

UMDF ROLE CRITICAL IN SECURING GRANT FUNDING FOR NORTH AMERICAN MITOCHONDRIAL DISEASE CONSORTIUM

Funding fosters coordination of mitochondrial disease research towards therapeutic strategies

The United Mitochondrial Disease Foundation (UMDF) is proud to collaborate with Columbia University Health Sciences after their successful award of a National Institutes of Health (NIH) Challenge Grant in Health and Science Research. The grant aims at establishing a consortium that will create the infrastructure to launch a mitochondrial disease patient registry, biorepository, and a North American Mitochondrial Disease Consortium (NAMDC), with the support of the UMDF. Salvatore DiMauro, M.D., will serve as the principal investigator for the project. Dr. DiMauro, who is a Lucy G. Moses professor at Columbia University, is also the former chairman of the UMDF's Scientific and Medical Advisory Board. Joining Dr. DiMauro as principal investigators are Michio Hirano, M.D., who is also at Columbia and Russell Saneto, D.O., Ph.D., Seattle Children's Hospital and University of Washington School of Medicine. The project was awarded a two year, \$992,538 grant under the American Recovery and Reinvestment Act (ARRA) of 2009 and will be funded through the National

Institute of Neurological Disorders and Stroke (NINDS).

The UMDF will serve as the liaison between members of the consortium and patients. "This NIH grant will enable the scientific and medical community to perform research now that will have a huge impact on the entire mitochondrial disease community. That is why it is critical that we have a patient registry and biorepository in place because that information will be vital to the consortium as they provide the building blocks for research and scientific studies that could lead to therapeutic trials for affected patients," said Charles A. Mohan, Jr., CEO and Executive Director of the UMDF.

The UMDF will play a critical role in the two year project. In order to obtain the grant, researchers needed to collaborate with a recognized patient advocacy group. The UMDF is a nationally recognized foundation whose mission is to promote research and education for the diagnosis, treatment and cure of mitochondrial

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disorders and to provide support to affected individuals and families.

In awarding the grant, the NIH recognized the

importance of the UMDF in the mitochondrial disease community and its ability to connect patient participants with researchers. Mitochondrial disease patients should know that NAMDC is moving as expeditiously as possible to begin enrolling patients in the registry and to make the biorepository available to qualified researchers. NAMDC is working to comply with federal

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Miranda's Mitomanics at the Indiana Mito Walk and Family Fun Day. The second annual Walk was held on October 10th and raised over \$23,000!!

See pages 4-9 for more events and fundraisers!



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regulations and to institute the mechanisms to facilitate access to both resources. Instructions for both patients and physicians will be posted on the NAMDC and UMDf websites with information publicized through the UMDf newsletter as well as with email information to those who are in the UMDf database.

Including Columbia, other centers identified in the grant as participants are the Mayo Clinic, the Cleveland Clinic and Case Western Reserve, McMasters University, University of Florida College of Medicine, The University of Texas Southwestern Medical School, Baylor College of Medicine, University of California – San Diego and The State University of New York at Buffalo. Additional centers will be identified at a later date. “The NAMDC will be instrumental in insuring collaboration among these centers involved in the study of mitochondrial disorders and in providing to clinicians all over North America access to accurate diagnosis, so that no mitochondrial patient goes unrecognized and unsupported,” said Dr. DiMauro.

SENATOR BOXER INTRODUCES “THE BRITTANY WILKINSON MITOCHONDRIAL DISEASE RESEARCH AND TREATMENT ENHANCEMENT ACT OF 2009

On Thursday, December 10, 2009, Senator Barbara Boxer (D-CA), introduced “The Brittany Wilkinson Mitochondrial Disease Research and Treatment Enhancement Act of 2009”. Boxer’s senate bill is also known as S. 2858. Three additional U.S. Senators signed on as original co-sponsors for the legislation. They are Richard Durbin (D-IL), John Kerry (D-MA) and Robert P. Casey (D-PA).

In introducing the legislation, Sen. Boxer said that it is crucial that the government encourage the development of new treatments and cures for diseases by investing in health and research innovation. “I am proud to introduce the Brittany Wilkinson Mitochondrial Disease Research and Treatment Enhancement Act of 2009, which, for the first time, would coordinate the federal investment in researching the cause of, and treatments and cures for, mitochondrial diseases,” Sen. Boxer said on the Senate floor.

The bill in the senate is a companion version to HR 3502, which was introduced by Representative James McDermott (D/WA-7). The house measure, introduced in July, carries 29 co-sponsors representing a mix of democrats and republicans, conservatives and liberals, as well as rural and urban areas. Both measures

The patient registry will be an invaluable tool for better understanding of relatively rare syndromes through natural history studies and/or the organization of rigorous therapeutic trials. “The biospository will be equally invaluable in providing both basic and clinical researchers with biological material for patients with disorders for which no animal models are available. Access to biological specimens will help scientists understand the molecular bases of still mysterious mitochondrial diseases, the pathogenesis of better known disorders, and the experimentation in vitro of novel therapeutic agents,” Dr. DiMauro added.

The ARRA grant provides for two years of funding. Doctors DiMauro and Hirano believe it is the launching point for a more ambitious and long term consortium. They see the ARRA grant as both an opportunity and a challenge. In two years, they are expected to set up the basic infrastructure upon which they can convincingly apply for a larger NIH grant, which will propose to continue and expand the NAMDC.

call for the creation of an ‘Office of Mitochondrial Medicine’ within the National Institutes of Health (NIH) and asks the NIH to develop a research plan to promote and coordinate efforts to educate researchers and health providers about mitochondrial disease. Both measures also call for the NIH to award grants to increase research of mitochondrial diseases and to establish Mitochondrial Disease Centers of Excellence to promote research, education and mitochondrial medicine training.

On the Senate Floor, Sen. Boxer said she named the measure after Brittany because of her advocacy work on behalf of those affected by mitochondrial disease and the UMDf. “Earlier this year, I met this young woman when she visited by offices as a UMDf Youth Ambassador. I was greatly impressed by her poise and dedication to her cause. I was devastated to hear that this September, Brittany passed due to the effects of her debilitating illness,” Sen. Boxer said.

“Senator Boxer promised our “Day on the Hill” California delegation that she would champion this measure through the Senate and she delivered on her promise,” said Charles A. Mohan, Jr., Executive Director and CEO of the United Mitochondrial Disease Foundation. “This bill would not have become a reality without the help and dedication of Sen. Boxer and her staff. S.2858 is a living legacy dedicated to the hard work and determination of Brittany Wilkinson, who remains an inspiration to all of us,” Mohan added.



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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.

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: Mary Kay Koenig, MD, of The University of Texas Medical School at Houston, TX, Jerry Vockley, MD, PHD, of Children's Hospital of Pittsburgh, PA, Michio Hirano, MD, of Columbia University Medical Center, New York, NY, and Gerard Berry, MD, of Children's Hospital Boston, MA.

THE QUESTION IS...

My two year old daughter was diagnosed with Cytochrome C Oxidase deficiency by muscle biopsy, but so far not genetically confirmed. More recently, the doctors are beginning to suspect that her mitochondrial disease diagnosis is probably secondary to an unknown primary disorder. In their words "she doesn't quite fit." However, she was recently diagnosed with severe Eosinophilic enteritis and colitis - but they are hesitant to start her on steroids to help alleviate the acute inflammation. Other medications tried do not seem to help. Are steroids a definite "no" for mitochondrial disease patients?

