

SUPPORT NEEDED FOR H.R. 3502

Mitochondrial Medicine Research and Treatment Enhancement Act

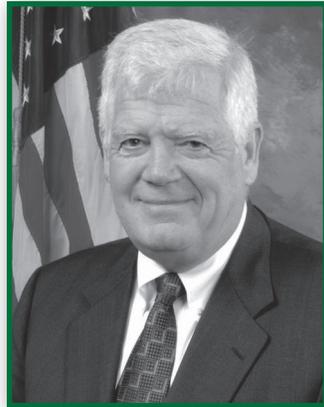
In a landmark move for those affected with mitochondrial disease, the United States House of Representatives will consider a bill that, if enacted, will create an Office of Mitochondrial Medicine within the National Institutes of Health (NIH) to enhance research aimed at improving the understanding of mitochondrial disease and dysfunction and the development of treatments for mitochondrial disease.

Known as the "Mitochondrial Medicine and Treatment Enhancement Act," H.R. 3502 was introduced by Rep. Jim McDermott (D-WA/7th) on July 31, 2009.

If approved, H.R. 3502 will expand existing research efforts at the NIH and foster greater coordination among NIH Institutes involved with different aspects of mitochondrial research.

The newly created Office of Mitochondrial Medicine will be directed to improve the coordination of research within the institutes at the NIH and with outside researchers. It also calls on the NIH to annually award five grants for research programs related to mitochondrial medicine.

In addition, H.R. 3502 calls on the NIH to establish a "Mitochondrial Medicine Center for Excellence" to promote interdisciplinary research and training related to mitochondrial medicine. It



Rep. Jim McDermott (D-WA/7th)

also calls on the NIH to establish a national registry for the maintenance and sharing for research purposes and creates a biorepository for DNA and tissues collected from patients with mitochondrial disease and dysfunction for research purposes.

"The legislation is a milestone for the hundreds of thousands of people affected by mitochondrial disease and their families," said Charles A. Mohan, Jr., CEO and Executive Director of the UMDF. "We thank Congressman McDermott for championing this legislation and helping to bring the many people affected by mitochondrial disease one step closer to a cure." Similar legislation is expected to be introduced in the U.S. Senate this fall.

H.R. 3502 will play a significant role in advancing science and medicine. Research has revealed that mitochondrial dysfunction is at the core of many common illnesses and chronic conditions such as Alzheimer's disease, Parkinson's disease, diabetes, heart disease, obesity, osteoporosis, cancer and even the aging process. Autoimmune diseases such as

multiple sclerosis, lupus and rheumatoid arthritis also may have a mitochondrial basis. Because mitochondria are so important to the health of cells, a full understanding of their function and dysfunction will have a significant impact on the health of our citizens. With the research initiative provided through H.R. 3502, discoveries could be made that will lead to prevention and cures for medical problems that currently affect millions of Americans.

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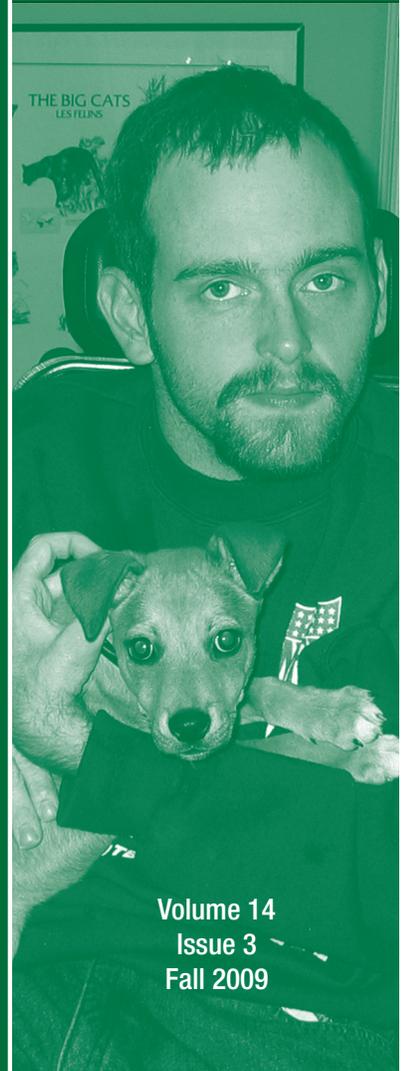
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The UMDF's first "Day on the Hill" was held on June 25th in Washington, DC. 248 UMDF members stormed the Hill for more federal funding for Mitochondrial Disease research!!

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FROM PAGE ONE

When H.R. 3502 was introduced, 13 members of Congress signed on as original co-sponsors. They are Rep. John H. Adler (D-3rd/NJ), Rep. Leonard L. Boswell (D-3rd/IA), Rep. Gerry E. Connolly (D-11/VA), Rep. Anna G. Eshoo (D-14/CA), Rep. Brad Ellsworth (D-8th/IN), Rep. Henry C. "Hank" Johnson (D-4th/GA), Rep. Mark S. Kirk (R-10th/IL), Rep. James P. McGovern (D-3rd/MA), Rep. Tim Murphy (R-18th/PA), Rep. Mike Thompson (D-1st/CA), Rep. William "Mac" Thornberry (R-13th/TX), Rep. Chris Van Hollen, Jr. (D-8th/MD), and Rep. Debbie Wasserman Schultz (D-20th/FL). "These representatives deserve thanks from the mitochondrial disease community because they understand the implications and the value in investigating the role mitochondria plays in human health," said Mohan. "We have co-sponsors who are both Democrats and Republicans, liberals, moderates and conservatives, and who represent both rural and urban areas. Their support shows how important this issue really is for all Americans."

Mohan is urging UMDF members to get involved in supporting H.R. 3502 and the upcoming senate measure. "There are 435 members in the House. Each one of them must hear from us many times in order to demonstrate the importance of H.R. 3502. We all need to start advocating for additional co-sponsors for this legislation and its ultimate passage in both chambers."

UMDF members, their friends, family and coworkers can simply go to www.umdff.org/hr3502 for more information about the bill. The page includes a link to the 'Advocacy Action Center,' where letters have been prepared for you to send to your Congressman asking for them to co-sponsor H.R. 3502. Our progress on communicating with Congress can be tracked by visiting www.umdff.org/track3502. The web page provides a state-by-state summary of the number of letters sent to each member of Congress. Has your Congressman been contacted?

MITOCHONDRIAL MEDICINE 2009: CAPITOL HILL

In June, the UMDF hosted the eleventh annual symposium, Mitochondrial Medicine 2009: Capitol Hill in Washington, DC. The conference was attended by 268 physicians, researchers and other professionals and 250 patients and family members. This year's conference had a couple new and exciting features. The UMDF and Autism Speaks worked together to offer both scientific and family sessions on mitochondrial disease and autism. The UMDF received a very special grant from the Edith Trees Charitable Foundation to hold special sessions on Friday for our Teen attendees.

Scientific Meetings

Day One - The first day's sessions fell under the headings of Medical Genetics of Mitochondrial Disease and the Mitochondrial Biology of

Complex Diseases. A highlight among the abstract presentations was given by Adeel Safdar, winner of the Kelsey Wright award, who demonstrated that regular endurance exercise protects against muscle wasting in mice with a polymerase gamma mutation that causes myopathy.

Day Two - The next day, multiple presentations covered the pathophysiology of mitochondrial

diseases, especially those associated with neurological disorders. An outstanding talk by Christie N. Jones addressed the effects of antibiotics on mitochondrial function in patients with mitochondrial translation defects.

Day Three - On the morning of the third day, advances in the use of animal and yeast models to better characterize mitochondrial physiology were the subjects of several presentations. That afternoon several faculty members participated

in a special session on mitochondrial disease and autism. Also, exciting research was presented by Sandra R. Bacman concerning the systemic delivery of mitochondria-targeted restriction endonucleases to alter mtDNA heteroplasmy in specific tissue.

