if you receive any duplicate or incorrect mailings.

UMDF MERCHANDISE

UMDF merchandise is a great way to raise awareness and to support UMDF and all those affected with mitochondrial diseases. All merchandise is available online at www.umdf.org or by phone at 412-793-8077. Prices include shipping.

- **ENERGY BANDS.** These silicone bracelets are UMDF green and encircled with "Energy for Life" and "www.UMDF.org." UMDF Energy Bands come in adult and youth sizes. \$4 each.



- **AWARENESS CAR MAGNETS.**

The UMDF Awareness magnets are UMDF green, measure about four by eight inches in size and contain the messages "SUPPORT www.UMDF.org" and "Redefining Hope." The cost is \$5 each or 10 for \$25.

- **WINDSHIRTS.**

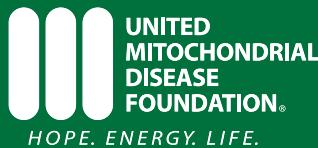
Be prepared for the long cold days of winter, and stay warm with a UMDF wind jacket. These green long-sleeved jackets are water repellent and 100 percent polyester. The jacket has a full v-neck collar, cuffs and full lining. Jackets are available in M, L and XL sizes, but quantities are limited. Jackets are \$30. Allow one week for delivery, or add \$5 for rush delivery.



- **THROW BLANKETS.**

A chill is in the air! Curl up with a fleece throw blanket from UMDF. Buy one for yourself, and give one as a gift. The blankets have an embroidered UMDF logo and are available in forest green, khaki, royal blue and black. Blankets are \$25. Allow 7-10 days for delivery.

SUBMISSION DEADLINE FOR ISSUE 2 IS APRIL 30, 2007!



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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.