RESPONSE FROM MARY KAY KOENIG, MD:

Eosinophilic enteritis and colitis are a finding we commonly see in our population of mitochondrial disease patients. We often provide our patients with steroid treatment to control their GI symptoms, especially in the setting of compromised nutrition. The main risks of steroid use are glucose abnormalities (diabetes mellitus), weight gain, behavioral problems, sleep disturbances, bone thinning (osteoporosis), and infection (suppression of the immune system).

For eosinophilic enteritis, the steroids are usually prescribed at lower doses and are given in a "swallowed" manner to target therapy to the GI tract. These methods decrease the systemic absorption of the steroids and therefore may decrease the risks for complications. Malnutrition itself can lead to many of the same complications as steroid use and nutrition should be optimized in any way possible in mitochondrial disease patients. If you and your physicians decide to proceed with steroid therapy I would recommend a thorough immunologic evaluation prior to starting the steroids. I wish you and your daughter the best.

THE QUESTION IS...

We have a 3 year old daughter with Complex I & II, and 22q11.2 Deletion Syndrome. She continues to get re-occurring bladder (UTI) infections- which creates a vicious cycle of antibiotics (mostly Amoxicillin). I've read that repetitive antibiotics for mitochondrial disease patients are not recommended. Any suggestions? Considering she has gut motility issues and is fed through a GJ Tube, it wouldn't surprise me if she also had dysmotility or reflux issues involving the urinary tract. A VCUG (voiding cystourethrogram) has not been done. Are repetitive UTIs common with mitochondrial disease patients?

RESPONSE FROM JERRY VOCKLEY, MD, PHD:

While it is never a good idea to use antibiotics indiscriminately, untreated infections can be a severe metabolic stress to individuals with mitochondrial disease. So antibiotics should be used if clinically indicated. More importantly, the cause of the repetitive infections should be investigated (including a VCUG if necessary) and treated so that the risk for future infections can be reduced.

THE QUESTION IS...

I am a 56 year old female with mitochondrial cytopathy. I recently went to the ophthalmologist as my sight was blurry. He stated I have "fast growing" cataracts and need them removed immediately. Is "fast growing cataracts" a symptom of mitochondrial disease?

RESPONSE FROM MICHIO HIRANO, MD:

Although not very common in mitochondrial diseases, cataracts have been reported in patients with mitochondrial disorders due to mitochondrial DNA or nuclear DNA mutations. In some mitochondrial diseases (Sengers syndrome

or autosomal recessive myopathy with cataracts due to GFER mutations), the cataracts are present at birth so they can develop rapidly.

THE QUESTION IS...

Are there benefits or risks to increasing dietary intake of branched chain amino acids, especially leucine, in patients with oxidative phosphorylation disorder who have high ammonia levels? What would the effect of stimulation of the glutamate dehydrogenase enzyme by leucine be in such patients? Would it be a good thing because of production of alternative energy sources, or could it increase the ammonia level? I was prompted to ask this question when a patient bought supplements I recommended and found that leucine was added as a filler!

RESPONSE FROM GERARD BERRY, MD:

Patients with defects in the mitochondrial electron transport chain and pyruvate dehydrogenase complex do not routinely manifest hyperammonemia. Yet, it may occur. When it does exist in combination, especially with respiratory chain defects, it may signal the presence of severe hepatocellular disease or even end stage liver disease. Leucine certainly can stimulate the glutamate dehydrogenase enzyme in the pancreatic beta-cell but I am unsure whether it will have the same effects in a patient with a primary mitochondrial disease process. However, even if it were to drive the production of 2-ketoglutarate, the resultant reducing equivalents may still not be handled (this would also be true for pyruvate as a fuel) if the block is at the level of the NADH dehydrogenase or cytochrome C oxidase complexes. And, as you suggest, it might retard ureagenesis and subsequently further worsen a hyperammonemic state. Because of these uncertainties, I would not suggest that the patient be given leucine supplementation. I hope this helps with your decision making process with this patient.

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 EVENTS

ATLANTA CHAPTER

- **September 18, 2009.** The Atlanta Chapter of the UMDF hosted an awareness night at Turner Field as the Atlanta Braves took on the Philadelphia Phillies in a National League East showdown. After the game, guests enjoyed a fabulous fireworks display. This event kicked off Awareness Week activities for the Atlanta Chapter.
- **September 26, 2009.** The Sheridan Family was touched by those who came out in the heavy rain and helped make the third annual Music for Megan event a huge success! Nearly 500 people were in attendance, including several mito families and event sponsors. Despite the weather, more than \$52,000 was donated to the UMDF this year! The Sheridans hope to be able to continue this event to give families hope year after year.



Team Mito-Man at the second annual All Aboard for a Cure

- **October 17, 2009.** The second annual All Aboard for a Cure One Mile Walk and Family Fun Day was a great success. Though they had a cold, somewhat rainy day, the hundreds in attendance had a fantastic time. Thank you to everyone involved for helping this event succeed. Nearly \$46,000 was raised from 27 teams, 586 participants, and countless volunteers. Save the date: The 3rd Annual All Aboard for a Cure will be April 24, 2010! If you want to help out, email the committee at Walk@AllAboardForACure.com - we'd love to have you "on board"! www.AllAboardForACure.com.
- **October 23, 2009.** Oktoberfest at Ravinia Club was held at the Ravinia Club's TGIF in Atlanta, GA. The event featured a children's art auction and local vendors including artists, a jeweler and make-up consultant for the pre-holiday bazaar. Thank you to Dr. Fran Kendall of Virtual Medical Practice for hosting this event.
- **October 26, 2009.** The sixth annual For-a-Cure Golf Tournament was held at Smoke Rise Golf and Country Club, just outside Atlanta. 70 participants enjoyed a great day of golf and camaraderie at this challenging course. The gift this year was a golf umbrella. Thankfully it was not needed on the 26th! The event raised over \$12,000 for the UMDF. Thanks go to all who helped put the day together, sponsored and participated.

CENTRAL OHIO CHAPTER

- **September 21, 2009.** The fourth annual KWGP Charity Golf Outing was held at Worthington Hills Country Club in Columbus, Ohio and benefitted the UMDF. After a round of 18 holes, the golfers convened in the clubhouse, along with additional guests who came out for the evening's festivities consisting of a dinner and silent auction. The event was in honor of 8 year old Ellie Kovalcik, daughter of Matt and Kris Kovalcik. A heart felt speech about how the disease has affected Ellie and their family reminded everyone of the importance of their participation in the event and the immediate need for funding. The room was filled with

family, friends and colleagues, as well as other people affected by Mito - all joined together for a great cause. The feedback from the event has been great and we are already looking forward to next year's event, scheduled for Friday, September 24, 2010.



Cherie Lawson, Dr. Berry-Kravis and Gail Wehling at Chicago Walk

CHICAGO CHAPTER

- **September 20, 2009.** The third annual 5K walk and Family Fun day was held at Pottawatomie Park in St. Charles, Illinois. The event featured more than 40 raffle items, face painting, tattoos, games, and activities for children. In addition, families brought picnic lunches to share with their team members. A team of dancers from the Elgin Academy of Dance in South Elgin performed and Kimberly Stover, also from South Elgin had a Zumba warm-up to get the walkers ready. Participants also had the opportunity to purchase wickless soy candles, UMDF merchandise, and handmade jewelry. To date, the walk has raised nearly \$45,000. Thank you to everyone who helped to make the walk a huge success!

