

TWO UMDF FUNDED RESEARCH GRANTS RESULT IN NEW INFORMATION

One of the main mission points for the United Mitochondrial Disease Foundation is research. Since 1996, the UMDF has funded more than \$6 Million in research projects aimed at finding better treatments, diagnosis and ultimately a cure for mitochondrial disease. That is why we are excited about two recent research projects that received partial funding from the UMDF Research Grant Program.

In 2004, Gregory Enns, MD, ChB, and his team from Stanford University School of Medicine and Lucile Packard Children's Hospital were the recipients of a grant for a project that devised a much needed way to monitor and find treatments for mitochondrial disorders. The team discovered a biological marker that can be used to monitor mitochondrial diseases.

"When a car engine doesn't work right, it smokes," said Dr. Enns, who is a professor of pediatrics at Stanford University School of Medicine and director of the biochemical genetics program at Packard. "What we looked for is, in essence, biochemical smoke."

The finding will enable researchers to hunt for treatments and help patients' status before health crises erupt. Patients who have a mitochondrial disorder were compared with healthy people in a control group. Since defective mitochondria produce large quantities of oxygen-free radicals (like a



Dr. Gregory Enns

smoking engine), Enns found that patients with a mitochondrial disorder had their natural antioxidant defense system overtaxed by the free radicals.

"Even when these patients are coming into the clinic looking pretty healthy, they have evidence of extra metabolic stress," Enns said, noting the findings were surprising because none of the patients were in the midst of a health crisis, such as organ failure, when blood samples were drawn.

"It is the first time such signs have been uniformly shown in the blood of patients across

a wide range of mitochondrial disorders," he added. The team saw that levels of glutathione, the body's primary antioxidant, were significantly reduced in white blood cells from the 20 mitochondrial disease patients in the study.

A second finding gave the researchers information on potential treatments. They found that patients taking antioxidant supplements did not have depleted glutathione. This research may help understand the effectiveness of supplements for a mitochondrial disease patient. "As a clinician, one of the most frustrating

things has been not being sure if supplements are doing any good," said Enns. "Now we are able to take a baseline blood reading and see 'before' and 'after' snapshots," Enns says glutathione measurements could help with a diagnosis by giving physicians a clear indication that something is wrong in the mitochondria.

The method that the Enns team used to measure glutathione, called high-dimensional flow cytometry, has limitations: it requires fresh blood samples, uses

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The California Chapter held a family meeting prior to the 4th Annual Dinner and Silent Auction on March 7th. Pictured left is Norma Gibson, Brittany Wilkinson and Chuck Mohan.

See pages 4-7 for more events and fundraisers!

FROM PAGE ONE

equipment only available in research labs and does not provide absolute glutathione measurements. Now that the team knows what metabolic change to look for, they're working to develop a more broad based measurement technique.

In March 2009, researchers at NYU Langone Medical Center announced that they may have

discovered a new targeted intervention for Barth Syndrome (BTHS). BTHS is a mitochondrial disorder occurring mostly in males. BTHS leads to infection or heart failure in children and can be a fatal disease. Research lead by Mindong Ren, PhD, shows the benefits of a targeted intervention with an iPLA2-VIA inhibitor that prevents a major symptom of the disease – cardiolipin deficiency.

People affected with BTHS have a defect in the cardiolipin metabolism which fights

infections. Additional symptoms may include a weak heart muscle, a reduction of white blood cells that fight bacterial infections, growth delay, and an increase in organic acids in urine. In healthy people, cardiolipin resides in the inner membrane of the mitochondria and is responsible for normal cell structure and energy production.

BTHS is a debilitating heart and skeletal muscle disease that causes muscle weakness and fatigue in those affected. Its cause is in a mutation in the genetic coding of tafazzin. Tafazzin is an enzyme of the cardiolipin pathway.

A previous study at NYU revealed the characteristics of a tafazzin deficiency in a fruit fly. The deficiency resulted in low and abnormal cardiolipin concentration, abnormal mitochondria, and poor motor function. In Dr. Ren's study, the research showed that the cardiolipin deficiency disrupted the fruit fly's final stage of spermatogenesis causing male sterility. "Using this fly model, the study showed that this trait of cardiolipin deficiency can be genetically suppressed

by inactivating calcium-independent phospholipase A2, which prevents the degradation of cardiolipin," Dr. Ren told Mitochondrial News. His team's method would keep the cardiolipin levels normal. "This is good news for patients because this enzyme (tafazzin) is now a potential target for therapeutic intervention."



Dr. Mindong Ren

The research has not been tested in humans. Dr. Ren cautions that it shows promise but is still years away from being developed into a treatment. At the present time, there are no treatments for Barth Syndrome patients.

As mentioned above, both projects were partially funded by research grants from the United Mitochondrial Disease Foundation. "Those who support the UMDF through donations and fundraisers can now see first hand how those dollars

are allocated to the projects and programs that will bring the best results for patients who suffer from mitochondrial disorders," said Charles A. Mohan, Jr., Executive Director and CEO of the UMDF. "We are very excited about both projects as research moves us forward to a cure," Mohan added. Findings from both projects demonstrate the urgency for federally funded research into mitochondrial dysfunction. "Dr. Enns and his research team have clearly shown that glutathione measurements may help scientists unravel the causes of many other diseases with mitochondrial involvement such as poor vision, hearing loss, kidney disease, autism spectrum disorders, diabetes, Alzheimer's, Parkinson's and cancers. Our scientific and medical community has urged the Obama Administration to include research into mitochondrial medicine among his administration's top medical and research priorities. UMDF members, families and friends must urge their congressional and senatorial representatives to do the same."



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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.

Gregory Enns, MB, ChB, was awarded a research grant in 2004 in the amount of \$34,179. His project was titled "GSH levels, reactive oxygen species production, lipid peroxidation, products and mitochondrial membrane potential in patients with mitochondrial disease."

Mindong Ren, PhD, was awarded a research grant in 2007 in the amount of \$157,450. His project was titled "Genotype-Phenotype Correlation and Genetic Modifiers in Barth Syndrome."

For more information on the UMDF Research Grant Program, visit www.umdf.org.



ASK THE MITO DOCSM

Living with mitochondrial disease presents many twists and turns and a maze of questions. UMDF is pleased to offer answers to some of those questions as taken from *Ask the Mito DocSM* at UMDF.org. Please note that information contained in *Ask the Mito DocSM* is for informational and educational purposes only. Such information is not intended to replace and should not be interpreted or relied upon as professional advice, whether medical or otherwise.

Responder for this issue: Richard G. Boles, MD, of Children's Hospital Los Angeles, CA, Russell Saneto, DO, PHD, of Children's Hospital and Regional Medical Center, WA, and Sumit Parikh, MD, of the Cleveland Clinic, OH.