Day Four - The final day was devoted to clinical aspects of mitochondrial medicine. Eric Gnaiger's excellent closing talk related the healthy state of mitochondrial research to the benefits that will accrue to improved public health in coming years. (Scientific summaries courtesy of Steven G. Bassett, PhD)



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MITOCHONDRIAL
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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.

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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: Sumit Parikh, MD, of the Cleveland Clinic, OH, Mark Tarnopolsky, MD, of McMaster University, Canada, Greg Enns, MD, University of California San Francisco, CA, and Russell Saneto, DO, PHD, of Children's Hospital, Seattle, WA.

THE QUESTION IS...

My granddaughter has complex 1 Mitochondrial Encephalomyopathy. Since lactic acid can be a problem at times (hers was fine at muscle biopsy time) can she take probiotics? I know most contain lactic acid.

RESPONSE FROM SUMIT PARIKH, MD:

Probiotic supplements come in several forms, and may contain lactobacilli, yeast and/or other healthy bacteria. I suspect you are referring to lactobacilli or lactose-containing probiotic supplements in your question.

First of all, in regards to lactic acid in mitochondrial disease - this finding is simply a sign that the mitochondria are not working as well as they should. However, the lactic acid itself is not harmful in most situations - especially if only modestly elevated.

Secondly, while it is true that we do not want to increase the lactic acid burden in the body (by avoiding ringers lactate IV fluids for example,) most dietary lactate (from dairy-containing products) is broken down into simple sugars by our gut prior to entering the body. So these substances do not increase the body's lactic acid burden.

Thus probiotics (whether lactose-containing forms or lactobacilli) are considered generally

safe in patients with mitochondrial disease - though we do not yet know of their overall efficacy in any patient. If there is known lactose intolerance, a lactose-free probiotic may be preferable.

THE QUESTION IS...

My 13 year old son was diagnosed with NARP T-C mutation 8 years ago. He was taking Co-Q10 and a multi-vitamin since then. I stopped them over this summer to see if any change would take place. I don't see any progression nor do I see any changes. Should I put him back on the Co-Q or not?

RESPONSE FROM MARK TARNOPOLSKY, MD:

All supplements should be taken under medical supervision. Coenzyme Q10 is not well absorbed as a powder in a capsule and that could be one reason for not working. Also, the dose could be too low. In addition, the improvements may not be clinically obvious. We have done many studies in a blinded double blind fashion and the folks did not "feel" anything but the blood measurements showed improvements. I strongly feel that mitochondrial disorders are an interaction of the gene and the environment and aging. Consequently, targeting the final common pathways of cellular dysfunction in mito disease may slow the progression of disease over time. For doses and types see articles such as the supplement article in Mito 101 on the UMDF website.

The following question was submitted and answered by two mitochondrial specialists.

THE QUESTION IS...

I have a 4 and 1/2 year old son who presented with mitochondrial disease at 3 days old. He was diagnosed via muscle biopsy at 11 months old with Leigh's Syndrome. He is now having trouble regulating his temp and dropping as low as 92.5. Our doctor can not tell me what this means other than his brain stem isn't functioning as well. This being said he referenced 6 months; however, I need a realistic picture to function and take the best care of my son as possible. What is your experience with mitochondrial disease and the brain stem? Does brain stem failure mean progression of the disease?

RESPONSE FROM GREG ENNS, MD:

I am sorry to hear about the severity of disease present in your son. Leigh syndrome is particularly devastating because of the

widespread effects on the brain, and brainstem involvement is serious. I understand your situation and your desire to know as much about the progression of Leigh syndrome as possible. However, in my experience it is difficult to predict exactly how well or poorly an individual child will do. I have seen children with very severe symptoms survive longer than I would have expected, as well as the opposite. Depending on the extent of disease, children may survive for a few years up to about teenager years. Unfortunately nobody has a crystal ball. Every child is different and we can only hope for the best.

RESPONSE FROM RUSS SANETO, DO, PHD:

I have several patients with Leigh syndrome as well as Leigh-like syndrome. How we predict (which is still not very good) outcome is based on what is the genetic etiology of the mitochondrial syndrome; but in the end patients surprise us, both for the good and not so good. I assume this since your son has an ETC abnormality without a genetic diagnosis. Brainstem dysfunction often can cause what we call dysautonomia, which just means that the autonomic nervous system (the nervous system outside the brain) that regulates our organ functions becomes uncontrolled to normal cues. This is common in Leigh syndrome or Leigh-like syndrome. For instance, there may be a respiration irregularity where a child will seemingly gasp for air when there have been no stimuli - sort of like an asthma attack. Temperature regulation can also be a problem as you describe. Some patients have problems with heat, some with cold, and some with both. The types of dysautonomia relate to where the lesions within the brainstem are located, so are very patient-dependent. What we tell our patients is to react as you would for any type of problem; for instance, if he is cold (even if it's 100 degrees outside) then you make sure he is dressed appropriately. If he seems overly hot when the temperature is 68 degrees, then dress him down. You may have to be creative on how you respond and the range of clothing that you have in hand.

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.

CHAPTER ACTIVITIES

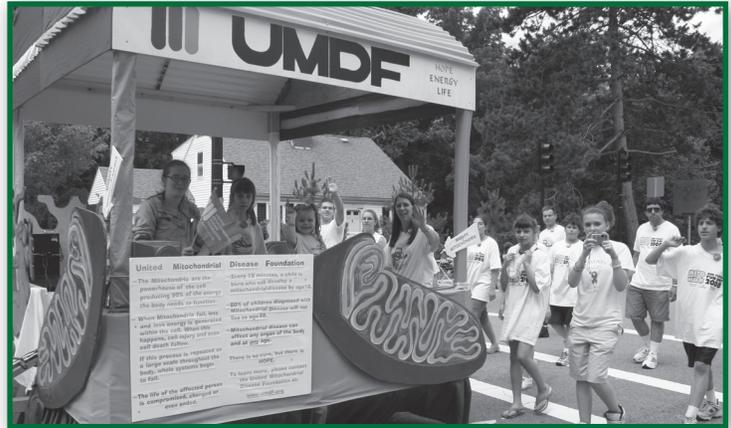
CHAPTER NOTES

ATLANTA CHAPTER

- **June 9, 2009.** The Chili's at North Point in Alpharetta, GA held a "Chili's Give Back for Mito." For every diner that presented their server with a UMDF voucher, Chili's contributed 100% of their total bill to the UMDF.

NEW ENGLAND CHAPTER

- **July 4, 2009.** At the annual Fourth of July celebration in Chelmsford, MA, the Bush family assembled a float, and with the company of more than 20 walkers, raised awareness in the community for the UMDF! From the sale of raffles, more than \$300 was raised! Thank you to the Bush family for your support and dedication!
- **July 25 2009.** Becky and Dan Genie hosted a Friends of Cameron picnic in Chicopee, MA. The weather was great and the turn out was even better! Nearly \$6,000 was raised in honor of Cameron Genie. Great job and a big thank you to the Genie family!



UMDF float at the Fourth of July celebration in Chelmsford, MA

OTHER NOTABLE EVENTS

- **June 5, 2009.** The fourth annual Josie Mazzo Golf Tournament was held at the Greystone Golf Club in Dickson, TN. The annual event benefits the UMDF, the Monroe Carell Jr. Children's Hospital at Vanderbilt and the Ronald McDonald House of Middle Tennessee.
- **June 6, 2009.** The Greater Mito Open Golf Outing was held at Olde Highlander Golf Course in Oconomowoc, WI. The annual event is held in honor of Brianna Dobkey and has raised more than \$50,000 in the past three years. Thank you to the Dobke family for your support!