DELAWARE VALLEY CHAPTER

- **September 12, 2009.** A decade of success was celebrated at the 10th annual Go for Mito Walk/Run at the Philadelphia Museum of Art. Over 340 walkers came out to show their support and raised over \$44,400 for the UMDF. Thank you to all who helped make this event a success over the years!
- **October 10, 2009.** The inaugural Oktoberfest for Mito took place at Cannstatter Volkfest in Philadelphia, Pennsylvania. The family-friendly event included rides, a pumpkin patch, inflatables, face painting, a DJ, and live entertainment. After the sun came out, everyone had a great time.

DC/BALTIMORE/NORTHERN VIRGINIA CHAPTER

- **October 24, 2009.** The DC/VA/Baltimore Chapter hosted Fall Into A Cure, the chapter's first major fundraising event. The event was held at the beautiful Belle Haven Country Club in Alexandria, VA. Over 75 people attended the event that included cocktails, a delicious buffet dinner, and silent auction. Over 150 items were donated to the silent auction from local and national businesses. Auction co-chairs, Sharon Goldin and Anne Tuccillo should be proud of their hard work as the event raised close to \$17,000 for the UMDF.

KANSAS CITY CHAPTER

- **October 19, 2009.** The KC Chapter of UMDF was so lucky to be selected as one of the charities for the First Annual Precision Roofing Golf Classic. The event was held at the Country Club of Blue Springs. There were 32 KC Royals players and celebrities along with an additional 112



Anne Tuccillo, Vibeke Azar and Bob Tuccillo at Fall into a Cure Gala

participants; to name a few George Brett, Frank White, Al Fitzmorris and Willie Wilson. Thank you to the generous work of the two owners of Precision Roofing; Mike Weber & Rich Hoffman. They did an awesome job pulling this off the first year. Their efforts and that of many others raised \$5,000 for the KC Chapter. Mike Weber is the uncle of Joe Atchley, II, who battles with Mito. Joe says you rock Uncle Mike!

- **October 20, 2009.** Awareness is spreading in Kansas thanks to a fundraiser hosted by Washburn University students and our Kansas City Chapter. The event was held at Buffalo Wild Wings in Topeka, Kansas where they donated a percentage of their sales. Throughout the evening there were prizes raffled and information was provided to all who attended. In the days leading up to the event the local news station WIBW-13 made announcements before reporting from the fundraiser that evening. Their feature interview was with Kansas City board member Angie Turnbow & her affected 7 year old son Brett Turnbow, they have also posted a link to the UMDF web site. Washburn also had their university paper do an in depth report and interview with Angie that included our link. Over \$1,300 was raised for UMDF and most importantly there were new connections made with students, doctors and one recently diagnosed family, all interested in helping UMDF find a cure! Anyone who would like to review the report on WIBW13 can go to <http://wibw.videogenesis.net/watch?v=5857>.

INDIANA CHAPTER

- **October 10, 2009.** The second annual Indiana Mito Walk and Family Fun Day was held at Forest Park in Noblesville, Indiana. Over 225 participants were in attendance for another successful walk, which raised over \$23,000. The children enjoyed an inflatable bounce house and obstacle course along with clowns, who provided face painting and balloon art. Attendees also enjoyed a live band and other family activities.

MINNEAPOLIS-ST. PAUL CHAPTER

- **September 19, 2009.** The fourth annual Mito 5K Walk/Run was held at Thomas Lake Park in Eagan, Minnesota. Event organizers exceeded their 2009 goal and raised more than \$28,000, up \$10,000 from last year! This year, the race was supported by more than 200 participants, 400 donors, and numerous volunteers. Senator Amy Klobuchar and Congresswoman Michelle Bachmann were in attendance to show their support for mitochondrial disease and the UMDF. Thank you to Brooke's Buddies, led by Stacey Pieper, for raising \$5,530 – more than any other team. Thank you to all of the participants who made the event a smashing success!
- **October 4, 2009.** Pete Hill ran his fourth marathon, the 29th annual Milwaukee Lakefront Marathon, in honor of his niece, Eleanor Toma. Throughout his months of training, Pete raised funds for UMDF by sharing

Eleanor's story with family, friends, and colleagues, and asking them to support his marathon and UMDF. Thanks to Pete's efforts, more than \$2,500 was donated.

MIDDLE TENNESSEE CHAPTER

- **September 21, 2009.** Kickin' it for Mito was a fun, and very successful event with nearly 100 guests in attendance at Kimbro's Pickin' Parlor in Franklin, Tennessee. Everyone enjoyed the live jazz music provided by Wing Tip, the spirited Silent Auction, and the full food & bar menu at Kimbro's! Great new connections were made and \$3,900 was raised for the UMDF! A special thanks to Don and Nancy Garrison for being the co-chairs of this great event.
- **September 22, 2009.** The second annual fundraiser, Scoopin' for a Cure took place at several Tennessee Maggie Moo's location during Awareness Week. In total, the event raised \$1,600. A special thanks to Fred Durham for serving as chairman of Awareness Week activities for the Middle Tennessee Chapter.
- **October 22, 2009.** The Western Tennessee Group and the Middle Tennessee Chapter hosted a joint fundraiser with Blue Coast Burrito. This event was loads of fun & very successful in raising higher levels of awareness about mitochondrial disease. In addition, \$1,322 was raised through a percentage of sales & cash donations!

NEW ENGLAND CHAPTER

- **October 10, 2009.** The second annual Mito Walk and Family Fun Day was held at the LEGO Campus in Enfield, Connecticut. The event was designed to raise awareness of mitochondrial disease and to allow families to come to the Lego Campus and have a day filled with activities and fun. The event has raised more than \$21,000 to date.
- **October 17-18, 2009.** The 20th annual Publick House Scarecrow Contest and Harvest Festival was held in Sturbridge, Massachusetts. A sand art craft was offered, from which \$150 was raised for the UMDF.
- **October 30, 2009.** To get in the Halloween spirit, Terri Connaughton hosted Messages From Beyond, a lecture from paranormal research. The event was held at the Chicopee Moose Lodge in Chicopee, Massachusetts, and raised \$1,000 for the UMDF.
- **November 16, 2009.** The annual Publick House Cooks for UMDF event was held in Sturbridge, Massachusetts. The Publick House offered a traditional Thanksgiving dinner, which raised more than \$600 for the UMDF.



Team Brooke's Buddies at the Minnesota Walk

OHIO CHAPTER

- **September 26, 2009.** Deb Fleming held a dinner party for family and friends at the Anello residence in Twinsburg Township, Ohio. Attendees enjoyed an evening of food, raffle baskets, and fun that resulted in a donation of \$2,000 to the UMDF.

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MITO FACTS

- Physicians suspect mitochondrial disease when three or more organs or multiple systems are involved.
- Adults or children are at the highest risk for neurological or organ damage during and for the two weeks following an illness.
- More research dollars are needed to find more effective treatments and ultimately a cure for mitochondrial diseases.



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LIVING IN THE MOMENT

A Day in the Life of Bob Brieff

On December 23, 2009, Bob Brieff and his wife, June Price, will be celebrating their 30th wedding anniversary. The love heard in Bob's voice as he speaks of his bride truly shows the extent of their vows.