THE QUESTION IS...

Can a mitochondrial disease patient donate blood, tissue, or organs? Will he/she spread the disease to the recipient?

RESPONSE FROM RICHARD G. BOLES, MD:

Blood in circulation does not divide, so mitochondrial disease cannot be passed on by a blood transfusion. However, since bone marrow failure is not uncommon in mitochondrial disease, and bone marrow is the tissue that makes blood, it may take a while to rebuild the lost blood following donation. This likely will stress the donor, and thus a blood donation could adversely affect the donor's own health.

Regarding organ/tissue donation, the bone marrow, liver, heart or kidneys from a mitochondrial disease patient might lead to mito-related problems in the recipient. For example, a non-mitochondrial disease recipient (or mitochondrial disease recipient) of a heart transplant from a mitochondrial disease donor could develop mito-related cardiomyopathy. The appropriateness of mitochondrial disease patients as organ donors has not been systematically studied, although I am aware of cases in which mitochondrial disease patients were rejected by physicians or agencies for not being appropriate donors.

Thus, it is my opinion that mitochondrial disease patients probably shouldn't donate blood,

organs or tissues, at least in the majority of cases. However, whether the donation is blood, tissue or organs, mitochondrial disease will not spread to non-donated organs/tissues. Mitochondrial disease is not "contagious." In humans, genes do not "jump" from one person to another or from one organ/tissue to another.

THE QUESTION IS...

We have been trying to toilet train our 11 year old son for many years. He was in underwear during day-time hours for one year and had some success, but his seizures increased dramatically so we took a break. We started up again in late June and he seemed to be doing okay. Sometimes he would go into the bathroom and void himself, only if we are at home. If we are away, he would just wet himself. Just three weeks ago he stopped going into the bathroom on his own. He goes through these cycles where his output is much larger than his input. Some days it is the opposite where he is drinking a lot and not urinating much. Is this a mitochondrial disease thing?

RESPONSE FROM RUSSELL P. SANETO, DO, PHD:

Output is usually related to input, so fluid in and urine out. It is not always equal. For instance, if it is hot and we sweat, then urine output would decrease. If you lose fluid due to illness (i.e., fever) then urine output would decrease. Sometimes, if there is a nervous system component to bladder emptying, then output can be altered as the bladder cannot empty by the usual neuronal inputs (i.e., bladder stretching). Sometimes output can be seemingly greater than input if the bladder fills without the person feeling the need to empty. Since mitochondrial disease can sometimes alter sensation (bladder filling or ability to empty), then this is a possibility. Medications can also influence amount of outgoing fluid. However, without knowing more details, it is impossible to tell you why this is happening to your son.

Toilet training is sometimes more dependent on the person needing to be trained than the person doing the training. Certainly, some neurologically impaired children never are toilet trained. Having frequent seizures can also affect this process. We

Submitting questions to *Ask the Mito DocSM* is a benefit of the UMDF "Energy" membership. If you are a member and would like to submit a question, log in to the UMDF website using your user ID and password. If you would like more information on becoming a member of the UMDF, email info@umdf.org.

often see developmental regression when seizures become longer in duration and/or more frequent. So, this can influence toilet training. Maybe better seizure control would allow him to learn how to use the toilet. I say this 'tongue in cheek,' as I take care of so many mitochondrial patients with intractable epilepsy. I do hope that you can toilet train your son in the near future.

THE QUESTION IS...

I have heard that tests are run on patients in the hospital on the basis of money rather than quality. How can we be sure we are getting appropriate quality testing? I work in a clinical diagnostic lab. In order to legally perform and offer testing, the lab is required to follow protocol and perform quality control procedures. Are the labs doing these tests required to do the same?

RESPONSE FROM SUMIT PARIKH, MD:

You are correct in that most if not all labs that offer clinical testing in this country are certified by a national agency (CLIA) and are required to ensure a level of quality, test reliability, etc. The vagary often arises when we are dealing with interpretive testing and/or testing that has the ability to offer differing levels of detection/results. Both of these issues are especially true for metabolic tests.

For example, amino acid analysis in blood or organic acid analysis in urine can 1) measure varying numbers of acids (from many to all); 2) detect each of the acids to a relative or exact level; 3) attempt to separate (or not separate) acids that show up in a similar region of the spectral scan; and 4) offer varying "depths" of interpretation depending on who the individual providing the interpretation is (there are "multiple elevations in a non-diagnostic pattern" OR "multiple elevations suggesting a post-prandial sample, possible liver disease").

Unfortunately, regardless of whether the lab is offering a more or less "precise" set of results, they are all certified tests and can state they are offering comprehensive amino or organic acid analysis. The lab offering the more precise data or interpretation may charge more and the hospital contracting out this test may not appreciate this added value. The person ordering the test may not realize which lab is better unless they read the "fine print" on how this testing is actually performed at the lab.

Most metabolic/genetic centers have the ability to pick and choose the better labs that perform this test. Many metabolic/genetic physicians often discard the lab-provided interpretation and interpret the numbers for themselves as well. So like most things in life, there are plenty of shades of gray when it comes to metabolic testing - and your way of ensuring a more accurate set of results is by finding a knowledgeable physician.

CHAPTER ACTIVITIES

CHAPTER NOTES

ATLANTA CHAPTER

- **January 11, 2009.** Brian and Lorie Gassel ran in the Disney Marathon at Walt Disney World in Orlando, FL. The couple raised more than \$17,000 for the UMDF in honor of their daughter, Morgan. Thank you to Brian and Lorie for making your Marathon for Morgan such a success!
- **February 10, 2009.** Lisa Tatum organized a Chili's Gives Back for Mito event at the Chili's restaurant in Alpharetta, GA. A total of 10% of the sales from the evening were donated to the UMDF. Thank you, Lisa, for organizing such a great fundraiser!



(Left to Right) Tori Bigelow 14, Alia Christian 14, Ali Bartlett 13, and Samantha Podwalski 16

- **February 21, 2009.** A night of live and inspirational music was held in honor of the Atlanta Chapter of the UMDF. The music was preformed by Tori, Alia, Ali and Samantha who are Cobb County high school students. The event had a \$5 cover charge and proceeds were donated to the UMDF. Thank you to everyone who was involved in making this event a success!

CALIFORNIA CHAPTER

- **December 2008.** For the month of December, 10% of the proceeds from spa sales were donated to the UMDF. The event was held in honor of Kyle Avila.

CAROLINA Foothills CHAPTER

- **February 21, 2009.** The first annual Hope.Energy.Life Charity Golf Tournament and Family Fun Day was held at the Island West Golf Club in Bluffton, SC. The event was held in honor of Olivia Custer and raised over \$20,000 for the UMDF. Thank you to the Custer family for your hard work on such a great event!