Atlanta Miles for Mito Riders

- **June 19-26, 2009.** Miles for Mito operated two routes to the UMDF annual Symposium in Washington, DC; one from Indianapolis and one from Atlanta. While riding, participants collected nearly \$27,000 in pledges that were donated to the UMDF.
- **June 25, 2009.** The inaugural Up 'n' Atom for Mitochondrial Disease tractor pull event was held in Tomah, WI. More than \$27,000 was donated to the UMDF in honor of Miranda Gettinger.
- **June 26, 2009.** The Spa & Share program donated 10% of spa proceeds to the UMDF in honor of Kyle Avila. Thank you to Monica Avila for your support!
- **June 27, 2009.** The annual Save Barnegat Bay 8K walk/run event was held in Lavallette, NJ. The event benefited several charities, including the UMDF.

- **July 11, 2009.** The second annual Chandler Hope Hurley Golf Scramble was held at the Bramblewood Golf Course in Holy, MI. Chandler is the youngest child of Rebecca and Mickey Hurley. Thank you to the Hurley family for your support of the UMDF!
- **August 1, 2009.** The second annual Run 4 Raley was held at the Big Fall Diamond in Philo, IL. Thanks to the hard work of the Kirby family, more than \$16,000 was donated to the UMDF in memory of Raley.
- **August 2, 2009.** Aubrey's Cut-A-Thon was held at the Beauty First Salon in Pittsburgh, PA. A portion of the proceeds from each hair cut was donated to the UMDF in honor of Aubrey Austin. A special thank you to Patrice Deshantz for organizing such a great event!



3rd annual Myles for a Cure

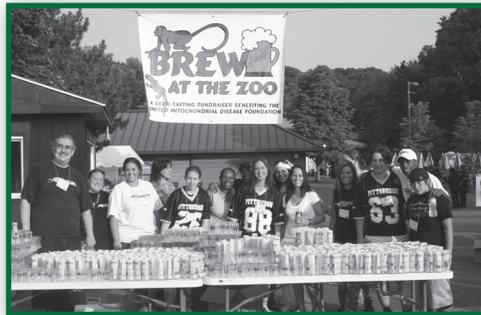
- **June 13, 2009.** The third annual Myles for a Cure was held in Cedar Falls, IA. The event offered all participants a fun-filled experience with entertainment, refreshments, and mitochondrial disease resources. Nearly \$3,000 has been raised to date!



Aubrey Austin

OTHER NOTABLE EVENTS (CONTINUED)

- **August 5, 2009.** The second annual Splishin' Splashin' for the UMDF was held at the Crooksville Pool in Crooksville, OH. The event was held in honor of Baylee Thompson. Participants enjoyed pizza, a bake sale, door prizes, a DJ and of course a day of swimming!
- **August 7-9, 2009.** The second annual Baylee's Ball Bash was held at the Cannelville Softball Field in Cannelville, OH. The ASA sanctioned tournament was held in honor of Baylee Thompson and raised funds for the UMDF and generated awareness of mitochondrial disease.
- **August 15, 2009.** The third annual Brew at the Zoo was held at the Pittsburgh Zoo & PPG Aquarium in Pittsburgh, PA. The event featured more than 120 national, local and home brewers as well as live entertainment from Here & Now, Sara Haze, 7 Saturdays, and Carolina Shine. The sellout crowd of nearly



3rd annual Brew at the Zoo

2,500 people helped to raise more than \$81,000 for the UMDF!

- **August 15, 2009.** The 16th annual Gibson Pot Luck BBQ was held in Ukiah, CA in memory of Heidi Daniels. The backyard BBQ was attended by 84 people and raised nearly \$5,000 for the UMDF. A very special thank you to Norma Gibson for your continued support of the UMDF and its mission.

- **August 27, 2009.** Casbah Mediterranean Kitchen & Wine Bar, a member of Pittsburgh's renowned Big Burrito Restaurant Group, hosted a special benefit dinner for the UMDF. For a \$100 donation to the UMDF, the restaurant donated a specially prepared, multi-course meal featuring seasonal foods for members and friends. The benefit dinner series is part of the restaurant group's commitment to the community.



16th Annual Gibson Pot Luck BBQ

GIFTS FROM THE HEART

- The Tiede family (Melissa, Todd, Lance, Jared & Shaun) of Texas won a raffle held earlier this year at Christopher's Heart Fun Run, and that is how they learned about the UMDF and mitochondrial disease. They wanted to do something to help find a cure for mitochondrial disease, so they donated four Easter themed baskets for a special raffle. The baskets raised \$55 for the UMDF! Thank you to the Tiede Family for your generosity!
- A benefit breakfast was held at the Outlaw Tractor Pull event in Rock Valley, IA. The event raised \$1,500 for the UMDF in honor of Autumn Hoekstra.
- Laynee Brunk, of Grand Ledge, MI celebrated her seventh birthday this past April. She asked that her friends and family make donations to the UMDF or to the Alley Brunk Memorial Run in lieu of giving her gifts. Laynee is very proud to have raised \$165 for the UMDF in memory of her beautiful sister, Allyce Danielle Brunk.
- The Alley Brunk Memorial Foundation held their sixth annual Alley Brunk Memorial 5k Run on June 13th. The event raised \$3,165 for the UMDF in memory of Allyce Danielle Brunk. Thank you to the Brunk family for your continued support of the UMDF!
- Josh Ackerman, of Jupiter, FL recently celebrated his Bar Mitzvah and chose to raise money for the United Mitochondrial Disease Foundation as his Bar Mitzvah project. Josh was able to donate \$500 to the UMDF in honor of his friend Charlie Dunn. Thank you Josh for your support of the UMDF!
- A Tea Party was held in Dayton, ME in honor of Ian Trottier. The party raised a total of \$1,000 for the UMDF! Thank you to the Trottier family for your support!
- The first annual Crops for a Cure...to Cut out Mito scrapbooking event was held in Cumming, GA this past May. The event raised more than \$2,200 for the UMDF. Thank you to Robyn Gravitt for your support!
- John Deere Waterloo Works held a "Casual for a Cause" day and donated proceeds to the UMDF! In total, the event raised \$2,184! Thank you to the employees!
- The St. Bruno School in Chicago, IL sponsored a charity dress down day for the UMDF. The school raised \$202 in honor of Kristen Charleston.
- The Vasilich family held their annual walk in Pittsburgh, PA. Donations were made in loving memory of Kaitlin Marie Vasilich and will be contributed to the annual Pittsburgh walk on October 3, 2009. Thank you to the Vasilich family and friends for your support!
- The fifth annual Carter Martin Classic was held in Iowa on July 18, 2009. Nearly \$250 was donated to the UMDF in honor of Carter Ray.
- The Vacation Bible School participants of The Church of the Hills in Duluth, GA participated in a Coins for a Cure campaign that raised more than \$450 for the UMDF. Thank you to all who helped!

If you are having or have held a fundraising event, we want to hear about it! Email events@umdf.org or call 888-317-UMDF.

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UMDF YOUTH AMBASSADORS

Georgia

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MITO FACTS

- Symptoms of mitochondrial disease are very diverse and often progressive.
- At least 1 in 200 individuals in the general public have a mitochondrial DNA mutation that may lead to disease.
- Every thirty minutes, a child is born who will develop a mitochondrial disease by age 10.



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CROSS THE COUNTRY CAMP

A Day in the Life of Jake Didinsky

Everyone likes to be able to get away for a short while over the summer. For adults or children affected with a mitochondrial disease, planning is imperative and in some cases incredibly stressful. But there is a place where kids with various illnesses can get away from it all for a while. It is a place called Camp Korey, located in the state of Washington. For a week this summer, they welcomed kids with mitochondrial disease. Camp Korey is a "Hole in the Wall" medically-supervised camp where kids can attend free of charge. This year, Camp Korey worked with the Mitochondrial Research Guild of Seattle Children's Hospital to hold a week long camp for children with mitochondrial disease.