Around the time of their marriage, Bob began to have muscle weakness. He sought medical attention and was diagnosed with a progressive neuromuscular condition called Charcot-Marie-Tooth Disease (CMT). At least one form of CMT disease is now known to be associated with mitochondrial illness. One of the results of this



June Price & Bob Brieff

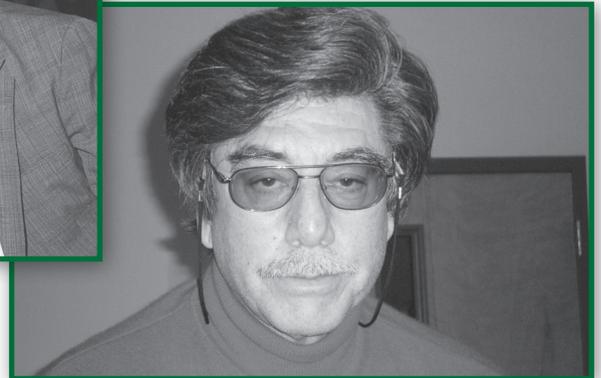
debilitating neuromuscular condition for Bob was that he had to wear leg braces, but in spite of that he was able to remain physically active. However, as Bob got older, and his leg muscles continued to weaken, walking became increasingly difficult, even with the use of a walker and more extensive leg braces.

For many years, Bob was (and still is) a patient at the Muscular Dystrophy Clinic at Columbia University Medical Center, where he was followed by Dr. Hirano, who suspected that Bob had a mitochondrial disorder. In 2006, after a muscle biopsy, he was diagnosed with mitochondrial myopathy. His muscle weakness was progressively getting worse and his once active lifestyle was fading. Bob had to retire from the career he loved in 2005. He was a Psychologist working at Kingsboro Psychiatric Center in Brooklyn New York, part of the New York State Mental Health System. "I was not ready to retire," says Bob, "it was a very difficult time for me." June retired around the same time to take care of her husband. In Bob's words "June's support brings tears to my eyes." Along with June, Bob has the support of a wonderful family and really good friends. "I have aunts, uncles, nephews and

cousins who help out a lot," says Bob. They have recently added home health care to their support system.

Meditation is something that Bob has found that helps him cope with his disease. He does a lot of reading and research on the subject and is training his mind to help him live more 'in the moment.' "I try not to worry so much about what will happen in the near and distant future, but that is easier said than done," Bob said. Bob does feel that his meditation helps with his energy levels to some extent.

Bob has a love for computers and technology and for most of his career at the hospital in Brooklyn he used computer-based instruction, as a method of skills training, to help rehabilitate severely impaired patients. More recently, he put his knowledge to good work with the Adult Advisory Council Team (AACT) and currently serves on the council. He took on the task



Bob Brieff at a New York Metro Chapter Meeting in 2007

of questionnaire development and analyzing the results this past spring. He is happy to be involved with AACT and says "I have the feeling of accomplishing something that is helpful to other people." He believes that AACT has enabled the adult mitochondrial community to have a stronger voice within the UMDF.

Bob uses his computer skills for fun as well! About five years ago, he created a game that he calls, 'The Boomer Squeeze' with 50's and 60's music. It is a more elaborate version of the old TV game, 'Name that Tune.' He uses his computer to edit the songs, cuts them down and loads them onto his ipod. "I take my ipod and portable speakers to parties and everyone plays! My friends and family think I should commercialize the game, but I do it for fun."

The song that best describes the love and support between Bob and June goes something like this - 'Through the years my love will grow, like a river it will flow.' Can you 'Name that Tune?' (Answer on page 14)

FROM THE CHAIRMAN

You are reading the last UMDF Newsletter for 2009. Looking back on the year, I am amazed at how much progress has been made, not only by the UMDF, but within the field of mitochondrial medicine. None of these accomplishments would have been achieved had it not been for the hard work, dedication and commitment made by our very active volunteers.



For example, in this newsletter, you will read about the creation of the North American Mitochondrial Disease Consortium (NAMDC). The consortium will be funded for two years under the American Reinvestment and Recovery Act (ARRA) at a level of just under a half million dollars each year. Who could have predicted last year that the UMDF would be recognized by the National Institutes of Health as a leading patient advocacy group required for the formation of this consortium? Dr. DiMauro says in this newsletter, that in order for the grant to be approved, the consortium was required to have the support of a patient advocacy group with the ability to identify patients for the consortium. The UMDF has met that critical requirement.

The work of this consortium is going to advance mitochondrial medicine at the NIH. In the coming months, patients or their family members will be able to visit the UMDF website and enroll in a registry. Once pertinent information is securely collected, the registry will be used by physicians and researchers to solicit patients for NAMDC. The NAMDC program is designed to begin a database to be used by our scientific and medical community to recruit patients for appropriate clinical trials. The program also is designed to start a biorepository. A biorepository will enable the scientific and medical community to gather tissue and other samples for their research. All of this moves us closer to potential treatments.

The new year will bring the continuation of a very important initiative started in the fall of 2009. Recognizing the need to respond to the needs of our chapters, groups and ambassadors in their fundraising efforts, the UMDF was able to obtain a grant to begin working with Steven

Biondolillo & Associates. Biondolillo & Associates is responsible for the dramatic growth and popularity of walkathons and other pledge-based fundraisers throughout the nation. Through these and other branded events, they have helped nonprofit organizations acquire millions of caring donors and raise hundreds of millions of dollars for their causes. But most importantly, they have helped propel the entire special-event fundraising industry to new heights.

Throughout October and November, those responsible for the organization of several UMDF walks were invited to participate in the training provided by Biondolillo & Associates. This training and support will continue into 2010 with the goal of better positioning UMDF events to raise millions of dollars for our research grant program.

A year ago, I could not have imagined that we would have legislation specific to mitochondrial medicine introduced in the United States Congress. Just before we sent you this newsletter, we received word that Senator Barbara Boxer (D-CA) introduced S.2858, The Brittany Wilkinson Mitochondrial Disease Research and Treatment Enhancement Act." Senator Boxer's Bill is the companion version to H.R. 3502. It is my hope that you have sent a letter to your own congressman and now your U.S. Senator through the UMDF Advocacy Action Center (www.umdf.orf/advocate). Last summer, we had more than 240 people visit their representatives in the House and Senate. These two pieces of legislation will fail if you do not become part of the cure and show your support. We need to keep progress on the advocacy front moving forward and make funding for mitochondrial medical research a law in the United States.

It has been an exciting year and I am very proud of our accomplishments. However, I truly believe, that 2010 will bring us even further down the path to the "cure" than we can even imagine. On behalf of my fellow trustees and the staff of the UMDF, it is our wish that you have a very happy and healthy holiday season.

Energy to all,



W. Dan Wright, UMDF Chairman

SECOND MITOCHONDRIAL DISEASE SESSION AT CAMP KOREY

Camp Korey in Carnation, Washington is seeking medical professionals who specialize in working with children with mitochondrial disease to volunteer August 1-6, 2010.

In 2009, Camp Korey hosted the first-ever camp session for children living with mitochondrial disease. Join us for session two! Watch campers discover their strengths and find acceptance in a supportive environment, and have an unforgettable week.

Please contact Hillary Carey at 425-844-3225, email hcarey@campkorey.org or visit www.campkorey.com for more information.

Camp Korey serves children and their families struggling with serious and life-threatening illness in the Pacific Northwest, providing summer camp sessions, family weekends, hospital outreach, and year-round programs at no charge to families. We rely on our generous volunteers to make Camp magical!

*Information provided to the UMDF by Camp Korey.

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DELAWARE VALLEY CHAPTER

• **March 1, 2010.** Join the Delaware Valley Chapter of the UMDF for a night of fun and Sixers basketball! A percentage of ticket sales will benefit the UMDF and can be purchased at www.umdf.org/Sixers.

