INDY 2008: Setting the Pace in Mitochondrial Medicine

The UMDF hosted the tenth annual symposium dedicated to mitochondrial medicine this past June. The annual event was held at the Hyatt Regency Hotel in Indianapolis, Indiana. INDY 2008: Setting the Pace in Mitochondrial Medicine brought 320 physicians, researchers and other health professionals and 180 patients and family members together to learn more about mitochondrial disease.

SCIENTIFIC MEETINGS

The Scientific Meetings covered a broad spectrum of issues related to mitochondrial function and disease. Presentations included detailed reviews by invited expert faculty and also cutting-edge abstract presentations by mitochondrial researchers from around the world.

Day One – Genetics of Mitochondrial Disease

Invited speakers covered topics that included the origins and prevalence of mtDNA mutations, how they relate to specific diseases, and impairment of energy metabolism by mutations in assembly genes that direct the formation of mitochondrial respiratory enzymes. Abstract presenter James Bennett of the University of Virginia demonstrated that it was possible to improve mitochondrial energy production in mutated cells by enhancing the activity of mitochondrial genes.

“I TRULY ENJOYED EVERY ASPECT OF THE MEETING - FROM THE SCIENTIFIC SESSIONS, THE DOCTOR IS IN PANEL, TO MEETING WITH THE PATIENTS”

Barb Mendelsohn and her father Herb are pictured left at Bowling for Barb held in Overland Park, KS on July 26, 2008. The event raised over $11,000!

See pages 4-7 for more events and fundraisers!

Day Two – Mitochondrial Dynamics and Diagnostic Paradigms

The importance to normal function of mitochondrial fusion and transport within cells were topics addressed by faculty. In a highly informative afternoon session, nine physicians shared their procedures for diagnosing mitochondrial disease. A noteworthy abstract presentation by Yisang Yoon of the University of Rochester addressed the relationship between high glucose levels in diabetics and damage to mitochondria.

Day Three – Diagnostic Techniques and Mitochondria and Neurodegeneration

Diagnosis of mitochondrial disease through the use of genetic analysis, microscopy, and exercise physiology were among the topics covered by invited faculty. The putative roles of mitochondrial dysfunction in neurodegenerative diseases such as Alzheimer’s and Parkinson’s disease and ALS were also addressed. Among the abstract presentations on this day, Suzanne Arnold of the Institute for Neuroanatomy in Germany gave an outstanding talk about her research on the protective effects of estrogen on mitochondrial function in brain cells.

Day Four – CoQ10 Deficiency and Mitochondria and Tumors

Despite three full days of sessions, this final day of the symposium still covered new ground. Subjects included the genetic causes of CoQ10 deficiencies and their related pathophysiology, metabolic consequences of mitochondrial

(continued on page 5)
The newest addition to the UMDF Board of Trustees is Atlanta Chapter President, Chris Swinn. Chris was appointed Chapter Liaison in June of 2008. The Chapter Liaison has a very important role within the Board of Trustees. He or she serves as the voice for all of the UMDF Chapters. The duty of the Chapter Liaison is to bring information from other chapter leaders to the board and communicate information from the board back to chapter leaders. “There is both General Manager and owner of the Peachtree Club in Atlanta, GA.

In 2002 when Emily, their oldest daughter, was diagnosed with a mitochondrial disease. Determined to make an impact, in 2003, Chris and Mary revitalized the already existing Atlanta Support Group. With the help of other local families, the support group quickly grew to become a full-fledged chapter. Under Chris’ leadership, the Atlanta Chapter has grown from just a few families to over 80 in the membership directory and many more who have some involvement in education, awareness, or fundraising. “We quickly learned how important the role of the UMDF is,” Chris says, “Not only to those who are receiving the daunting diagnosis for the first time, but for those who are continuing the UMDF mission.”

The Atlanta Chapter holds many fundraising and awareness events each year. Among them is the annual “Fore-a-Cure” Golf Tournament. For the past five years, Chris has chaired the tournament and helped to raise over $230,000 for the UMDF. The event continues to be a huge success because of the hard work of Chris and the golf committee. The fifth annual Fore-a-Cure Golf Tournament will be held on October 6, 2008 at the Standard Club in Duluth, GA.