Jake Didinsky, 16, first heard about Camp Korey when he was attending a 'Hole in the Wall Camp' in Victory Junction, North Carolina. He was excited to learn that Camp Korey would be a camp for kids like him- kids who had a mitochondrial disease. While at the UMDF annual Symposium in June, he spoke with Dr. Russell Saneto about Camp Korey's mitochondrial disease session and decided that he wanted to attend.

Jake is the oldest son of Sharon Goldin of Lorton, VA. He has two younger twin brothers, Clay and Cole. In 2005, Clay was diagnosed with mitochondrial encephalomyopathy complex I defect. Just a few years later, Jake and Cole were both diagnosed with mitochondrial encephalomyopathy complex I defect as well.

For the past three summers, Jake has attended the Victory Junction camp. He was sad to learn that he would not be able to attend anymore because he has passed the age requirement. When he learned that he would be able to attend the mitochondrial week at Camp Korey he knew he had to attend. "After meeting so many kids my age at the UMDF Symposium, I really wanted to attend a camp with other kids that had

a mitochondrial disease," Jake said. "Knowing this would be a chance for me to just be a 16 year old teen for once." Jake, a veteran camper, had some idea of what to expect. "Victory Junction is a very high tech and glitzy camp and I knew that Camp Korey was going to be more of a regular camp," Jake says, "I was looking forward to that!"

After a 5 hour plane ride from Virginia to Washington, Jake was met at the airport by the Director of Camp Korey. "As soon as we got to camp, everything from that point on was awesome," Jake remembers.

"The camp was amazing; the camp grounds were beautiful and exceeded my wildest expectations."

Camp Korey offers children with mitochondrial disease a chance to meet other children who are going through similar situations. "It was great to be at a camp where ALL the kids had a mitochondrial disease, although each kid was affected differently," says Jake. Jake made great friends at camp and plans on keeping in touch with them. "One in particular, Chance, he has a g-tube like me and we have very similar situations." The campers

were all able to talk about their battle with mitochondrial disease, but were also given the chance to be regular campers.

Campers were able to play tennis, play ultimate Frisbee, go swimming, ride horses and participate in pet therapy, take a ride in a hot air balloon, or play golf. They also had a talent show where all

campers participated, a movie night and a spa night. "Camp in one word was so amazing that nothing I can do will ever compare to the friends I have made and the people that I have met. I hope that all of the kids who go to Camp Korey enjoyed it as much as I did. I hope that Camp Korey is always around, so that kids like me can have the chance to be a kid and ignore the world of medical problems that make being a normal kid so hard to achieve." Jake hopes to attend Camp Korey next summer as a Leader/Counselor in Training.

Camp Korey is located in Carnation, Washington. For more information, please visit www.campkorey.org.



Hot Air Balloon at Camp Korey



Jake (middle) with his brothers, Clay (L) & Cole (R)

FROM THE CHAIRMAN

Two hundred and forty eight members of the UMDF and their families joined together to become part of the cure when they participated in our "Day on the Hill" on June 25, 2009. The advocacy effort was designed to allow those attending a chance to advocate for additional mitochondrial medicine research funding during meetings with their Congressman, Senator or a member of their respective staff. It was the UMDF's first "Day on the Hill" and it coincided with the annual symposium, "Mitochondrial Medicine 2009: Capitol Hill." Many of those participating in the advocacy effort had the opportunity for face-to-face meetings with their elected officials. Some were given private tours of the Capitol. All were pleased to share their personal stories about the struggle that unifies all of us, mitochondrial disease. While we are sure those who participated will agree the day was a tremendous success, what you may not know is that our participation in this advocacy event was more than two years in the making.



The idea for a special advocacy day came from Rick Leach, UMDF trustee and chairman of the foundation's Governmental Affairs Committee. Nearly two years ago, Rick told the board of trustees that the only way to secure additional governmental support for mitochondrial medicine funding and research was to make a strong case before members of Congress. However, in order to create a strong advocacy effort, the UMDF needed to start building the foundation for the effort. The first step was trying to determine, through communication with members of Congress, the extent of financial support provided by the federal government for mitochondrial medicine research. Through that effort, the UMDF was able to determine the status of current research projects within the National Institutes of Health (NIH) and the amount of research dollars allocated for those projects. The data provided a solid starting point in formulating an advocacy plan that would be impactful.

With NIH research information in hand, the UMDF needed to start creating the materials that would be needed to help UMDF members speak to their members of Congress. In December of 2007, the UMDF engaged the firm Porter Novelli to help develop the materials for the effort.

The Washington, DC based organization worked with the UMDF's Governmental Affairs Committee and our Scientific and Medical Advisory Board to develop an advocacy communication plan and toolkit that contained

talking points, a background on mitochondrial disease, and the links between mitochondrial dysfunction and other well known diseases. Porter Novelli also helped devise a toolkit for our members to use to effectively communicate with their own member of Congress. The UMDF unveiled the toolkit in June, 2008 during the symposium in Indianapolis. Members started using it right away and began the process of sending letters and meeting with their elected officials.

Armed with a toolkit and messages, UMDF members were encouraged to begin their advocacy journey by supporting a very important letter to President Barack Obama. Signed by more than 70 members of the scientific and medical community, the letter called on the president to include research into mitochondrial medicine among his administration's top medical and research priorities. The UMDF asked members, their families, friends and co-workers to log into a newly designed Advocacy Action Center on the website and send a letter to their Congressman and Senator asking for support for additional federal funding. More than 3,500 people sent a letter of support. Many scheduled meetings with their elected officials.

During the winter and spring months of 2009, the UMDF continued our grassroots effort towards a "Day on the Hill." With constant communication to our members, we were able to schedule more than 400 meetings for 248 people. With the help of Holland+Knight, we managed to have Appropriations Language drafted and included in both the House and Senate. Before those who indicated their participation in our "Day on the Hill" arrived in Washington, DC, Rick and Susie Leach worked tirelessly, along with key members of the SMAB, to draft and ask Representative Jim McDermott (D-WA/7) to introduce H.R. 3502 on the House floor. As we've reported in this issue, H.R. 3502 was introduced on July 31, 2009.

"Day on the Hill" was our first step. We still have many miles to travel. Now we need to focus on getting a companion version introduced in the Senate. It is also important that we all log onto the Advocacy Action Center and demonstrate our thanks to Rep. McDermott, the original 13 co-sponsors and educate both chambers of Congress about the need to have this measure supported and approved when it comes up for a vote in the future.

Energy to all,



W. Dan Wright, UMDF Chairman

IN MEMORY OF BRITTANY WILKINSON - UMDF YOUTH AMBASSADOR

The UMDF's first Youth Ambassador, Brittany Wilkinson, lost her battle with mitochondrial disease on September 6, 2009. Brittany is the daughter of Linda and Doug Wilkinson of Clovis, CA, sister to Derron and Ashley and best friend of her service dog, Freedom.

Brittany's battle with mitochondrial disease did not stop her from creating awareness in her home town of Clovis, CA and spreading it to neighboring towns, cities and the entire state of California. Brittany was featured in newspaper articles, on local television stations, on billboards and busses. Brittany was part of the driving force in having a permanent resolution in California designating the third week of September each year as "Mitochondrial Disease Awareness Week."

Brittany told her story and explained mitochondrial disease to friends, family, news reporters, radio stations, government officials and celebrities. Brittany and her family traveled to Washington, DC this past June and met with their elected officials for the UMDF's "Day on the Hill."

Brittany, you are loved and will be truly missed by all of us at the UMDF.



Brittany & Freedom with Rep. Devin Nunes in June 2009

UNITED MITOCHONDRIAL DISEASE FOUNDATION

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UMDF member Debra Fleming with the Cleveland Cavaliers mascot Moondog.

GIVE HOPE.ENERGY.LIFE THROUGH PLANNED GIVING

Planned Giving is not just an important part of your financial planning and tax management, but it can play an integral role in helping you fund the UMDF's mission and critical mitochondrial research. Here are just a few examples of ways you can "take charge" of your financial future and help the UMDF as well.