HOUSTON CHAPTER

• **February 6, 2010.** The fourth annual Christopher's Heart Fun Run will be held at Sam Houston Park in downtown Houston. Activities will include a 5K Run and 1 Mile

Walk with children's activities. Last year, nearly \$80,000 was raised for the UMDF. For more information, visit www.umdf.org/christophersheartfunrun.

MIDDLE TENNESSEE CHAPTER

• **March 27, 2010.** The first annual Jackson Culley Mito-What? 5K will be held in Millington, Tennessee at USA Stadium. For more information please contact Angie Hayes at angie.hayes07@gmail.com or visit www.mitowhat5k.blogspot.com/.

SPECIAL OPPORTUNITIES

The holidays are almost here! Here is a list of retailers who contribute a portion of their profits to UMDF. NOTE: Links to all of these opportunities are listed at www.umdf.org.

Entertainment Books. The 2010 Entertainment Books are now available for purchase through the UMDF. Entertainment Books are available in over 150 editions! Get yours today! Go to www.entertainment.com/discount/?groupID=642223 to order your book and a portion of the proceeds will be donated to the UMDF!

Hello Designs. Hello Designs offers a line of professionally printed custom photo birth and adoption announcements, invitations and holiday cards. Each is customized to suit your needs and vision; you are not restricted to using predesigned templates. FOR EVERY ORDER PLACED UNTIL DECEMBER 31, 2009, Hello Designs will donate 10% to UMDF. YOU MUST USE CODE UMDF2009 for UMDF to receive the donation. Go to www.myhellodesigns.com to start!

Mer+ge Apparel Company. Mer+ge Apparel Company is based in Boston and is run by a philanthropic young woman, Victoria Jones. Victoria's line currently has 15 pieces and she has selected 15 nonprofits she works with based on the message of each shirt. Victoria has designed a shirt featuring the ATP molecule, which is the energy creating molecule. Victoria will donate \$1 from each shirt sold to the UMDF. To get yours, go to www.makethemerge.bigcartel.com and type "UMDF" into the search box.

Plates with Purpose. Plates with Purpose is a special series by the Riverside Design Group, a glassware manufacturer located in Pittsburgh, PA. There are seven nonprofits featured in the series. The UMDF has its

own specific design that is related to its cause, a ladybug designed in memory of Morgan Reynolds who succumbed to a mitochondrial disease in 2006. The UMDF receives 15% of each ladybug plate sold. Go to www.plateswithpurpose.com today.

GoodSearch.com. Type www.goodsearch.com/?charityid=806412 into your browser. Search the internet just like you normally would, and a donation of one penny per search is contributed to the UMDF.

GoodShop.com. Go to www.goodshop.com and select the UMDF as your charity. Select from a variety of stores, shop online and a percentage will be donated to the UMDF!

iGive.com. www.iGive.com allows you to shop online and have part of your purchases donated to the UMDF. If you are a last minute shopper or like to make purchases online, register at [iGive.com](http://www.iGive.com) and support the UMDF at the same time. Encourage your family and friends to use www.iGive.com to help the UMDF. Don't forget, you can use [iGive.com](http://www.iGive.com) for purchases year round.

Charity Candle Shop. Buy a candle and support the UMDF! Visit the online Charity Candle Shop where you can buy a Cinnamon Stick Soy Candle. 10% of the proceeds from your purchase will fund life-saving mitochondrial disease research and awareness. Get your UMDF candle today at http://charitycandle.com/candle_UMDF.php.

Cards by Suzanne. Cards by Suzanne sells note cards and prints designed by Suzanne Cizek who passed away on May 17, 2009. Her husband, Rick, kept her Etsy shop open for business. For every item sold, Rick will donate \$2 to UMDF. Go to www.cardsbysuzanne.etsy.com to view Suzanne's artwork.



Atlanta Chapter Mito-Mom's at Oktoberfest (L-R) Mary Swinn, Ashley DiLorenzo, Kristi Cole and Stacy Coburn

DONORS - THANK YOU

APPRECIATING THOSE WHO HAVE HELPED ALONG THE WAY!

While we would like to list ALL of our donors individually, please understand that it would be very difficult to do so with 6,341 donors of \$1-\$99 (**THANK YOU!**), 1,501 donors of \$100-\$249 (**THANK YOU!**) and 440 donors of \$250-\$499 (**THANK YOU!**).

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

The following acknowledgements include donations of \$500 or more entered into the system between January 1, 2009, and June 30, 2009. If your name or company's name is incorrect or not listed, please contact info@umdf.org.

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MEMBER RESOURCES

Traveling long distances for a hospital admission, diagnostic testing, or to see a specialist can potentially be stressful and expensive. The following is a list of medical travel resources that includes travel tips, charity flight transportation, and special housing accommodations in numerous cities.

Access Able Travel Source. Disability travel tips, including information about such issues as traveling with oxygen, service animals, and mobility equipment. To view their website, visit www.access-able.com/tips/.

Air Charity Network. Matches “people in need with ‘free’ flights and other travel resources that can provide healing and hope.” For more information, call 877-621-7177 or visit Air Charity Network’s website at <http://aircharitynetwork.org/>.

Brave Kids. Directory of medical services and resources for children with special needs. Includes special lodging information in various locations for families with a hospitalized child. For more information, visit www.bravekids.org/results.aspx.

Miracle Flights for Kids. “To improve access to health care by providing free air transportation to hospitals across America.” For more information, call 702-261-0494 or visit www.miracleflights.org.

Mitochondrial News Volume 12 Issue 1. The UMDF Newsletter lead article – practical article titled ‘Traveling with Disabilities.’ You must be a HOPE member to view past newsletters. For more information, go to www.umdf.org.

National Association of Hospital Hospitality Houses. “Non-profit organization serving facilities that provide lodging and other supportive services to patients and their families when confronted with medical emergencies.” For more information, call 828-253-1188 or toll free 800-542-9730. You can also visit them online at www.nahhh.org.

National Patient Air Transport Helpline. “Provides information about all forms of charitable, long-distance medical air transportation and provides referrals to all appropriate sources of help available in the national charitable medical air transportation network.” The helpline is available 24 hours a day, 7 days a week, 365 days a year. Call 800-296-1217 or visit www.patienttravel.org.

U.S. Department of Transportation’s Hotline to Assist Air Travelers with Disabilities. Call 800-778-4838 (TTY 800-455-7880) for the toll-free hotline available 7am - 11pm (EST). To view a PDF, type this into your web browser - www.friendshipventures.org/pdf/Forum%20Flyer%204%20AG.pdf.

SUBMIT A RESOURCE

The United Mitochondrial Disease Foundation currently has a national resource guide that is available upon request, and we have state resources posted on the web site. In an effort to better serve our patients and families, we would like your help. We will be updating our web site in 2010 and would like to upgrade the state online resources and add the national resources. If there is a resource you feel would be helpful to patients and families, we encourage you to submit it to us for consideration.

Not sure of what types of resources you could suggest? Our current resource guides include, but are not limited to, the following: trach care, developmental disability care, canine companions, care giving, grief, special needs, epilepsy, advocacy, financial, fatty acid disorders, gene tests, genetics, insurance, Medicaid, Medicare, networking, hospitality houses, federal and state government agencies, tube-feeding, adaptive equipment, diet & nutrition, vacations/camps/sports/travel assistance, and much more. Resources can be on the local level or national level.