HOUSTON CHAPTER

- **January 31, 2009.** To raise money for their team participating in Christopher's Heart Fun Run, Jane Troutner and friends worked with Chick-fil-A in Katy, TX, to hold a benefit night. Chick-fil-A donated 10% of the sales from the evening to the UMDF.

- **February 7, 2009.** The third annual Christopher's Heart Fun Run was held at Sam Houston Park in downtown Houston, TX. Activities included a 5K run and one-mile walk along with children's activities. More than \$80,000 was raised to benefit the UMDF. Thank you to the race committee for all of your hard work!



The third annual Christopher's Heart Fun Run

INDIANA CHAPTER

- **February 28, 2009.** The Indiana Chapter worked in conjunction with the Indiana Ice of the USHL to sell tickets for the annual Pack the House for Charity event. In return for their sales efforts, the Ice rewarded the UMDF with a monetary grant, as well as \$5 for each ticket they sold. A special thanks to Chris and Camille Gaughan for organizing this great event!

OHIO CHAPTER

- **December 20, 2008.** IHRA Champion and UMDF member Mark Thomas sold autographed memorabilia at Motts Greenhouse in Louisville, OH. Proceeds from the event benefit the UMDF in honor of Mark's daughter, Valarie.



Hope.Energy.Life Charity Golf Tournament & Family Fun Day

THE UMDF WELCOMES THE MIDDLE TENNESSEE CHAPTER

The United Mitochondrial Disease Foundation would like to introduce its 16th Chapter, Middle Tennessee. The Middle Tennessee Chapter was inducted on March 2, 2009. Chuck Mohan, UMDF CEO, and Kara Strittmatter, UMDF Director of Member Services, traveled to Tennessee in early March for the induction of the chapter. Joe Rice, UMDF Board Member, was also in attendance to congratulate Middle Tennessee on their Chapter Status.

The chapter will be lead by Courtney Fellers as President, Jane Phillips as Vice President (assisted by Sarah Phillips), Fred Durham as Treasurer, Courey Elliott as Secretary, and Board Member Mendy Mazzo. The Chapter is privileged to have excellent local physician, corporate and community support and looks forward to serving the Middle Tennessee area.

The Chapter's first event was to host a family meeting and Grand Rounds at Vanderbilt Children's Hospital on March 2, 2009. Dr. Sumit Parikh of the Cleveland Clinic was the speaker at both meetings, and Chuck Mohan spoke at the family meeting.

The newly elected board has established aggressive goals for the first year, including but not limited to some new fundraising and awareness events and special educational meetings. The chapter will continue to work with other UMDF Mito Groups across Tennessee and northern Alabama to raise awareness, exchange information about upcoming UMDF events and activities, and offer support to patients and families.

If you would like to learn more about the Middle Tennessee Chapter, contact midtennchapter@umdf.org or visit www.umdf.org/midtennessee.



Courey Elliott, Courtney Fellers, Sarah Phillips, Fred Durham, Jane Phillips and Mendy Mazzo

For information on starting a Chapter, Mito Group, or to become an Ambassador in your area, contact the UMDF Member Services Department at 888-317-UMDF (8633). To find a Chapter, Mito Group, or Ambassador in your area visit www.umdf.org.

GIFTS FROM THE HEART

- Marty Fischer hosted a holiday party on December 5, 2008, in honor of Michael DiLorenzo. The proceeds from the event were donated to the UMDF. Thank you, Marty, for your support!
- The National Honor Society at Minnechaug Regional High School in Wilbraham, MA, held their fourth annual Themed Basket Raffle Fundraiser. Thank you to all of the students and staff for their continued support of the UMDF mission.
- Girl Scout Troops 8544 and 152 from St. Antoninus Church in Cincinnati, OH, sent in a donation of \$75 in honor of Ayden Hingsbergen. The girls took part in singing Christmas Carols on a cold winter night! A special thank you to Hannah, Emma, Madison, Sarah, Ann Marie, Jessica, Sammy, Zoey, Sarah, Rebecca, and Mary Catherine! Thank you for your love and support of Ayden!
- The law firm of Ackerman, Link & Sartory in West Palm Beach, FL, conducted a "Dress Down for Charity Day" in honor of Michael and Christopher Link. As a result, \$120 was donated to the UMDF! Thank you for your continued support!



Girl Scout Troops 8544 and 152

- The employees at Fortuna Energy in Horseheads, NY, held an in-house auction in memory of Kaydon Kent. Proceeds were donated to the UMDF.
- The UMDF staff has been participating in "Dress Down Days" for the UMDF. On designated days, the staff is permitted to wear jeans for a fee. Thank you to the staff for your support!
- Sholar and Maddie Petit made and sold jewelry to raise money in honor of their cousin, Ellie Kovalcik. Sholar and Maddie have raised a total of \$134 for the UMDF! Great job, girls! Keep up the creativity!
- Christine Lardon ran a marathon in the Outer Banks, NC, in honor of Therese Garvin. She collected pledges from friends and family and was sponsored by a firehouse in Philadelphia, PA. Christine said, "The pain I'll endure during this marathon is just a small testament to the pain Therese and all mito patients feel during a normal day." Thank you, Christine, for your support of Therese and the UMDF!
- During the holiday season, "Doggie Stockings" filled with dog treats and toys were sold to raise money for the UMDF. A total of \$392 was donated in memory of Gina Mohan.
- Michelle Mohan recently celebrated her 16th Birthday with friends and family. In lieu of gifts, Michelle requested that donations be made to the UMDF. In total, more than \$7,000 was donated in her honor. Happy Sweet 16, Michelle!
- On December 14, 2008, Sarah Franklin ran in the Honolulu Marathon in memory of Owen Hollar, the son of Travis and Dena Hollar. Sarah raised \$550 to date for the UMDF! Thank you for your hard work Sarah!

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MITO FACTS

- Mitochondrial disease results when there is a defect that reduces the ability of the mitochondria to produce energy.
- Mitochondrial disease can affect any organ of the body and at any age.
- Mitochondrial disease was first recognized in an adult in the 1960's and in the 1980's for pediatric onset cases.

RACING AGAIN

A Day in the Life of Peter Lubelczyk
By: Juli Lubelczyk

How do you help a 10 year old accept the fact that he won't walk or run again? That was our dilemma a year ago. Peter, who has mitochondrial disease from PolG1 mutations, enjoyed a stable early childhood of tee ball, golf, tag and playgrounds. But after a round of status seizures at age 7, he began a slow decline as his ataxia and various neurological effects worsened. Finally, the day arrived when a wheelchair was needed for more than temporary support.