At the UMDF annual symposium this year, Chris was honored to be the first recipient of the Stanley A. Davis Leadership Award. The award is the most prestigious UMDF National Award honoring a UMDF Chapter President who best represents the selfless dedication and commitment to the UMDF Mission as that of its namesake. Although Chris had known of the award, he was unaware that he was the recipient. Chris’s daughter Emily, who had just received the Heartstrings Award, rose to the podium to announce the winner of the Stanley A. Davis Leadership Award. There was not a dry eye in the house when Emily stated “and the recipient of the Stanley A. Davis Leadership Award is my daddy, Chris Swinn!” “I was extremely honored to be the first recipient,” Chris said. As he made mention in his acceptance speech, he believes that Atlanta’s success is directly attributable to the amazing volunteers who work selflessly, trying to make a difference. “I believe we are only successful because of the drive we feel and the great support we receive from the UMDF National Office,” Chris said. “It is truly a team effort!”
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 Doc SM at UMDF.org. Please note that information contained in Ask the Mito Doc SM is for informational and educational purposes only. Such information is not intended to replace and should not be interpreted or relied upon as professional advice, whether medical or otherwise.

Responder for this issue: Richard G. Boles, MD, of Children’s Hospital Los Angeles, CA, Sumit Parikh, MD, of the Cleveland Clinic, OH and Maria Yialamas, MD, of Massachusetts General Hospital, MA.

**THE QUESTION IS...**

My daughter is 6 years old and diagnosed with a “probable” mitochondrial disease. She can walk, but she can’t talk or communicate in any way or understand anything. She has severe diarrhea problems at times, which we've been told by numerous doctors is due to patches of abnormal motility due to a true cellular energy-poor areas.

Other symptoms that have not been explained include: 1) Sensitivity to heat in that they ‘wilt’ in hot weather -> I do not think we know if there is an inability to regulate body temperature or sweat. Dehydration may play a role in symptom exacerbation. 2) Blue lips/extremities -> typically not causing discomfort. I have not seen this but have had parents report it. There are biopsy proven reports of neuropathy in mito patients - but I do not know if this would explain episodic color changes in the patients (especially with rapid resolution of the symptom). 3) Postural tachycardia or orthostatic/positional hypotension -> this is a common complaint in many individuals (some with abnormal autonomic testing on the tilt-table) - not just mitochondrial patients and we do not know if this is more common in DNA or biopsy proven mito patients.

**RESPONSE FROM RICHARD G. BOLES, MD:**

The gastrointestinal (GI) tract is one of the organ systems that are most frequently affected in individuals with many different mitochondrial disorders. Generally, the problem involves motility, which means that the movement of food and its byproducts through the GI tract is abnormal. It is well appreciated that mitochondrial disease patients can suffer from constipation. However, many other mito patients suffer from diarrhea, while others alternate between constipation and diarrhea.

In many mito patients, special diets can be helpful with motility, while not so in others. However, as is generally the case in these complex disorders, there is no simple answer to your question. Some mito patients do better with small frequent feedings. Some mito patients do well with a degree of fat restriction (what is generally considered to be a “healthy diet”). Some mito patients cannot tolerate a lot of starch, and do better on whole grains and/or on higher protein diets (close to the “Paleolithic” diets sometimes advocated in children with autistic spectrum disorders). Your description of rice, corn and soy intolerance in your daughter suggests to me that this could be the case. Furthermore, some mito patients have intolerance to various foods; milk being possibly the most common.

Finally, carnitine supplementation often can contribute to diarrhea. Two suggestions to discuss with your physician are spreading out the carnitine into smaller amounts given more frequently, and/or decreasing the total dose given to a small degree.

Unfortunately, GI symptoms and diet in mito disorders are areas that are not well studied, and opinions are far more numerous than facts. What works in your child may be the best answer. (In addition, I personally believe that all mito patients should avoid fasting, unless carefully shown that this is not a problem.)

**THE QUESTION IS...**

Could you please provide some information about dysautonomia?

**RESPONSE FROM SUMIT PARIKH, MD:**

In regards to dysautonomia - some mito patients seem to have several symptoms where dysautonomia has been invoked as a possible etiology - but not proven by autonomic testing. The symptom that might be most linked to dysautonomia would be dysmotility since the gut is controlled by the autonomic nervous system. The dilemma with this explanation is that the gut also has its own internal nervous system and some of the motility issues may be due to patches of abnormal motility due to a true cellular energy deficiency. The explanation for cardiac arrythmias may be similar - not due to abnormal signals from autonomic controls in the brain stem but rather aberrant electrical generation/conduction in energy-poor areas.

Other symptoms that have not been explained include: 1) Sensitivity to heat in that they ‘wilt’ in hot weather - I do not think we know if there is an inability to regulate body temperature or sweat. Dehydration may play a role in symptom exacerbation. 2) Blue lips/extremities - typically not causing discomfort. I have not seen this but I have had parents report it. There are biopsy proven reports of neuropathy in mito patients - but I do not know if this would explain episodic color changes in the patients (especially with rapid resolution of the symptom). 3) Postural tachycardia or orthostatic/positional hypotension -> this is a common complaint in many individuals (some with abnormal autonomic testing on the tilt-table) - not just mitochondrial patients and we do not know if this is more common in DNA or biopsy proven mito patients.