To provide a potential resource, simply fill out the form below and return it to the UMDF. You can mail to: 8085 Saltsburg Road, Suite 201, Pittsburgh, PA 15239 or fax to 412-793-6477. The form is also available online at www.umdf.org/submitaresource.

1. In case we have questions about the resource, please provide your name and email.

Name: _____ Email: _____

2. Resource Information:

Name of Resource: _____

Address 1: _____ Address 2: _____

City/Town: _____ State/Province: _____

Zip/Postal Code: _____ Country: _____

3. Additional Information:

Web Link: _____

Main Business Number: _____ Fax Number: _____

Toll-Free Number: _____ Email: _____

4. Description of Services:

5. Is this a local or national resource? _____ Local _____ National _____ National but has local contacts

If local, which state(s) does it serve? _____

PLEDGE BASED FUNDRAISING

The United Mitochondrial Disease Foundation is very excited to announce that we are working with Steven Biondolillo & Associates on a new pledge based fundraising initiative that will allow us to expand our ability to attract awareness, volunteers and additional revenue. Over the past few months, the UMDF staff and several walk/run chairs from around the nation have participated in information sessions about this new initiative. Steven Biondolillo and his staff conducted the first round of training, which took place over various conference calls and one face-to-face meeting in Pittsburgh November 5-8, 2009.

Biondolillo and Associates are the nation's leading developer of branded, large-scale special-event fundraising programs, which typically link the nonprofit, for-profit and public sectors. Additionally, Biondolillo has developed what is widely regarded to be the nation's premiere training program in the field of special-event fundraising.

The creator of the nation's first corporate sponsorship model based on employee participation, Biondolillo sparked the national renaissance in walkathons and other pledge-based fundraising events. Among the firm's landmark walkathons are national leaders in the areas of breast cancer and

hunger. Since 1984, fundraisers developed by Biondolillo have raised over \$750 million.

Walk/Run representatives from the cities of Cleveland, Houston, Kansas City, Indianapolis, Atlanta, Chicago, Saint Louis, Minneapolis, and from New England, Carolina Foothills and Iowa are the first to take part in the training. Those attending were schooled in a specially designed 'pledge based' fundraising program for the UMDF. They are being given the tools to dramatically increase both volunteers and walkers by strengthening volunteer outreach skills. When the plan is successfully followed, the end result is a substantial increase in money raised in each walk-a-thon. Those attending the training session heard how Biondolillo and his team have successfully advanced walks that were raising \$50,000 to the million dollar level, using the pledge based fundraising module.



If you have been thinking about staging a walk to benefit the UMDF, please contact Carol Milsovic, National Events Manager at 888-317-UMDF (8633) or email carol.milsovic@umdf.org.

UMDF ACTIVITIES

OTHER NOTABLE EVENTS

- **May 31, 2009.** The sixth annual Bull and Shrimp Roast was held in honor of Peter Lubelczyk. The event was a tremendous success with over \$5,000 raised! Chesapeake Physical & Aquatic Therapy again hosted the event the end of May in Clarksville, Maryland. The festivities included a silent auction and raffle, and former NFL Baltimore Colt Joe Ehrmann, of Building Men and Women for Others, Inc. provided an inspirational message. A special thanks to Jared Goldstein and the CPAT staff for coordinating the event.



Payton's Race for a Cure

- **September 12, 2009.** Payton's Race for a Cure was hosted by the family and friends of Payton DeWitt at the Cedar Springs Practice Track in Cedar Springs, Michigan. This event, which raised \$10,000, included 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 included games, face painting, clowns and a magician.
- **September 13, 2009.** The Amanda's Journey Remembrance Walk was held at the Crossings of Colonie in Loudonville, New York in memory of Amanda Perrotta. The event benefited the UMDF, as well as the Albany Medical Center. The UMDF received \$3,800.
- **September 13, 2009.** The second annual Elena's Hope Cut-a-Thon was held at the Krave Salon in Kimberly, Wisconsin. The enthusiasm was so great, that two additional stylists were brought in to the salon to handle the additional clients. The event grew from previous years to include drawings for great baskets that were donated by Krave.

In total, 9 stylists donated their time for the entire day to provide hair cuts, styles, and manicures and pedicures, which resulted in a donation of \$2,000 to the UMDF via the Elena's Hope Research Fund.



Elena's Hope Cut-a-Thon

- **September 19, 2009.** The third annual Idaho Bowl-a-thon was a great success. This day filled with fun and bowling raised about \$1,000. Thank you to all who helped!
- **September 19, 2009.** The second annual Savannah's Hope Mito Walk was held at Adventure Life Reformed Church in Altoona, Iowa. The event included several family-friendly activities and raised more than \$2,300.
- **September 26, 2009.** The Wilkinson Family held their annual walk in Clovis, California in memory of Brittany Wilkinson, a UMDF Youth Ambassador who passed away on September 6, 2009.
- **September 26, 2009.** The third annual Sip and Savor the Moment for a Cure at the La Casa Narcisi Winery in Gibsonia, Pennsylvania. The annual wine and chocolate tasting gala raised more than \$21,000 for the UMDF.
- **September 27, 2009.** Bowling for Mito was held by the Central Florida Group in Orlando, FL. A total of 65 people came out to bowl and a great time was had by all! Thank you to those who helped make our first fundraising event a success!



Bowling for Mito

- **October 3, 2009.** Megan Adams worked very hard all year and studied to read from the Torah. She became a Bat Mitzvah and donated the gifts made in her honor to the UMDF. Thanks to the generosity of the Adams Family, more than \$1,000 was donated in Megan's honor.
- **October 3, 2009.** The third annual Delta Gamma 5K took place on Parents' Weekend at the University of Miami, in Coral Gables, Florida. The race was a great way for Greeks, and their friends and families to come support the UMDF. The event serves a wonderful opportunity for people to see some of the most beautiful parts of the University of Miami campus, as well as contribute to the research efforts of UMDF. Through their efforts, the sisters of Delta Gamma raised nearly \$1,300.



Delta Gama 5K

- **October 3, 2009.** One Step Closer to a Cure Walk & Energy Fest was held at Monroeville Community Park. The walk and family fun day helped raise over \$15,300. Thank you to all UMDF friends and families for your support!

OTHER NOTABLE EVENTS (CON'T)

- **October 10, 2009.** Held at South Lakes Park in Denton, Texas, the third annual Kure for Kat offered all participants a fun-filled experience with entertainment, refreshments, and mitochondrial disease resources. In total, the event raised nearly \$6,000 for the UMDF in honor of Katherine Dickens.



Katherine Dickens with Anne and Tim Casteel at Kure for Kat

- **October 17, 2009.** Thanks to our members across the nation for purchasing Macy's Shop for a Cause passes and helping UMDF raise a total of \$1,820!

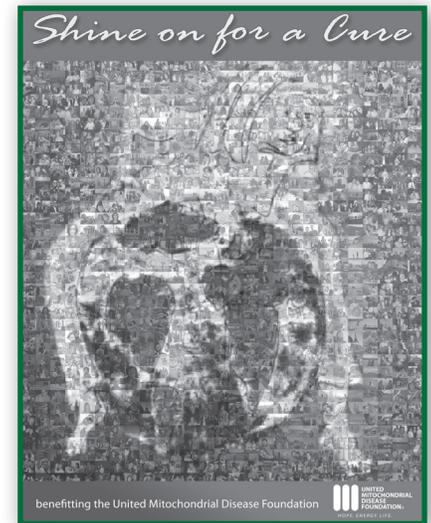
- **October 25, 2009.** Bruster's of Ingomar hosted a Halloween Costume Contest, collected donations, and donated 10% of all food sales to UMDF. A total of \$188 was donated to the UMDF! Thank you to Bruster's of Ingomar and all those who came out to support this event.