Peter with his medal from the 2007 Bennett Blazers Track Fest

The bouts of frustration were intense, and the degrading self talk was hard to hear. We spent time with counselors and did lots of talking, but what made the most difference during this transition was stumbling upon the Bennett Blazers. Run by Kennedy Krieger in Baltimore, Maryland, the Blazers are a sports program for physically challenged youth. Their motto: Teaching kids what they can do before they think they can't.

That spring Peter started track. He used an adaptive piece of equipment new to the US called a Petra or RaceRunner. Similar to a three wheeled bike in appearance, the frame has no gears or pedals. The athlete runs to propel the frame. The transformation in Peter's attitude was amazing as he once again had the chance to run. He could be fast; he could compete; he could win! He won every heat in his first track meet, and his self esteem soared.

That summer, he participated in their summer camps and once again played golf, tennis, baseball, volleyball, basketball, swam and even paddled a kayak around a pool. I learned techniques and modifications to increase his involvement away from Bennett and

raise his activity level at home. He was surrounded by children and families dealing with conditions ranging from spina bifida, cerebral palsy and missing limbs to survivors of cancer, polio and other childhood diseases. He was inspired to make the best of his situation instead of feeling sorry for himself. The coaches offered half-day participation and willingly allowed rest and hydration as needed so he wasn't overly fatigued.

In the fall, he started wheelchair basketball and loved being part of a team. As he faced another school year needing more support with more declines, he could often be heard saying, "you should see me play basketball!" Feeling confident in his chair, he branched out on his own and participated in a youth curling league and was the only special needs attendee. His chair was no longer a liability but tool for success.

Peter's decline has continued so that team sports are now too confusing for him, though he still loves shooting hoops. Through a fundraiser, we purchased our own RaceRunner; and Peter uses it at school, qualifying for the 5 mile club in PE this year. At home, he enjoys getting out on the



Peter on his RaceRunner

weekends year round as weather allows and going for walks in shady parks or early morning runs at a high school track over the summer. He's excited about the upcoming track season with the Blazers.

Every day, more and more older children, teens, and adults are being diagnosed with mitochondrial disease. Many struggle with the often sudden loss of abilities. Doctors emphasize the need to maintain muscle strength and cardio health while paying careful attention to fatigue levels. Adaptive sports programs can provide opportunities to maximize one's health both physically and mentally. For my son, it provided

(continued on page P3)



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FROM THE CHAIRMAN

Since our last newsletter, significant developments have happened in the field of mitochondrial medicine and research. Both of these developments have a common link - the United Mitochondrial Disease Foundation.

Before Barack Obama walked out of the United States Capitol Building and took the oath of office, the UMDF was working quietly behind the scenes to make sure the incoming administration was aware of mitochondrial disease. Rick Leach, a member of the UMDF Board of Trustees and chairman of our Governmental Affairs Committee, drafted an important letter to President Obama. The letter was signed by more than 70 experts in mitochondrial disease medicine.

In the letter, the scientific and medical community called on the new administration to make good on a campaign promise. As you may recall, candidate Obama stated that he wanted to make an increased investment in science and medicine. The letter urges the administration to fund research that will produce a greater understanding of the mitochondria, providing insights into treatments for a wide range of diseases and conditions that affect millions of Americans. The letter highlights the links between mitochondrial dysfunction and Parkinson's, ALS, diabetes, Alzheimer's, and many other more common diseases. "We respectfully urge your Administration to include research into mitochondrial medicine among your top medical and research priorities," the letter states. That letter was hand delivered to the White House in January.

At press time, we are awaiting a response and will let you know when it is received. The letter by the scientific and medical community is a great example of how the UMDF is working towards a cure. It was the UMDF that prepared the letter, provided the information to the scientific and medical community, collected the signatures, and delivered the letter. And our work in this area is not finished.

Since this letter was delivered to the President, Congress passed and the President made good on his promise by signing the American Recovery and Reinvestment Act of 2009. This Act will provide a much needed \$10 billion increase in funding for National



Institutes of Health (NIH) for research — the largest funding increase for NIH in 5 years. For the mitochondrial community, this increase in funding may bring scientific breakthroughs if some of this funding is directed towards mitochondrial research. We are hard at work to make sure that they hear our

voice. We applaud Congress and the Obama administration for increasing funding into scientific research that works to save lives. This again emphasizes the importance of having influence in Washington and why we chose to have our next Symposium there. Please join us this summer to tell our story.

Another example of how the UMDF is working towards a cure can be found in the latest news coming from Stanford University School of Medicine. In 2004, your contributions provided a research grant to Dr. Greg Enns through the UMDF's Research Grant Program. With that funding and grants from others, Dr. Enns and his team discovered a biological marker they can use to monitor mitochondrial diseases. The finding by Dr. Enns and his team will enable researchers to hunt for treatments and possibly help in the diagnosis of mitochondrial disorders. You can read more about his research in this edition of the newsletter. We are excited about the research and congratulate Dr. Enns, who is a current member of the UMDF's Scientific and Medical Advisory Board, and the rest of his team. His hard work is part of our effort to bring us all closer to faster diagnosis and a cure. This is just one of the positive results that are coming from our research. Like planting seedlings, our research is beginning to grow into big trees.

You have heard me say before that I believe that treatments and drugs will be coming in the near future. There are old medicines and new ones alike that may prove to be helpful in the future. I know that we are all experiencing economic problems right now, but I believe that the future will be bright.

Energy to all,



W. Dan Wright, UMDF Chairman

UNITED MITOCHONDRIAL DISEASE FOUNDATION

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Tucker & Skylar MacFiggan from California. Skylar is 4 years old and suffers from a mitochondrial disease.

UMDF SYMPOSIUM GRANT SUPPORT

The UMDF has received a number of grants to support activities at the upcoming International Symposium in Washington, D.C. this June. We thank our funders to date and look forward to adding more before we gather in the nation's capital. Our supporters are helping to provide travel scholarships for families and speakers, critical programmatic support, and a special opportunity for teenagers attending this year's Symposium.

The Pittsburgh-based Edith Trees Charitable Trust has provided a grant to support the Symposium and more specifically to fund special programming for teenagers affected by mitochondrial disease. Teens face difficult challenges as they deal with mitochondrial disease personally, within their family, or through their affiliation with a classmate who is affected. The mental and physical challenges that affect teenagers require special attention. Through the generosity of the Edith Trees Charitable Trust, UMDF will be able to:

- Create specialized programming to address teenagers' concerns
- Offer support and encouragement at a critical stage of development
- Ease mental and emotional strains on teens facing mitochondrial disease
- Provide opportunities for teens to meet and converse with those who face similar challenges
- Support the annual Symposium in Washington DC
- Extend opportunities for needy teens and their families to attend the Washington, D.C. Symposium

Funding from the Dominican Sisters Blessings Fund and the Eberly Foundation will help to provide travel scholarships for needy individuals. The Dominican Sisters, through their Blessings Fund, have been a

regular supporter of the Symposium. Their gifts have enabled many individuals, who might otherwise not get a chance, to attend the annual gathering. Travel scholarships from the Eberly gift will be restricted to patients and families coming from the Fayette County region of Pennsylvania.