1. **Give Cash** – A cash gift is the most popular way to support the efforts of the UMDF. If you itemize donations on your tax return, charitable contributions qualify for tax deductions of up to 50 percent of the donor's adjusted gross income, and any unused balance can be carried forward for five years.
2. **Give Appreciated Assets** – A commonly used technique for tax planning and management, a properly structured gift of highly appreciate property results in a charitable deduction for the full fair market value of the gift. This type of gift has the added benefit of helping the donor escape any related tax liability for large capital gains.
3. **Give a Memorial Gift** – Remember, acknowledge and honor the memory of an important individual in your life with a gift in their name. Gifts can range from a one-time contribution to an annual gift paid over several years that can help underwrite an event or program.
4. **Give Life Insurance** – Many people own policies for purposes that no longer exist such as insurance purchased to cover an old mortgage or to pay for a child's college education. Donating the policy produces a current tax donation. If the potential exists for need of the cash value, retain ownership (and control of the money) but make the UMDF the beneficiary. If the money is no longer all needed for the policy's original purpose, or is more than you want to donate, liquidate the policy and give the UMDF a portion of the proceeds. You receive the balance and the gift may reduce or eliminate tax liability from the sale.
5. **Make a Bequest** – Include the UMDF in your will, trusts and estate plans with a general bequest of a specific dollar amount; a specific bequest of property or real estate; or a residuary bequest of any remainder after distributions to your children and heirs.
6. **Name the UMDF as a Beneficiary** – You can specify the UMDF as the contingent beneficiary of your insurance policies, IRAs and qualified plans, annuities, or will. This avoids assets passing to unintended parties should your named, primary

beneficiaries not survive you.

7. **Purchase a Gift Annuity** – Purchase a UMDF gift annuity and guarantee an income stream for life. Rates are age-based and many older, retired donors may do better than CDs, bonds or low-yielding stocks. Annuities provide a regular, generous non-fluctuating stream of payments unaffected by the market or changing interest rates—and a portion of the payment is tax free. Annuities may be funded with highly appreciated assets, avoiding capital gains and increasing the assets on which the income stream is based. The portion that comprises the charitable contribution yields a deduction to offset current income. Straightforward, with no need for a new will or legal documents, the features of a gift annuity make this type of gift feasible and potentially beneficial to individuals of even moderate means.
8. **Establish a Charitable Remainder Trust (CRT)** – A CRT is an extremely flexible tool to address any number of financial and tax planning issues and goals. Donors retain the legal right to income from the trust, but the assets funding the trust are removed from the donor's taxable estate, as is any subsequent growth. The trust is tax-exempt and can receive highly appreciated assets and liquidate them without incurring a tax on massive capital gains. The donor receives a substantial tax deduction when funding the trust. By varying trust components, CRTs can be used for retirement funding, college and educational funding, active investment management, business succession planning and exit strategies, funding special needs trusts for dependent individuals, increasing retirement income, and estate planning, including "zero tax" plans, among others.

Planned giving provides many ways to help and benefit you and the UMDF. Through planned giving, you can use the considerable incentives for charitable gifts found in the tax code to your advantage as well as the UMDF's and you can redirect your tax dollars to support the UMDF's mission of research, education and support.

"Take Control" of your financial plan today, and help UMDF at the same time. Please contact your financial advisor to evaluate these options or take advantage of consultations through UMDF with a senior financial advisor. For information, contact Donald Gielas in UMDF's Development Office toll-free at 1-888-317-UMDF or email don@umdf.org.

UPCOMING EVENTS

ATLANTA CHAPTER

- **September 18, 2009.** The Atlanta Chapter of the UMDF will host an awareness night at Turner Field as the Atlanta Braves take on the Philadelphia Phillies in a National League East showdown. After the game, guests will enjoy a fabulous fireworks display. For more information, please visit www.bravesmitonight.com.
- **September 26, 2009.** The third annual Music for Megan in Alpharetta, GA will feature Atlanta's favorite "high-energy, hard-kicking" band - Banks & Shane! Children will enjoy pony rides, inflatables, a rock climbing wall and much, much more! Buy your tickets today at www.musicformegan.com.



All Aboard for a Cure

- **October 17, 2009.** The second annual All Aboard for a Cure walk will be held at Thrasher Park in Norcross, GA. Activities include inflatables, a magician, a d.j., games and prizes for kids, a craft area and a cookie decorating booth. Music Class will do a live audience participation performance. Register today at www.allaboardforacure.com.
- **October 26, 2009.** The sixth annual Fore-a-Cure Golf Tournament will be held at the Smoke Rise Golf and Country Club in Stone Mountain, GA. Please note, for those participating in the past, this is a NEW location! For information regarding playing, sponsoring or providing prizes, please visit the tournament website at www.foreacuremito.com or contact Chris Swinn, Event Chair, at 404-817-0999.

CALIFORNIA CHAPTER

- **September 19, 2009.** The fifth annual Steps to a Cure Walk-a-thon will be held

in Clovis, CA. The annual event is held in honor of Brittany Wilkinson and benefits the Brittany Wilkinson Research Fund with the UMDF. For more information, please contact Linda Wilkinson at dotoheven@aol.com

- **September 26, 2009.** The fourth annual Golf 4 a Cure Golf Tournament in honor of Brittany Wilkinson will be held in Madera, CA. For more information, please contact Linda Wilkinson at dotoheven@aol.com.

CAROLINA Foothills CHAPTER

- **October 25, 2009.** Stan Hickson of Blythewood, SC will be participating in the Marine Corp Marathon in Washington, DC to raise money for the UMDF. Stan is running his second marathon in honor of his son, William. For more information, visit www.umdf.org/marathonforwilliam.

CENTRAL OHIO CHAPTER

- **September 21, 2009.** The fourth annual KWGP Charity Golf Outing will be at the Worthington Hills Country Club in honor of Ellie Kovalcik. Register your foursome today at www.umdf.org/kgwpgolf.

CHICAGO CHAPTER

- **September 20, 2009.** Join hundreds of individuals and families at the third annual Chicago Walk and Family Fun Day at Pottawatomie Park in St. Charles, IL. Register at www.umdf.org/chicagowalk to enjoy a day of fun in support of funding for mitochondrial disease research.



Chicago Walk

DELAWARE VALLEY CHAPTER

- **September 12, 2009.** Come celebrate a decade of success at the 10th annual Go for Mito Walk/Run at the Philadelphia Museum of Art. Join a team, start one of your own, or register as an individual at www.umdf.org/goformito.

- **October 10, 2009.** The Delaware Valley Chapter has combined two successful events into one new and exciting day! The inaugural Oktoberfest for Mito will be held at Cannstatter Volkfest in Philadelphia, PA. The family-friendly event will include, kid rides, moon bounces, face painting, DJ and live entertainment featuring Juliano Bros., The Toonz, Mummers, plus other bands! For attendees over 21 years old, a beer and wine tasting event will be held for an additional fee. For more information, visit www.umdf.org/oktoberfest.

DC/BALTIMORE/NORTHERN VIRGINIA CHAPTER

- **October 24, 2009.** The first annual Fall Into a Cure Gala will be held at the Belle Haven Country Club in Alexandria, VA. The gala will feature food, drinks and a wonderful silent auction! For more information, visit www.umdf.org/dcgala.

INDIANA CHAPTER

- **October 10, 2009.** The second annual Indiana Mito Walk and Family Fun Day will be held at Forest Park in Noblesville, IN. For more information, visit www.umdf.org/indianawalk.

MINNEAPOLIS-ST. PAUL CHAPTER

- **September 19, 2009.** The fourth annual Mito 5K Walk/Run will be held at Thomas Lake Park in Eagan, MN. The walk raised more than \$17,000 last year. Help us build on that success by registering today at www.umdf.org/minnesotarace.