- **November, 2009.** The UMDF was a proud recipient of The Christie Cookie Contest Charity giveaway. Thanks to awesome voting efforts, the UMDF was awarded \$1,000! In addition, until December 25, 2009 anyone who purchases cookies from Christie's Cookies and uses the discount code 25K08 at checkout will have 20% of their purchase donated to the UMDF.

- **November 7, 2009.** The first Photos for Mito fundraiser held in Gainesville, Florida was a success. This-soon-to-be annual event raised over \$1,000 with all proceeds donated to the UMDF.

- **December 4, 2009.** New York City's Theatre Within hosted the 29th annual John Lennon Tribute Concert with UMDF as this year's beneficiary. The concert kicked off UMDF's Shine on for a Cure, which will also host an online auction showcasing

lithographs from John Lennon and signed Mad Magazine covers. In addition, UMDF supporters can submit their photos to be embedded in a mosaic of John Lennon's famous "Imagine All The People." For more information, visit www.shineonforacure.com.



*Shine on for a Cure Photo Mosaic...
Submit your photo today!
www.shineonforacure.com*

GIFTS FROM THE HEART

- In lieu of gifts, Eddie Curtis asked friends and family to send donations to the UMDF. As a result, \$700 was donated to the UMDF in honor of his birthday.
- Georgian Court University, in conjunction with its student chapter of the Council for Exceptional children held an awareness event at GCU's family day. Thanks to generous donations, \$76 was donated to the UMDF.
- A barbeque chicken dinner benefit was held in Brusly, Louisiana, on October 3rd in honor of Lydia Poché. The support and generosity of the community was amazing, as 800 dinners were sold. Including additional donations, more than \$7,600 was donated to the UMDF in Lydia's honor.
- Northwestern Middle School, in Zachary, Louisiana, hosted "Lydia's Day," in which students were allowed a uniform-free day. Donations were accepted in honor of Lydia

Poché to participate, resulting in a \$2,300 donation to the UMDF.



Lydia Poché

- Continuing with her successful Art for Rachel fundraiser, Marjorie Olson donated \$240 in proceeds from art shows in the New England region.

- The Epstein School, a Jewish day school in Atlanta, Georgia, chose the UMDF as the beneficiary of their Nediv Lev program. Rather than exchanging gifts, students chose a charity to support, and as a result, \$550 was raised by the students.
- Alyssa Rogers held a lemonade stand in honor of her brother Carson and donated all the proceeds to the UMDF. Thank you Alyssa for your contribution!
- A special thanks to Kathy Masters for initiating the "Take Steak" fundraising program at the Statesville Lone Star Steakhouse. Thank you Kathy for your support!

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.

ADVOCACY IN ACTION

One of the best ways to spread awareness about mitochondrial disease is to invite elected officials to your events or schedule a meeting with them. Minnesota Senator Amy Klobuchar was the invited guest and 'Official Starter' for the '4th Annual Minnesota Mito 5K Walk/Run.' It gave the Senator an opportunity to meet with members of the Minnesota mitochondrial disease community, to hear about the issues and our pending legislation.



Minnesota Senator Amy Klobuchar, Official Starter at the 4th annual Minnesota Mito 5K Walk/Run

In November, UMDF Youth Ambassador Joe Wise of Menlo Park, CA was invited to meet with California Governor Arnold



Joe Wise with California Governor Arnold Schwarzenegger

Schwarzenegger. Joe was able to tell the Governor his personal story, as a U.S. Paralympic Swimmer who is also affected with a mitochondrial myopathy. Joe reports the Governor was very interested in mitochondrial diseases and some of the ideas Joe had relative to physical education for affected kids.

So how have you helped?

Did you send a letter to advocate or schedule a meeting with your Congressman? Visit www.umd.org/advocate to lend your voice!

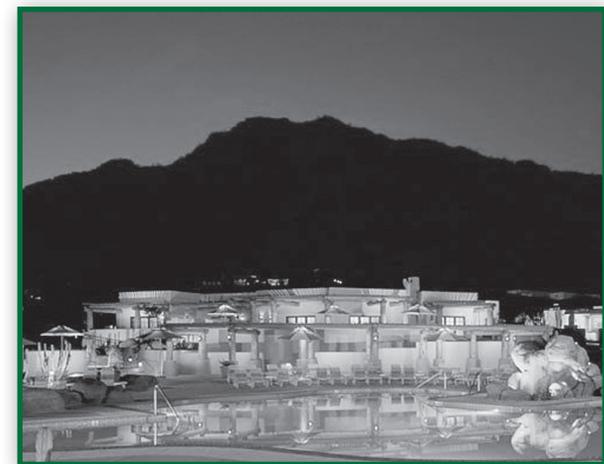
We can't pass any legislation without your help and support.

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



PROMOTIONAL AND EXHIBIT OPPORTUNITIES

You will find Mitochondrial Medicine 2010 an unmatched setting for showcasing your products and services through your booth display, networking opportunities and access to the educational sessions. For companies and organizations involved in cross disciplinary fields, this is a marketing opportunity you cannot afford to miss!

Supporters can range from Exhibitors, Platinum Supporters, to placing an advertisement in the Banquet Program. Families can also take a part in supporting the symposium. You can become a Family Session Speaker Travel Supporter or a Scholarship Supporter.

If you are interested in learning more about supporting Mitochondrial Medicine 2010, contact us at 888-317-8633 or email symposium@umd.org. All Supporter Levels are listed at www.umd.org/symposium.

FEEDING MY SOUL - BY: BEATE POHLIG

I just returned from a two-week trip to Spain. This is my second European trip traveling with mitochondrial disease and my first with Celiac disease. They are like having extra buddies that demand constant care and attention. One demands that I eat constantly while the other makes me watch every morsel I put in my mouth. So, they have added some roadblocks to the way I travel, but have not caused me to forgo doing what I'm so passionate about.

The seeds of travel were planted early by my uncle when I was a little girl. When he visited, he always brought photo slides from his most recent trips. Looking at his slides and listening to his adventures, I began to dream of a world outside the borders of Cape May County. Along with my mother's love of archeology and *National Geographic*, I was destined to leave my hometown the first chance I got.

Much to my mother's dismay, I boarded a plane bound for Phoenix, Arizona at twenty years old with just a blue nylon duffle bag and a couple hundred dollars. I picked Phoenix because it's warm and I knew I would not freeze to death. I had planned on staying there long enough to attend college but the economic picture was much harsher than their weather, so I resorted to plan B. My father served in the military and my brother was in the navy. So, once again, I was off and traveling. Only this time, I wore lots of green and my travel destinations were selected for me. The Army sent me to live in West Germany for almost four years. I spent every weekend and holiday on their wonderful trains, traveling around Europe. Unfortunately, the Cold War was in full swing and I had a top security clearance. So I was banned from venturing beyond the Berlin Wall into any Soviet Bloc county. But I managed to visit many European countries and hopped over to Africa for a Kenyan safari. I traveled so much that when I returned to the US in 1987, I had little more than a green duffle bag and a college fund.