The Foundation has long been associated with its support of the programs and residents of Fayette County, just south of Pittsburgh.

GNC, headquartered in Pittsburgh, is the largest global specialty retailer of nutritional products, including vitamin, mineral, herbal and other specialty supplements and sports nutrition, diet and energy products. GNC has provided support for Family Session programming during the Symposium.

The NIH Office of Rare Diseases, through the National Institute of Environmental Health Sciences, has also awarded funding for programming and travel scholarships. This funding recognizes the strong links between mitochondrial disorders and many more well known diseases.

Watch our web site at www.umd.org/symposium for information about new grant awards in anticipation of the Symposium.



**Mitochondrial Medicine
2009: Capitol Hill**

Scientific: June 24-27

Family: June 26-27

CONTINUED FROM PAGE ONE

a scaffold during tumultuous times as he struggled to accept his increasing limitations and still maintain his self esteem. The Bennett Blazers helped him focus on what he could do rather than what he couldn't. They helped him see himself as a champion.

Every person thrust into the battle against mitochondrial disease is a champion simply in how they fight to survive. Those around Mito kids, teens and adults know that. But adaptive programs like these hopefully can help them see it for themselves as well.

Resources

Programs like the Bennett Blazers exist throughout the United States. The National Center on Physical Activity and Disability website supplies links to programs in all 50 states and beyond. Here are some websites that cover opportunities for both children and adults. There are also websites provided about the Race Runner which has gained huge popularity overseas with interest growing in the United States. The ease of use makes it successful for a wide range of disabilities while targeting important core muscle groups such as the hips, legs, head and neck. Available in multiple sizes, it can be used by preschool children, adults and everyone in between. Coaches Gerry and Gwena Herman of the Bennett Blazers, instrumental in introducing the RaceRunner to the US, are happy to provide more information as well.

Bennett Blazers, Gerry and Gwena Herman

www.kennedykrieger.org/kki_school.jsp?pid=1481&bl=1

National Center on Physical Activity and Disability
www.ncpad.com

Wheelchair Sports, USA
www.wusa.org

National Junior Disability Championships
www.wnjdc2009.com

National Wheelchair Basketball Association
www.nwba.org

Great Lakes Adaptive Sports Association
www.glasa.org

BlazeSports - Georgia
www.blazesports.org

San Diego Adaptive Sports Foundation
www.sdasf.org

Adaptive Sports Center - Colorado
www.adaptivesports.org

RaceRunner links
www.quest88.com/allability-racerunning/petra-running-bikes.html

CAROLINA FOOTHILLS CHAPTER

- **April 24-25, 2009.** The fourth annual Caroline's on My Mind Weekend will once again feature a golf tournament, a 5K Family Walk/Run and a BBQ/Band Party on Saturday evening. All proceeds will benefit the UMDF through the Caroline Virginia Pulliam Mitochondrial Disease Fund. For more information, please visit www.carolinesonmymind.com.

KANSAS CITY CHAPTER

- **May 30, 2009.** The sixth annual Mito What? Family Fun Run will be held at The Northland in Lake Waukomis, MO. The event will include a kids dash, family activities, music by BJ the DJ, a silent auction and a raffle. For more information or to register, visit www.umdf.org/kcmitowhat.
- **2009.** Louann Carnahan is a classical pianist, medical student and an adult affected by MERRF. To create awareness about "mito" and raise funds for research, her CD titled "Louann Carahan, Piano Masterpieces" is available for purchase at www.beatmito.com. For more information contact Louann at lcarnahan@kcumb.edu.

OHIO CHAPTER

- **April 3, 2009.** The sixth annual Guest Bartender Night in honor of Kyle Kobunski will be held at the 82nd Street Grill and Pub in North Royalton, OH. Guest bartenders for the evening will be Diane Kobunski and Anita Ripepi, and all donations will benefit the UMDF. For more information, contact John Kobunski at jkobunski@aol.com.

- **May 9, 2009.** The eighth annual Run Wild for a Cure 5K Run and 1 Mike Walk will be held at the Cleveland Metroparks Zoo in Cleveland, OH. Last year, more than 3,000 participants took part and raised over \$200,000 for the UMDF! For more information, visit www.runwildforacure.com.

CINCINNATI MITO GROUP

- **April 18, 2009.** Mito Mania will be held at St. Antonius Church in Cincinnati, OH. The event will feature dancing, a 50/50 raffle and silent auction to benefit the UMDF. For more information, contact Shelly Hingsbergen at sah03@yahoo.com
- **2009.** The family of Ayden Hingsbergen is sending Ayden's special friend "Toby the Turtle" on a cross-country trip with semi-truck drivers to raise awareness for mitochondrial disease and the UMDF. Toby is a stuffed turtle who will be full of information about the UMDF, mitochondrial disease and Ayden. Disposable cameras will also be sent along with Toby to track his journey across America!

IOWA MITO GROUP

- **June 13, 2009.** The third annual Myles for a Cure Walk will be held at the Cedar Valley Nature Trail in Cedar Falls, IA. The event is held in honor of Myles Eick. For more information, contact Ronda Eick at mitoiowa@yahoo.com.

ST. LOUIS MITO GROUP

- **April 11, 2009.** The sixth annual Family Fun Day will be held at the Shrine of Our Lady of the Snows in Belleville, IL. The event

will feature a 5K run, fun walk and kids run. For more information, visit www.umdf.org/stlouisrace.

PITTSBURGH MITO GROUP

- **May 2, 2009.** In conjunction with the Pittsburgh Pirates, the UMDF will be hosting an awareness night at PNC Park when the Pirates take on the Cincinnati Reds. This opportunity will allow the UMDF to raise money and awareness in the Pittsburgh area. For more information, contact Kylie at 888-317-UMDF or visit www.umdf.org.

AROUND THE COUNTRY

- **May 11-15, 2009.** The ninth annual Kites for Kristen will be held at St. Daniel the Prophet School in Chicago, IL. Students will enjoy week long activities including a kite decorating contest! Proceeds to benefit the UMDF through the Kristen Charleston Research Fund.
- **May 25, 2009.** OlliePalooza will be held at Strata in New York City, NY in honor of Oliver Scheier. The evening will include food and drinks, as well as live and silent auctions. For more information, visit www.umdf.org/olliepalooza.
- **May 30, 2009.** Landon's Hope will be held at Eastman Park in Windsor, CO. This new event, organized by Tami Weatherby, will feature a walk, activities for kids, refreshments, mitochondrial disease resources, and much more! For more information, please visit www.umdf.org/landonshope or contact Tami Weatherby at tamiweatherby@msn.com.



