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 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...
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.
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 Michio 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.

**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**

**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!

**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**

**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 chrisnsharonk@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**

**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.

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

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 kcchapter@umdf.org.

NEW ENGLAND CHAPTER

• 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

• 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.
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!

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.

- **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.

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 Amphitheater in Bend, Ore. For information, contact David Doyle at 541-383-4253 or at daviddusa@hotmail.com.
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

- **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.

- **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!

- **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!

- **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.

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:

  - 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.
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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.
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 months old. 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!
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,

Stanley Davis
UMDF Chairman
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 Syndrone.

- **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.
COINS FOR A CURE™ 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 Cure™ campaign started or to reserve your Home Collection Box (see below)!

TEA FOR MITO™
Tea for Mito™, 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 Mito™ 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 Mito™, 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.

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.

COINS FOR A CURE™ HOME COLLECTION BOXES
We are pleased to introduce our Coins for a Cure™ 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!
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.

**BENEFACTOR $10,000+**

**Corporations, Organizations and Foundations:**
- Nikos S. Kefalidis Foundation Inc.
- Winifred & William O'Reilly Foundation

**Individuals:**
- Milton & Eunice Forman
- Thomas & Elizabeth Hefferon
- Laurie Kefalidis
- John and Bonnie Osher
- Joe & Tanya Schindler
- Bob & Irene Sheridan
- Harry & Roslyn Weinrauch

**PATRON $5,000-$9,999**

**Corporations, Organizations and Foundations:**
- BILo Charities Inc.
- Grady Charitable Gift Fund
- Neuberger Berman
- Philadelphia Activities Fund Inc.
- UPS Foundation Inc.

**Individuals:**
- John & Terri Danner
- John & Julie DiCecco
- David & Theresa Langer
- James & Laura Lawrence
- Judy Leach
- Yolanda Turoyo
- Patricia Walker
- Dan Williams

**GUARDIAN $1,000-$4,999**

**Corporations, Organizations and Foundations:**
- Activa Holdings Corp
- ADC Construction, LLC
- All About Packaging, Inc.

**Individuals:**
- Andrea Bryant
- David Burch
- Brent & Heidi Burton
- Thomas & Ann Calandrucci
- Elliott & Elaine Caplow
- Charles Casaralla
- Colin & Stacy Coburn
- James Todd & Courtney Croker
- Stan & Carole Davis
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- Anthony & Mary DiPietro
- Steven & Jacqueline Easley
- Ed & Karen Feeney
- Blake & Cynthia Fine
- Tom Flanagan
- Kenny & Teressa Freeman
- Burton Garrett
- Daniel & Becky Genie
- Edward & Kathleen Gidseg
- Mike & Mary Gillen
- David & Phyllis Gray
- John Grossman & Katherine Olmsted
- Christopher & Stephanie Gump
- Doug Hopkins
- Steven Hughes
- Marion Hunsberger
- Keri Hurney
- Casey Kemerly
- Matthew & Kristy Kovalcik
- John & Deborah Kucharczyk
- William Largent
- Brendan & R.M. Lavelle
- Jane Lenz
- Bryan & Julie Manley
- Martin & Norma Markowitz
- Greg & Carolyn Martin
- Robin McDonough
- Ron & Donna Miklos
- Robert & Ruth Mirvis
- Robert Morris
- Jim & Patricia Mowrer
Donors - Thank You!

Appreciating Those Along the Way (Cont.)

Sustaining $500-$999

Corporations, Organizations and Foundations:

- Accu Line Contracting Inc.
- Anderson Plumbing, Heating & Electric Inc.
- Armitage & Co. Inc.
- Barrand Inc.
- Baschnagel Brothers Inc.
- Benson Hlavaty Architects
- BFZ Electric LLC
- Canal Asphalt Inc.
- Central Elementary School
- Classic Chevrolet
- Classic Lexus
- D.O.S. - 50 Company
- De Felippis Enterprises Inc.
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- EHC Cleveland LLC
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- Fox Hill Remodeling
- Garito Contracting Inc.
- Gravatt’s Inc.
- Heery Company
- Illinois Tool Works Foundation (ITW)
- Infoshred Inc
- John B. Lovett & Associates Ltd.
- John Hancock Financial Services Giving Campaign
- K.I.D.S.
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- Kellogg Company
- Knights of Columbus Fairview Council No. 4044
- Larry’s Markets Inc.
- Liebert
- MassMutual
- Mass-West Construction Inc.
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- Morgan’s Foods Inc.
- Mountainview Mechanical Inc.
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- Northstar Asset Management LLC
- Palmer Candy of Kansas LLC
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- Prestige Delivery Systems
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- Redemption Rock Westminster/ Foursome Square Church
- Safeway Construction Ent. Inc.
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- Unishippers
- United Brotherhood of Carpenters & Joiners of America
- Wal Mart Stores Inc.
- Willets Point Asphalt Corp.

Individuals:

- Don & Catherine Augenstein
- Dean & Kimberly Benamy
- Richard & Nancy Bertges
- David & Felicia Borreson
- Maurice & Betty Burgener
- Chuck & Margaret Bush
- Brian Calvano
- Mark & Kathleen Campbell
- Art Caylor
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- Hal & Ronna Uhrman
- Patrick & Kristie VanAbel
- Ronald & Bette Wagner
- James & Tara Walker
- Peter Jake Wallace
- Joe & Clara Waller
- David & Lonnie Walters
- Michael & Laura Weinrauch
- Shawn & Renee Welch
- Mary Ann West
- 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 Medlin 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 Buena will be held March 17 during the Shamrock Sportsfest in Virginia Beach, Va. The Shamrock Marathon will be held the following day. Contact Deb Buena 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@firstcitizensonline.com.

- **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 marshamarmarsham@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 Amphitheater 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 Freni, 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@umd.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 Pottsville, Mich. For more information or to find out how you can help, contact Dan or Julie Brunk at 517-627-3715 or e-mail brunkfarm06@aol.com.


- **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 kkchapters@umd.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@umd.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

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!

RESERVE YOUR HOTEL ROOMS NOW!

JOIN US FOR A LUAU ON MISSION BEACH
FRIDAY, JUNE 15!

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!

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.

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

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**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!

**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 CURE™

- Marion Hunsberger of the Delaware area 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.
- Rita Grosso of Indiana collected $100.
- 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.

CURRENT ‘COINS’ CAMPAIGNS

- Sheri 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 Lesington 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.
- 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 Quaries of the Atlanta area raised $7,437.95 in memory of Palmer Quaries 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.
- Mike and Kristen Quarles of the Atlanta area in honor of Riley Henderson.
- Norman Kohnen of Western Pennsylvania in honor of Riley Henderson.
- Paul and Maura Buckley of New England will campaign at schools #8 and #17 in honor of John Kohnen.
- Jennifer Kokora of Clifton, N.J., will campaign at schools #8 and #17 in honor of Andrew Pisarczyk.

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)!

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A new 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.

“When 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.

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.
THE ISSUE WITH PATIENTS WHO HAVE ELECTRON TRANSPORT CHAIN DISORDERS

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 counter-intuitive 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.

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.

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• 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.

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 (Scalambil), 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.
**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.

**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 Eliyas, 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. Eliyas 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 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!

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.

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.
HEARTSTRINGS℠ AND LEAP℠ AWARDS
UMDF wants to recognize our champions and heroes, and we need your help! Nominations are open for the 2007 UMDF Heartstrings℠ and LEAP℠ 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!