- **October 4, 2009.** Pete Hill will attempt to qualify for the Boston Marathon by running his fourth marathon, the 29th annual Milwaukee Lakefront Marathon, in honor of his niece, Eleanor Toma. Throughout his months of training, Pete has been raising funds for the UMDF by sharing Eleanor's story with family, friends and colleagues asking them to support his marathon and the UMDF at www.umdf.org/marathonforeleanor. Best of luck to Pete!

MIDDLE TENNESSEE CHAPTER

- **September 21, 2009.** The Middle Tennessee Chapter will kick-off Mitochondrial Disease Awareness Week at Kimbro's Pickin' Parlor in Franklin, TN. Live jazz music with Wing Tip and a silent auction will highlight the Kickin' it for Mito event! For more information visit, www.umdf.org/kickinitformito.

UPCOMING EVENTS

- **September 22, 2009.** The second annual family fundraiser, Scoopin' for a Cure will take place at several Tennessee Maggie Moo's locations! For more information contact midtennchapter@umdf.org.



1st annual Scoopin' for a Cure with Maggie Moo's

NEW ENGLAND CHAPTER

- **October 10, 2009.** The second annual Mito Walk and Family Fun Day will be held at the LEGO Campus in Enfield, CT. Come to view many of the intricate designs by LEGO's master builders and try your hand at a model of your own! Register at www.mitowhat.org to enjoy the day of family-friendly fun!
- **October 17-18, 2009.** The 20th annual Publick House Scarecrow Contest and Harvest Festival will be held in Sturbridge, MA. A sand art craft will be offered to raise money for the UMDF. Information about UMDF and mitochondrial disease will be provided to each participant.
- **November 16, 2009.** The Publick House Cooks for UMDF will be held in Sturbridge, MA. The Publick House will offer a traditional Thanksgiving fare meal to raise funds for the UMDF. A cash donation of \$13 for adults and \$5 for children (4-13 years old) will enable you to attend the all-you-can-eat buffet from 5-7 pm.

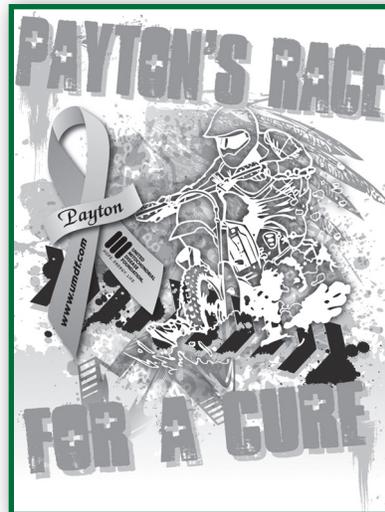
PITTSBURGH MITO GROUP

- **September 26, 2009.** The third annual Sip and Savor the Moment for a Cure is a wine and chocolate tasting gala in honor of Hannah Pallas. Buy your tickets at www.SipSavorCure.com, and then come to the La Casa Narcisi Winery in Gibsonia, PA for an evening of auctions items and great fun!

- **October 3, 2009.** Pittsburgh's One Step Closer to a Cure will be at a new location this year! The newly renovated Monroeville Community Park in Monroeville, PA. Immediately following the walk, join us for a Fall Fest community fun day! For more information, visit www.umdf.org/pittsburghwalk.

AROUND THE COUNTRY

- **September 12, 2009.** Payton's Race for a Cure is being hosted by Patyon DeWitt's family and friends at the Cedar Springs Practice Track in Cedar Springs, MI. This event will include a charity dirt bike/quad race for all ages and experience levels, a six-band concert series with a DJ in between sets and a carnival that will include games, face painting, clowns and a magician. For more information, visit www.umdf.org/paytonsrace.



Payton's Race for a Cure

- **September 13, 2009.** The Amanda's Journey Remembrance Walk will be held at the Crossings of Colonie in Loudonville, NY. The event is held in memory of Amanda Perrotta and benefits the UMDF, as well as the Albany Medical Center.
- **September 19, 2009.** The second annual Savannah's Hope Mito Walk will be held at Adventure Life Reformed Church in Altoona, IA. The event is held in memory of Savannah Bagby and will include several family friendly activities, music and much more! For more information, visit <http://savannahshope.weebly.com>.

- **October 3, 2009.** Megan Adams has been working very hard all year and studying to read from the Torah. She will become a Bat Mitzvah and is donating the gifts made in her honor to the UMDF. Her parents, Barry and Sue, and her brother and sister, Ben and Allyson, are so very proud of her! Please visit www.umdf.org/meganadams to show your support for Megan and her family.



Megan Adams

- **October 10, 2009.** Held at South Lakes Park in Denton, TX, the third annual Kure for Kate offers all participants a fun-filled experience with entertainment, refreshments, mitochondrial disease resources, and much more! Please visit www.umdf.org/kureforkat for more information.
- **December 4, 2009.** The 29th annual Lennon Tribute in New York City will feature musicians and comedians performing songs inspired by John Lennon. A portion of the proceeds will benefit the UMDF! Watch the UMDF website for more information in the coming months!



29th annual Lennon Tribute

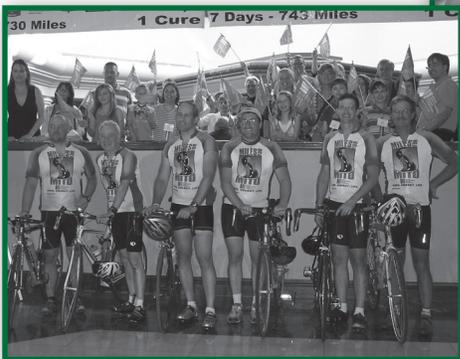
FROM PAGE TWO

Day on the Hill - Thursday, June 25, 2009

From as far away as California to as near as Virginia, close to 250 people came to Washington, DC, for the UMDF's "Day on the Hill" on June 25, 2009. The massive advocacy effort took place during Mitochondrial Medicine 2009: Capitol Hill. Despite 90 degree weather in our nation's capitol, UMDF members traveled between the House and Senate side of the U.S. Capitol for the scheduled meetings with their representatives.

It was a very busy time on Capitol Hill. UMDF Advocates were just one of hundreds of groups that had meetings scheduled as well. Meetings were typically held with the representatives legislative aid. However, some members had meetings scheduled with their actual congressman or Senator.

Many left Capitol Hill that day feeling very positive about asking for additional federal funding for mitochondrial medicine research. Most members of the House and Senate agreed to lend their support and become part of the cure.



Miles for Mito

One of the highlights of this year's symposium were the dedicated bicyclists who took part in the "Miles for Mito" fundraiser. Two teams of riders left from their home states of Indiana and Georgia to make the week long cross-country trip to Washington, DC. The Indiana riders were lead by Mike Hanlon of Indianapolis and traveled 740 miles through Ohio, Pennsylvania and Maryland. Mike was joined by Bob Jenkins, of Indianapolis and Eric Boling, of New Castle, IN. Matt Kovalcik of Columbus, OH joined the group as they rode through Ohio.

The Georgia group traveled 730 miles through Georgia, North Carolina and Virginia before coming into Tyson's Corner. The group was made up of Ray Pagano of Smoke Rise, GA, Marc Reich of Atlanta and Richard Sheinis of Dunwoody, GA. The teams raised nearly \$27,000 for the UMDF! The teams were greeted in the lobby of the Sheraton Premiere Hotel by a cheering crowd of symposium attendees on June 26th. Thank you to all of the riders who gave their energy for 7 days in order to help the many who can not.