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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EASY WAYS TO RAISE FUNDS

Fundraising is at the core of the UMDF's ability to award research grants to the world's top mitochondrial specialists. Thanks to the dedication of our volunteers, the United Mitochondrial Disease Foundation raised over \$1.7 million in the past fiscal year for life-saving research and awareness. To build on that success, the UMDF needs YOU to increase awareness of mitochondrial disease in your community. A great way to educate others about mitochondrial disease is to organize a fundraising event.

GOODSEARCH.COM

GoodSearch, powered by Yahoo, developed a way to direct some of that money to the causes you care about most.

It's easy...every time you search the internet at GoodSearch.com, the UMDF earns money, and the more you search, the more dollars we make to find better treatments and cures. Add up the money generated from all your searches and those done by millions of other people who we hope will use GoodSearch, and we can make a real difference to the people and causes that need funds most.

How does it work?

Go to www.goodsearch.com, and in the "Who do you GoodSearch for?" box, type in The United Mitochondrial Disease Foundation. Then search the internet just like you normally would, and a donation of one penny per search is contributed to the UMDF.

GOODSHOP.COM

GoodSearch now offers a new feature called GoodShop. Every time you click over to one of the partner merchants from the GoodShop site and then make a purchase, the UMDF earns money. The more you shop, the more will be donated to the UMDF! 100% of the donation displayed on GoodShop will go to the UMDF!

How does it work?

Simply go to www.goodsearch.com, and click on the GoodShop link or go to www.goodshop.com. In the "Who do you GoodSearch for?" box, type in The United Mitochondrial Disease Foundation.

Next, click through to the GoodShop partner retailers and start shopping! A percentage of your purchase will go to the UMDF.

COINS FOR A CURESM

It's a very simple way to raise money for mitochondrial disease research. It's so easy even a child can do it— and a lot of them do.

Schools, churches and local youth groups accept coin collections for a designated time period. The Coins for a CureSM program shows children that they can make a difference in the world through their actions, one penny, nickel or dime at a time.

The UMDF has secure, lockable acrylic coin boxes that you can place in stores and businesses in your community. We also have 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 Home Collection Boxes can be used anywhere in your home where you find extra change, such as your laundry room, kitchen or bedroom.

The Special Events Department will provide you with sample flyers, collection stickers, correspondence and support through the event planning process. Register today at www.umdf.org/coinsforcure.



TEA FOR MITOSM

This "virtual" tea party will be one of the easiest fundraisers you will ever do! The UMDF will

provide you with a Tea for MitoSM host/hostess kit, including 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 and support your cause with a donation to the UMDF! Register today at www.teaformito.com



50 WAYS TO FUNDRAISE

The ideas put forth in 50 Ways to Fundraise are a mere sample of what a little imagination can do. Put your own touch on one of these ideas or create an entirely new fundraiser all on your own. The important thing is that you put the FUN in FUNdraising. No event is too big or too small and every contribution brings HOPE. ENERGY. LIFE. to a family in need.

ONGOING FUNDRAISERS

COINS FOR A CURESM

The following families participated in the Coins for a CureSM campaign and sent in funds raised in the months of December, January and February:

- Tom Arnold with Premier Restaurants (KFC) *in honor of Bobby Arnold*
- John DiCecco *in memory of Gina Mohan*
- Bob & Denise Greenberger *in memory of Jake Lyons*
- Drs. Ken Kanatani & Baker Chambliss *in honor of Joey Paulin*
- The Mohan Family *in honor of Michelle Mohan*
- Ribkens *in memory of Gina Mohan*
- St. Bernadette Catholic School *in memory of Gina Mohan*
- The Towell Family *in honor of Ryan Towell*

TEA FOR MITOSM

The following family participated in Tea for MitoSM and sent in funds raised in the months of December, January, February.

- The Carter Family *in honor of Ian Trotter*

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

For information about how you can become involved, contact the special events department at 888-317-UMDF or events@umdf.org.

MEMBER RESOURCES

Medical and Prescription Assistance

With growing health care costs, many people are finding themselves unable to afford doctor visits or prescriptions. The United Mitochondrial Disease Foundation has compiled a list of agencies that may be able to help.

NeedyMeds.com

NeedyMeds.com is a non-profit with the mission of helping people who cannot afford medicine or health care costs. The information at NeedyMeds.com is available free of charge. NeedyMeds.com provides information on Patient Assistance Programs, Disease-Based Assistance, Free or Low Cost Clinics, and State Programs. Note: NeedyMeds.com has information on medicine and health care assistance programs only. They do not run patient assistance programs, supply medicine, or financial assistance. Visit www.needyMeds.com for more information! NeedyMeds.com is a web-based organization and currently does not offer a phone help line.

Partnership for Prescription Assistance

The Partnership for Prescription Assistance brings together America's pharmaceutical companies, doctors, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that's right for them. Many will get them free or at low cost! To access the Partnership for Prescription Assistance by phone call 1-888-4PPA-NOW (1-888-477-2669) or visit www.pparx.org.

Abbott Nutrition

Abbott Nutrition (formerly Ross) has a section of their website devoted to links for Medicare/Medicaid coverage, including nutritional & enteral products, by state. Visit http://abbottnutrition.com/home/third_party_coverage or call the Abbott Nutrition reimbursement help line at 1-800-558-7677.

Songs of Love

The Songs of Love Foundation is a nonprofit organization that provides personalized songs to children and teens that are facing medical, physical, and emotional challenges. The foundation produces these personalized songs, that are never duplicated, for your child FREE of charge! A patient's parent, legal guardian, or hospital staff member can request a song. Requesting a song is very easy to do! You can request a profile sheet by calling the foundation at 1-800-960-SONG(7664). You can also visit www.songslove.org to fill out the form online or you could download and print the profile sheet. The profile sheet will ask you information regarding your child so the songwriter can personalize the song. The information includes your child's name, family, friends and pet names, along with your child's hobbies, interests and the type of music your child enjoys listening to.

Summer Camps

With summer quickly approaching, now is the time to think about summer camps! The United Mitochondrial Disease Foundation has put together a list of summer camps that tailor to children with disabilities. Many of these camps are free for children with life-threatening diseases to attend and have medical staff on hand in the event of an emergency.

Camp Sunshine

Camp Sunshine is a free camp for children with life-threatening diseases and their families. Their mission is to address the impact of a life threatening illness on every member of the immediate family. Camp Sunshine is located in Casco, Maine. For more information, call 207-655-3800, email info@campsunshine.org or visit www.campsunshine.org.