Since my stint wearing green, I've never stopped traveling. I've been fortunate to partner with someone who loves to travel as much as I do and thankfully, carries my bag. Last year, I made it beyond the former 'Iron Curtin' to Poland, Prague, Budapest, Slovenia and Croatia. It was the first trip where I was forced to make major accommodations. I had to pace myself, to take naps in the early afternoon each day. On travel days between countries, I slept to recover. I carried PowerGel and protein bars for extra energy and drank a fair amount of caffeine. I had to limit the number of tourist sites that I photographed. And finally, I had my bags hauled around. I'm a realist. One day mitochondrial disease may prevent me from traveling, but until that time, I will continue to feed my soul.



Jill Connell & Beate Pohlig in Central Europe

Adult Advisory Council Team (AACT)

- Sharon Shaw, AACT Chair, Arizona
- Gail Wehling, AACT Co-Chair, Illinois
- 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.

United Mitochondrial Disease Foundation Heartstrings Award Recognizing a youth commitment that tugs on the heartstrings

Purpose: To recognize a child or teen who has donated or raised funds for the UMDF, enabling the UMDF to continue its mission.

Eligibility: The individual recognized must be under 18 years of age at the time of the donation or fundraising activity.

Criteria: The winner is chosen based on related criteria of age, time invested, talents demonstrated, effectiveness, and generosity. For nominees who implement fundraising projects, the judges will consider the uniqueness and creativity of the project, communication, time invested, and the amount raised in comparison to the age of the individual. For nominees who donate funds, the judges will consider the generous spirit shown, communication, and amount donated in relation to the age of the individual.

Instructions: Any UMDF member can nominate an individual for this award. Fill out the form below and attach the requested information. The UMDF will announce the winner at the annual symposium and will present the winner with a plaque. The Heartstrings Award winner will be featured on the UMDF web site and recognized in the UMDF Mitochondrial News newsletter.

In 100 words or less, please explain how this individual has "tugged at your heartstrings" through fundraising for or donating to the UMDF. Identify important features of the nominee's activity, such as the time invested, creativity, communication skills, determination, effectiveness, and generosity. You may also attach supporting information on the fundraising project (published articles, pictures, comments from others involved with or participating in the project) or the communications of the nominee (letter explaining intended use of the gifted funds, thank you letters, letters sent with the donation, and so forth).

Please type your essay and attach it to the nomination form.

Mail the nomination by April 14, 2010 to:
United Mitochondrial Disease Foundation
Attn: Heartstrings Award
8085 Saltsburg Road, Suite 201
Pittsburgh, PA 15239

Or fax to 412-793-6477 or e-mail the nomination by April 14, 2010 to info@umdf.org .

Person Nominating

Name: _____

Address: _____

Phone: _____

Email: _____

Nominee for the Award

Name: _____

Address: _____

Phone: _____

Diagnosis (if known): _____

Age (must be less than 18 years old at time of donation or event): _____

United Mitochondrial Disease Foundation LEAP Award

Living, Encouraging, Achieving & Persisting

Purpose: To recognize an individual living positively with mitochondrial disease, highlighting the person's accomplishments and volunteer service.

Eligibility: Age 14 years or older.

Criteria: Individual with confirmed or suspected mitochondrial disease who overcomes daily challenges to achieve goals in career, family, and volunteer service. The individual demonstrates a positive attitude, hope for a brighter future, and an enthusiasm that inspires others.

Instructions: Any UMDF member can nominate an individual for this award. Fill out the form below and attach the requested information. The UMDF will announce the LEAP Award winner at the annual symposium and will present the winner with a plaque. The LEAP Award winner will be featured on the UMDF web site and recognized in the UMDF Mitochondrial News newsletter.

In 100 words or less, please explain how this individual overcomes daily challenges to achieve goals in career, family, and volunteer service. Please provide examples of how the individual demonstrates a positive attitude, hope for a brighter future, and an enthusiasm that inspires others. You may also attach copies of articles about the nominee and lists of projects, activities, or clubs the nominee is involved with.

Please type your essay and attach it to the nomination form.

Mail the nomination by April 14, 2010 to:

United Mitochondrial Disease Foundation
Attn: LEAP Award
8085 Saltsburg Road, Suite 201
Pittsburgh, PA 15239

Or fax to 412-793-6477 or email the nomination by April 14, 2010 to info@umdf.org.

Person Nominating

Name: _____

Address: _____

Phone: _____

Email: _____

Nominee for the Award

Name: _____

Address: _____

Phone: _____

Diagnosis (if known): _____

ANNOUNCEMENTS

MITOCHONDRIAL DISEASE AND THE H1N1 FLU

The UMDF is making an effort to provide relevant information about H1N1 for mitochondrial disease patients. On the front page of umdf.org, we have a link to the page that provides information from the Centers for Disease Control (CDC) as well as a statement from the UMDF Scientific and Medical Advisory Board on the H1N1 Vaccine and mitochondrial disease patients. The statement is written by Bruce Cohen, M.D. Please visit our H1N1 information area on the website from time to time as we will update as information becomes available.

NEW UMDF STAFF MEMBERS

The UMDF would like to introduce two of the newest members of the Special Events and Development Departments. Please help us welcome Carol Milsovic as National Events Manager and Marian Weil as Development Director.

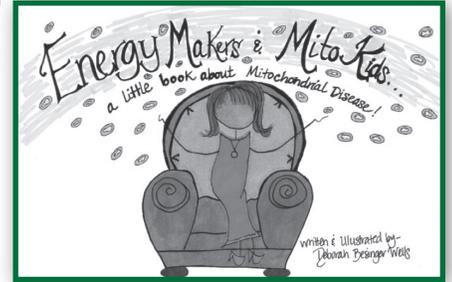
Carol has more than twenty years experience working in the hospitality industry in sales, marketing and event planning. She is a Certified Meeting Professional and a past President of the Pittsburgh Chapter of Meeting Professionals International. Carol will be assisting our members as we transition to Pledged Based Fundraising for UMDF walks.

Marian comes to the UMDF after working as the president of a consulting group that offered fundraising and marketing services to the not-for-profit sector with a focus on capital campaigns.

We would like to welcome both Carol and Marian to the UMDF family!

ENERGY MAKERS & MITO KIDS

"Energy Makers and Mito Kids is a delightful and understandable way to explain Mitochondrial disease to the people in your community. Whether you are trying to help your Mito-kid understand their own disease, or trying to understand it yourself, you'll love reading this book to the kids in your life. This is also a great tool to use in your child's classroom, with neighbors, extended family members and friends to help them in understanding the variable issues that children with Mitochondrial Disease face. The author and illustrator was very sure to illustrate children with all degrees of abilities in this book. The text also educates that some children with Mito may look perfectly 'normal' on the outside while others may not be able to walk or talk. It even explains the importance of not visiting a mito kid when you are sick and educates about hand-washing, in a fun and memorable way. Finally, the book breaks barriers by saying 'Kids with mito like the same things you do...they have big dreams, soaring hopes and great aspirations.' By the end of this easy-to-read 28-page book, everyone will feel lucky to know a Mito kid!" To learn more about Energy Makers and Mito Kids, visit www.mitokidsrock.com.



Answer: 'Devoted to You' by the Everly Brothers

SUBMISSION DEADLINE FOR VOLUME 15 ISSUE 1 IS JANUARY 30, 2010!



UNITED
MITOCHONDRIAL
DISEASE
FOUNDATION®

HOPE. ENERGY. LIFE.

IN THIS ISSUE:

North American Mitochondrial Disease Consortium.

Read page 1!

Are steroids a definite "no" for mitochondrial disease patients?

See page 3!

What's new in my area?

Check out pages 4-9!

LEAP & Heartstrings Award Nomination Forms.

On page 12-13!