Friday Night Banquet and Awards Presentations

Scientific and family attendees came together on Friday night to celebrate all of the UMDF's accomplishments and the volunteers who make them possible. The evening started with the arrival of the Miles for Mito riders, and continued with a wine reception in which all of the wine was donated by Elizabeth Spencer Wines of Rutherford, CA. The evening was filled with heart-felt songs by two UMDF members and a special performance by an up-and-coming star. During dinner, attendees enjoyed the beautiful singing of the UMDF's first Youth Ambassador, Brittany Wilkinson of Clovis, CA. The evening was wrapped with a performance by UMDF member Stefani Bush as she sang two songs from her fundraising CD, Project: Cure. Lastly, world

class singer and songwriter, Sarah Haze, performed songs of hope.

Awards were presented to the 2009 Research Grant Recipients as well as the LEAP, Heartstrings Award and the Stanley A. Davis Leadership Award winners.

This year's LEAP Award winner is Perri Elaine Miologos of Chicago, IL. Perri was diagnosed with Kearns-Sayre Syndrome during her freshman year at Boston University. Perri excelled academically at Boston University and graduated with a BS degree in Public Relations and a minor in Art History. She has set high goals for herself without dwelling on the potential impact of her disease. Her future plans include obtaining a Master's Degree, possibly an MBA. Meanwhile, she thrives in her market research position at ConAgra, while working for her mother's real estate agency on the side. Perri's cheerful, caring, and optimistic attitude has inspired all those around her. It is obvious to those who know and love Perri that she embodies the spirit of the LEAP award.



The Heartstrings Award was presented to 14 year old Emily Lyons of Atlanta, GA. Emily lost her younger brother, Jake, to Leigh's Disease in 2007.

Although Emily does not have a mitochondrial disease herself, she has a passion for raising funds and awareness for mitochondrial disease and the UMDF because of Jake. Emily has volunteered at many Atlanta Chapter fundraising events, whether it is manning a booth, filling goody bags, helping with childcare at meetings, or handing out toys at the holiday party. She is always ready and willing to help. The impact mitochondrial disease has had on Emily's life is best summed up in her own words from one of her papers: "Disabled children might not be what anyone would think of as 'life changers,' but I know many kids with disabilities that have changed my life." One of her personal goals includes entering the medical field in some capacity, or becoming a teacher. In the meantime, she has already committed to volunteering for future UMDF events. Because of her selfless devotion to those affected by mitochondrial disease, the UMDF awards the Heartstrings Award to Emily Lyons.

The Stanley A. Davis Leadership Award was awarded to Lisa Arnold of Aurora, OH. Lisa is the Vice President of the Ohio Chapter and has been one of the driving forces of the Chapters annual Run Wild for a Cure Run/Walk and has raised more than \$1 million to benefit the UMDF. Lisa's leadership goes well beyond fundraising – she has served as a chapter officer and worn many hats over the years. As the current Vice President, she works with her fellow board members to support physician outreach, patient education, and mitochondrial disease awareness in the Northeast region of Ohio. When called upon to talk with other patients or parents, she is more than willing to step into that role. Several years ago, she created a book to explain mitochondrial disease to the children at her son's school and consistently spreads awareness in physician offices when time allows. Lisa Arnold truly embodies the spirit of leadership in the UMDF.

CHECK LIST FOR A HEALTHY & HAPPY HOLIDAY SEASON LIVING WITH A MITOCHONDRIAL DISEASE

The UMDF office asked the Adult Advisory Council Team (AACT) to submit their suggestions and tips for how they get through the holiday season. We received wonderful suggestions and thought we would highlight a few of them for you!

- Take extra time to reflect and give thanks.
- I take a nap whenever I can as it helps to keep up my stamina.
- When others ask to help, I gladly assign them a task.
- Don't "survive the holidays" but to "thrive in them."
- I fill my cup with gratitude.
- I do not expect myself to do more than I am physically able to do.
- I use safeway.com home delivery service or have meals catered.
- I adopt a "Peace on Earth, Goodwill toward ALL" attitude.
- I only do what is most special, meaningful and fulfilling to me.
- I plan my schedule with "breaks" in-between so I am rested and able to get through each day.
- I choose "themed" gifts each year.
- I start my holiday shopping early, wrap and tag everything and place in a storage bin in my garage.
- We stay in our pajamas all day and play board games. Then we raid the refrigerator for leftovers and eat them "picnic style" in front of the TV with a DVD movie, usually something with a holiday theme. The day is quiet, calm and loving.
- I have learned to say "NO."
- I have learned to limit the number of things I commit to for the holidays.
- I use the internet for shopping as it is a huge help for those of us with "energy" issues.
- To supplement the amount of energy I need for holiday events, I carbo load like I used to when I was running marathons. This won't work for everyone. *(Please consult your physician first!)*
- Be particularly mindful of the people doing all the work and providing support for you. Do whatever you can to find ways to support them.

Adult Advisory Council Team (AACT)

Sharon Shaw, AACT Chair, Arizona
 Gail Wehling, AACT Co-Chair, Illinois
 Cynthia Rosen, AACT Secretary, New Mexico
 Bob Brief, New York
 Marge Calabrese, Arizona
 Linda Cooper, California
 Rev. David Hamm, Maryland
 Etan Harmelech, Connecticut
 – Young Adult Subcommittee
 Pam Johnson, MD, Missouri/Kansas
 Deb Makowski, New York – Adult Liaison Coordinator - West Coast
 Beate Pohlig, Pennsylvania – Adult Liaison Coordinator - East Coast
 Erica Schwartz, Connecticut – Young Adult Subcommittee
 Gregory Yellen, Maryland

Medical Advisors:

Bruce H. Cohen, MD
 Amy Goldstein, MD

PURPOSE OF AACT

To represent and serve the unique needs of the affected adult community and to ensure that those needs are adequately represented to UMDF resulting in enhanced services to the affected adult population. AACT is a liaison to the UMDF Board of Trustees and will assess, provide advice and guidance, and make recommendations to UMDF on adult related issues.

MEMBER RESOURCES

COMING HOME - YOUR GUIDE TO IN-HOME HEALTH-CARE

Created by a mito-mom, Penny Hanlon, Coming Home's mission is to provide resources to people with in-home health-care needs. Coming Home has created a Medical Organizer to assist you as you transition from hospital care to home care. The Medical Organizer will help you to keep all of your loved ones medical information organized and in one place. You will also be provided with information on making your home health-care friendly, ways to help you to feel more confident, which allows you to stop worrying and focus on the care of your loved one. For more information on the Coming Home Medical Organizer, visit www.cominghomeguide.com.

C•A•R•E MEMORY WRISTBAND

The C•A•R•E Memory Wristband is the world's first electronic Medical ID bracelet that allows you to take your entire health care history with you, wherever you go! When you purchase a C•A•R•E Memory Wristband, you will receive easy to use software that allows you enter all of your important medical information. You then connect the C•A•R•E Memory Wristband into the USB on your computer and download all of the information. The C•A•R•E

Memory Wristband has the internationally recognized medical alert symbol to alert emergency medical personnel. The C•A•R•E Memory Wristband can be connected to any computer and will instantly display all of your medical history, without the use of the internet! You can purchase online or in many retail stores. For more information, visits www.carememoryband.com.

WANT INFORMATION ON CLINICAL TRIALS?

The UMDF is happy to post information on the national website about clinical trials. The information is listed on the 'Patients, Families and General Public' side of the website under the Life category and under the Helpful Resources tab. For easier access, use this link - www.umdf.org/clinicaltrials. Before clinical trial information is posted on our website, it is submitted to the UMDF's Scientific and Medical Advisory Board. After a positive review from the SMAB, the information is posted. In addition, clinical trial information is sent via email from our Membership Services Department. Information on the website is frequently updated – so check back often! Additional clinical trials can be found at www.clinicaltrials.gov.