Camp for All

Camp for All provides week long camps, weekend retreats and day programs for more than 55 different special needs groups. Camp for All is located in Burton, Texas. For more information, call 713-686-5666, email houstonoffice@campforall.org, or visit www.campforall.org.

Camp Korey at Carnation Farm

Camp Korey is a "Hole in the Wall" medically-supervised camp where kids can attend for free. In the 2009 summer season, they are featuring their first mitochondrial disease camp. Camp Korey is located in Carnation, Washington. For more information, call 425-788-1511, email seekinginfo@campkorey.org, or visit www.campkorey.org.

Canyon Ranch

Canyon Ranch camp sessions through Dream Street Foundation are free of charge. Canyon Ranch is located near Tuscan, Arizona. For more information, call 800-55-DREAM, email dreamstreetca@aol.com, or visit www.dreamstreetfoundation.org/campers.html.

Dream Street Foundation

The Dream Street Foundation's purpose is to provide a unique camping program, free of charge, to children with chronic or life-threatening diseases. The Dream Street Foundation offers camps in California and Arizona. For more information, call 323-951-1227, email dreamstreetca@aol.com, or visit www.dreamstreetfoundation.org.

Hole in the Wall Camps

The Association of Hole in the Wall Camps offer camps for seriously ill children at no charge. The camps are spread out across the United States and around the world. Visit www.holeinthewallcamps.org for a list of camps. For more information, call 203-562-1203 or email info@holeinthewallcamps.org.

Kiwanis Camps

Many Kiwanis Clubs offer camps in their local area. Visit www.kiwanis.org to find your local Kiwanis Club.

MDA Camps

The Muscular Dystrophy Association supports nearly 90 camps across the country; these camps are for children with neuromuscular diseases. For more information and to find a camp near you, visit www.mda.org/clinics/camp.

The Woodlands

The Woodlands is open to all Pennsylvania residents and is committed to enriching the lives of children and adults with disability and chronic illness. The Woodlands is located in Wexford, Pennsylvania. For more information, call 724-935-6533, email info@woodlandsfoundation.org, or visit www.woodlandsfoundation.org.

The following web sites provide links to summer camps for all needs:

Kids Camps.com - www.kidscamps.com

Exceptional Parent - www.eparent.com

American Camp Association - <http://find.acacamps.org>

The Rhode Island Developmental Disabilities Council - www.riddc.org



ADULT ADVISORY COUNCIL TEAM UPDATE

It has been one year since the Adult Advisory Council Team (AACT) started working on behalf of our adult mitochondrial community. I would like to highlight our efforts under the five arenas we developed that are the Council's focus and direction:

1. Marketing, Communications & Collateral

We have audited all existing brochures, pamphlets and flyers ensuring that the word "adult" is included and that adult issues are mentioned alongside child issues. We continue to ask for personal adult stories to print in this newsletter and on our web site.

2. Website & Internet

Please take a look at the "For Adults" section of the UMDF website; we have added numerous resources for adults. There are links to resources on disability information, patient rights, and national and state resources with specific article links addressing many adult issues.

3. Outreach & Education

In the last eight months, we have been developing an Adult Resource Guide that will be available online. It will include adult-specific resources, such as medical doctors that see adult mitochondrial patients, medical centers in the United States that have proper diagnostic labs, and information on how to navigate in the medical world.

We have also created an Adult Liaison National Network. We have already appointed nine adult individuals who will act as a liaison between AACT and the adult community to disseminate important and useful information. Our goal is to continue adding to this network. If you know someone who might be interested in serving in this capacity and would like more information, please contact our council! We are very excited about our AACT Adult Liaison National Network!

4. UMDF Symposium

Our council reviews all adult symposium evaluation forms that are turned into the UMDF at the end of the symposium. The evaluation forms provide vital and useful feedback regarding the adult sessions and the symposium in general. All feedback and comments received are forwarded to the UMDF for future consideration.

AACT is also very proud to host the annual Adult Gathering where adults and their families meet one another and hear AACT news and updates. The Adult Gathering has now become a very important part of the UMDF symposium.

Nominations are now being accepted for the UMDF LEAP Award. The LEAP award is presented annually at the symposium banquet to an affected adult who is living with mitochondrial disease in a positive and productive way. So, please think about that adult you know deserving of this award and nominate them today!

5. New Materials

Calling All Adults! Please check out the revised adult questionnaire available online. If you have not completed and submitted to the UMDF, please do so. Your comments and feedback are very important for the council and the work we are currently doing. Every questionnaire is read and passed along to the UMDF. The questionnaire has become a communication link from you to the council, which helps us to better assist the UMDF national office in representing you, the adult mitochondrial patient community.

Lastly, we wish to stress the importance of sending in your advocacy letter. Your involvement is critical and will assist the UMDF's efforts this June when we storm the Hill in Washington, DC!

We count on your feedback, and we are here to serve and represent you; together we have more energy – thank you!

Yours in service,



Sharon Shaw
Chair, Adult Advisory Council Team (AACT)

Adult Advisory Council Team (AACT)

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Gail Wehling, AACT Co-Chair, Illinois
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Cynthia Rosen, New Mexico
Catherine Stefanavage, Georgia
Dan Stout, Kentucky
Gregory Yellen, Maryland

Medical Advisors:
Bruce H. Cohen, MD
Amy Goldstein, MD

AACT MISSION

To ensure equal representation and service of the affected adult community to the affected pediatric community -- and to better represent, serve and assist adults with mitochondrial disease.



Heidi Martin-Coleman & her service dog, Mercury

CALLING ALL ADULT MITOCHONDRIAL PATIENTS!

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

ADVOCACY

MITOCHONDRIAL MEDICINE 2009: CAPITOL HILL

DAY ON THE HILL

For nearly a year, a large portion of our advocacy effort has concentrated on our June 25, 2009, visit to Capitol Hill. Last summer in Indianapolis, we outlined some very specific action items that you, your family and friends could do as part of our effort leading up to visits on Capitol Hill. This column will serve as a final checklist to help your voice to be heard on behalf of the thousands affected by mitochondrial disease.

Have you advocated by letter, fax or email?

We've made advocating a very simple online process. From the front page on the UMDF website, click "Advocacy Action Center." You will be taken to a page that will enable you to show your support for additional research by sending a letter, fax or email to your House or Senate member. If you don't have a user name or password, simply sign up online. It's free and doesn't automatically make you, your friends or family members of the UMDF.

Have you followed up with a meeting with your House or Senate member or their staff in your home district?