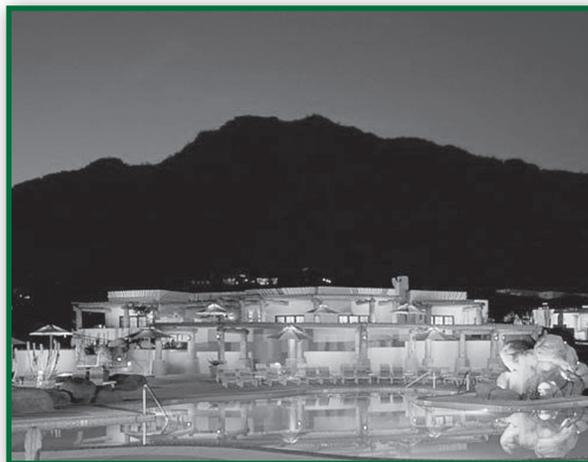
SAVE THE DATE & MAKE YOUR PLANS TODAY

MITOCHONDRIAL MEDICINE 2010:

SCOTTSDALE, ARIZONA

SCIENTIFIC SESSION - JUNE 16 - 19, 2010

FAMILY SESSION - JUNE 18 - 19, 2010



CAMELBACK INN - SCOTTSDALE, AZ

MITOCHONDRIAL DISEASE AWARENESS WEEK - SEPTEMBER 20-26, 2009

The third week of September (20th-26th) is Mitochondrial Disease Awareness Week! UMDF Chapters, Mito Groups, Ambassadors and members will be holding awareness and fundraising activities during Mitochondrial Disease Awareness Week. The activities are listed below by state; for more information on these events and to see what is happening in your state, visit www.umdf.org/map. (Please note: the following events and activities were provided to the UMDF prior to the Mitochondrial News print deadline.)

ALABAMA

- **Robertsdale.** Awareness week posters will be displayed in local Wal-mart stores and in local schools. Mitochondrial disease information will be distributed to the students.

CALIFORNIA

- **Clovis.** UMDF Youth Ambassador Brittany Wilkinson will be holding an art contest at Clovis Area schools for the opportunity to illustrate the children's books that she will be writing. The art contest will be announced during Mitochondrial Disease Awareness Week and the winners will be selected in December. For more information on the art contest, please visit Brittany's website at <http://brittanywilkinson.org>.
- **Madera.** The fourth annual Golf 4 A Cure Golf Tournament will be held on September 26, 2009. The annual event is held in honor of Brittany Wilkinson. For more information, contact Linda Wilkinson at dotoheven@aol.com.

GEORGIA

- **Alpharetta.** The Atlanta Chapter will hold the third annual Music for Megan & Mito Fest on September 26, 2009. For more information, visit www.musicformegan.com.
- **Ball Ground.** Awareness week posters and mitochondrial disease information will be posted in Ball Ground, GA for the week.
- **Rome.** A mitochondrial disease awareness night will be held at the Coosa Valley Fair during awareness week.

ILLINOIS

- **Frankfort.** RoseMary Wasielewski will set up an awareness display at her local library and in a physician's lounge at her place of employment for the entire week.
- **St. Charles.** The Chicago Chapter will hold the third annual Walk and Family Fun Day on September 20, 2009. For more information, visit www.umdf.org/chicagowalk.

INDIANA

- **Bainbridge.** The Indiana Chapter will hold a Family Picnic at Hope's Way on September 26, 2009. For more information, visit www.umdf.org/inchapter.

LOUISIANA

- **Baton Rouge.** Awareness week posters and information on mitochondrial disease will be displayed at the Town Hall and in all of the area schools.

MICHIGAN

- **Ferndale.** Barb Yarina will be posting awareness week posters in her classroom and in the hallways as well as passing out mitochondrial disease information to all of her students.

NEVADA

- **Las Vegas.** Awareness week posters and information on mitochondrial disease will be distributed at local schools and during the Governor Proclamation.

NEW YORK

- **Schaghticoke.** Mitochondrial disease information will be distributed at a local school in two kindergarten classes and in a 5th grade classroom.
- **Schenectady.** Awareness week materials will be distributed at a local church to raise awareness of mitochondrial disease.

NORTH DAKOTA

- **Williston.** Awareness week posters and information on mitochondrial disease will be distributed at a local day care and school.

OHIO

- **Cleveland.** The Ohio Chapter will be holding their ninth annual Mini-Symposium on Sunday, September 27, 2009 at the Beachwood Library in Shaker Heights, OH. For more information, please visit www.umdf.org/ohchapter.
- **Columbus.** The Central Ohio Chapter will hold the third annual KGWP Charity Golf Outing on September 21, 2009. For more information, visit www.kgwpgolf.com.

PENNSYLVANIA

- **Gibsonia.** The third annual Sip & Savor the Moment for a Cure Wine and Chocolate Tasting event will be held on September 26, 2009. For more information, visit www.sipsavorcure.com.
- **Pittsburgh.** The Neurology Department at Children's Hospital of Pittsburgh will place mitochondrial disease information in the cafeteria all week.

TENNESSEE

- **Franklin.** The Middle Tennessee Chapter will hold the Kickin' It for Mito event on September 21, 2009. For more information, visit www.umdf.org/kickinitformito.
- **Middle Tennessee.** The second annual family fundraiser, Scoopin' for a Cure will take place at several Tennessee Maggie Moo's locations on September 22, 2009.

TEXAS

- **Wichita Falls.** The Kennedy family will be placing awareness week posters and information on mitochondrial disease in their children's school and classrooms.

VIRGINIA

- **Bassett.** A Mitochondrial Disease Awareness Week booth will be set up at a local festival and at a local mall during the entire week.

ANNOUNCEMENTS

UMDF SYMPOSIUM AUDIO TAPES ARE NOW AVAILABLE!

The United Mitochondrial Disease Foundation has made available, for purchase, the audio (MP3) and PDF presentations from Mitochondrial Medicine 2009: Capitol Hill. Hard copies and PDF versions of the Scientific and Family Syllabus are also available.

- Family Sessions - Audio & PDF presentations\$15 each
- Family Session Syllabus (Hard Copy)\$16 each
- Family Session Syllabus (Electronic PDF) \$ 5 each
- Family Session Complete Set\$50 each
(Complete set includes: audio and PDF presentations of all sessions and a PDF version of the Family Syllabus. Hard Copy must be purchased separately.)

If you are interested in ordering more than two sessions, you may want to order the complete set as it contains all sessions.

- Scientific Sessions - Audio\$15 each
- Scientific Session Syllabus (Hard Copy)\$40 each
- Scientific Session Syllabus (Electronic PDF)\$ 5 each

You can order all of the above online at www.umdf.org/2009av. If you have any questions, please contact the UMDF at info@umdf.org or call 888-317-UMDF.

MITOCHONDRIAL DISEASE AND THE H1N1 FLU

The UMDF continues to monitor the H1N1 flu situation very closely. For information on 'common sense' guidelines to protect yourself or your affected family member against the virus, visit the front page of the website. At the bottom of the page, click on the H1N1 VIRUS INFORMATION box. This link will take you to the latest information about the virus. Also, in our news section, you can hear an interview conducted with Dr. Amy Goldstein on the H1N1 virus.

NEW UMDF STAFF MEMBERS

The UMDF Special Events Department would like to welcome Amanda Reinhardt and Rachel Mazur to their team. Amanda graduated from Chatham College, where she earned her MBA in English. Amanda gained special events experience while working as the Director of Healthy Teens, Inc. Rachel graduated from Saint Vincent College in 2008 where she earned her BS in Business with a concentration in Marketing and International Business. Amanda and Rachel will be helping our UMDF members with their upcoming fundraising and awareness events. The UMDF is happy to have both Amanda and Rachel on board!

SUBMISSION DEADLINE FOR VOLUME 14 ISSUE 4 IS November 27, 2009!



IN THIS ISSUE:

Mitochondrial Medicine and Treatment Enhancement Act, H.R. 3502 Introduced.
Read page 1!

Does brain stem failure mean progression of mitochondrial disease?
See page 3!

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

Mitochondrial Disease Awareness Week Activities.
On page 11!