These meetings are important because it gives you an opportunity to meet face to face with your representatives to educate them about mitochondrial disease and the effect it has had on you or your family. It is an educational session for them or their staff members. Even if you are not planning to attend the symposium, the letters and the face to face meetings on the local level help those who are planning to attend. We want members of the House and

Senate to be familiar with mitochondrial disease and not hear about it for the first time in Washington, DC on June 25th.

Are you going to attend our Day on the Hill?

The UMDF needs to know for a couple of reasons. We need to make sure we have enough transportation from the Sheraton Premiere to Capitol Hill. We will need to know if you or anyone in your party has special needs during our visit to the Hill. Lastly, we need to make the appointment for you with your House and Senate member or their representative. We ask that you complete a simple survey that is online and can be accessed by following this link: https://www.surveymonkey.com/s.aspx?sm=7_2fJT0RFgcX7DSdQkgWYyMQ_3d_3d.

If you do not have computer access, call the UMDF National Office at 888-317-UMDF (8633) and ask our communications department for a hard copy of the "Day on the Hill" survey. We will be happy to mail it to you.

MOST IMPORTANT: The online survey or printed survey must be completed and returned to the UMDF national office by **April 30, 2009**. It could take four to six weeks to get a meeting with a representative of the House or Senate. If you do not complete the survey online or via the mail, we won't have transportation or be able to set up a meeting for you.

This is going to be a great day to let our voices call for more research dollars. We hope to see you there!

ADVOCACY - HOW ARE WE DOING?

We thought you might be interested in knowing the progress we're making on educating our members of the US House and Senate about the need for more research dollars to study mitochondrial issues at the NIH level. Our advocacy effort began in June 2008 in Indianapolis, IN. It was there we showed you the new "Advocacy Tool Kit." In September, we put the toolkit online and showed you how to make your voice heard through the Action Center. We urged you to log in and send a letter to your elected official or to send a letter to your local newspaper editor. With the dawn of a new administration, we gave you a third opportunity to advocate. Our scientific and medical community sent a letter to President Obama urging him to make good on his promise to fund medical and scientific research. We gave you the opportunity to join the effort through the Action Center. The UMDF Board of Trustees set a strategic goal to have 1000 members take an advocacy action by April 1, 2009. We surpassed that goal in December, 2008. For that, we thank you! But, we're not done. We still need you to send your letter through the Action Center if you have not done so already.

Here is a list of the top 5 states

- 1 - Pennsylvania
- 2 - Ohio
- 3 - Indiana
- 4 - Georgia
- 5 - California

Here is a list of the bottom 5

- 1 - Hawaii
- 2 - Alaska
- 3 - Montana
- 4 - Nevada
- 5 - New Mexico, Utah, Oregon, South Dakota, New Hampshire, Delaware

You can see the complete list at www.umdf.org. Under the Energy section, you will find Advocacy Actions State by State. We will update this online on a weekly basis!

MITOCHONDRIAL DISEASE AWARENESS WEEK SEPTEMBER 20-26, 2009

*We need your help to designate a nationwide
Mitochondrial Disease Awareness Week*

WHAT CAN YOU DO?

*Contact your local Senator or Representative today!
Start to plan an awareness activity during
Awareness Week!*

NOT SURE WHAT TO DO?

*Log on to www.umdf.org to download the
Awareness Week "Toolkit", and learn how to get
started with sample letters, a sample bill template
and letter writing tips!*

STILL NEED HELP?

*Contact the UMDF at 888-317-UMDF or email
news@umdf.org.*

The United Mitochondrial Disease Foundation, The Mitochondrial Medicine Society, The Mitochondria Research Society, Mitochondrial Physiology Society (MiP2009) and The Cleveland Clinic

Present

Mitochondrial Medicine 2009:

Capitol Hill

Sheraton Premiere at Tysons Corner
Vienna, Virginia - Washington, DC area

Scientific Program June 24-27, 2009 - Family Program June 26-27, 2009

Capitol Hill Visit - June 25, 2009

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



ANNOUNCEMENTS

ENTERTAINMENT BOOK FUNDRAISER

The UMDF is offering the 2009 Entertainment Books for sale! Now is the time to purchase your 2009 Entertainment Books ~ save money on things you do every day and support the UMDF at the same time. Dine, shop, travel and SAVE! Buy Entertainment Books for yourself or as gifts. Entertainment Books are available throughout the country in more than 150 editions. Type <http://www.entertainment.com/discount/?groupID=642223> into your web browser to order an Entertainment Book close to home. Entertainment Books will be shipped directly to your house at no additional cost. The UMDF will receive a percentage of each book purchased!

PLATES WITH PURPOSE

Riverside Design Group, located in Pittsburgh, PA, continues to help the UMDF raise money for research through the sales of Plates with Purpose. The UMDF receives 15% from the sale of the UMDF ladybug design plate! The UMDF plate design is in memory of Morgan Reynolds, who loved lady bugs very much. You can purchase your special UMDF ladybug design plate through the Plates with Purpose website at www.plateswithpurpose.com. For more information on Plates with Purpose, contact info@riversidedesigns.com. To date, Plates with Purpose has donated \$1,453 to the UMDF.



NEW MEMBERSHIP LEVELS

The UMDF announced in January the addition of a basic, free membership for individuals interested in joining the UMDF. The free "HOPE" membership is designed to increase the number of members who belong to the UMDF while offering information to individuals and families about mitochondrial disease. The "Hope" membership will allow individuals to retrieve electronic information from the UMDF website that is not available to the general public. These include online access to the UMDF Newsletter archives, online versions of MITO101 and MitoFIRST, online access to pre-recorded webinars, advocacy opportunities, and regular e-blasts from the UMDF. The free "Hope" membership is valued at \$300!

Members who support the UMDF annually at the \$50 level will now be included in the "ENERGY" membership level. The "ENERGY" membership will continue to have access to all areas of the website and enjoy enhanced benefits. These benefits include the ability to submit questions to Ask the Mito DocSM, the latest UMDF Newsletter delivered to your email account (will be mailed on special cases; contact the UMDF), the ability to participate in MITO Connect, the ability to watch and participate in live webinars, a mailed copy of MITO 101, and a new member packet, if desired. The "ENERGY" membership is valued at over \$800!

For more information, visit www.umdff.org or call 888-317-UMDF.

**SUBMISSION DEADLINE FOR VOLUME 14 ISSUE 2 IS
APRIL 30, 2009!**



UNITED
MITOCHONDRIAL
DISEASE
FOUNDATION®

HOPE. ENERGY. LIFE.

IN THIS ISSUE:

UMDF Grant Recipients make exciting breakthrough!
Read page 1!

Potty Training Issues?
See page 3!

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

**Mitochondrial Medicine 2009:
Capitol Hill**
Find out more on page 11!

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