**RESPONSE FROM MARIA YIALAMAS, MD:**

Unfortunately, most of the supplements and herbs commonly advertised as being helpful for hot flashes and night sweats have been shown to be no better than placebo. If you have severe symptoms, you can always ask your physician whether you are a good candidate for the nonhormonal medication venlafaxine which has been shown to improve night sweats and hot flashes.

Submissions questions to Ask the Mito Doc SM is a benefit of UMDF membership. If you are a member and would like to submit a question, please email your question and user ID and password to askmitodoc@umdf.org. If you would like more information on becoming a member of UMDF, please email us at info@umdf.org.
**ATLANTA CHAPTER**

*June 25, 2008.* The third annual Fine Open Charity Golf Tournament was held at Pineisle Golf Club in the Lake Lanier Islands near Atlanta, GA. The event was held in honor of the three Fine brothers, all dealing with mitochondrial disorders - Price, age 7, Spencer, Age 4 and Dylan, age 3. The tournament featured a silent auction and a round of challenging golf in a beautiful setting.

**CENTRAL OHIO CHAPTER**

*July 26, 2008.* The third annual Race for Ellie was held at Adventure Park in Powell, OH. More than 500 people participated in activities including a 5K run/walk and Kids Run. Race for Ellie was a great family event that generated more than $55,000 for mitochondrial disease research and support for affected families.

*July 26, 2008.* In conjunction with the third annual Race for Ellie, Tastefully Simple representative Ann Slusser donated 100% of her profits to the event in honor of Ellie Kovalcik. Thank you Ann for your generosity!

**CHICAGO CHAPTER**

*June 8, 2008.* A Tea for Mito - For the Love of Lora was held at the Pickwick Society Tea Room in Frankfort, IL. The afternoon featured great tea, food and an auction. The event was held in honor of Lora Wasielewski. Thank you to Rose Mary and the Wasielewski family for your continued support!

**DELAWARE VALLEY CHAPTER**

*July 26, 2008.* The fifth annual Brew at the Zoo was held for the first time at the Philadelphia Zoo. The event featured more than 20 national, local and home brewers as well as live entertainment by Soniqboom and complimentary food. Over 1,700 beer enthusiasts attended the Brew at the Zoo to raise more than $50,000 for the UMDF. Thank you to all who helped make this event successful again this year!

**KANSAS CITY CHAPTER**

*June 21, 2008.* The annual Mito-What? Family Fun Run was held in the Northland at Lake Waukomis, MO. More than 250 people participated to raise more than $21,000 for the UMDF. A special thank you to all of the participants and volunteers who made the event a success!

*July 26, 2008.* In line with her passion for bowling and finding a cure for mitochondrial disease, Barb Mendelsohn held her first annual Bowling with Barb event at the AMF College Lanes in Overland Park, KS. The event raised over $11,000 for the UMDF. A special thank you to all the bowlers who came out in support of Barb!

**NEW ENGLAND CHAPTER**

*July 26, 2008.* New England artist Marjorie Olson sold her inspiring watercolors at Veasey Memorial Park in Groveland, MA. 100% of the proceeds from each painting sold will be donated to the UMDF in honor of Marjorie’s niece Rachel Varriano. Marjorie has five more shows scheduled for 2008. Thank you Marjorie for your support of the UMDF!
‘INDY 2008’ (cont. from page 1)

Impairment, and mitochondrial aspects of cancer development and treatment. A special session for general practitioners provided updates on mitochondrial disease and on the effectiveness of exercise therapy. Also, Michael Miles of the University of Cincinnati presented work from his research group in which they measured muscle CoQ10 concentrations in children with suspected mitochondrial myopathy and correlated it with the level of respiratory enzyme function. (Summaries courtesy of Steven G. Basset, PhD)

From Page One

Sacred Heart Academy students discuss their poster presentation with the scientific community

Below are some reactions from scientific attendees:

• My brain is overloaded with spectacular information – I would attend this meeting more than once per year!
• I am a dietitian who has been working with both children and adults with mitochondrial disorders for 5 years. This was my first UMDF symposium. I am amazed by the amount of information I was able to absorb in a very nicely organized 3 days! I would love to attend again in the future and hope that as the research expands, there will be an increasing focus on clinical application.

FAMILY MEETINGS

• I loved it all! Wonderful experience – very glad I came. It was great to meet others dealing with the same things and to know that “I am not crazy.” It was difficult to decide which sessions to go to as a “mito mom” and “mito patient.”
• Great meeting other parents who are going through the same things we are! We liked that we were able to attend sessions from the parent’s panel to ask the researcher panels. A great variety of information!
• It was great meeting other families and hearing that my child is “normal” for mito and that I am not losing my mind! Fatigue and difficulty with school is common among mito patients. The Doctor Is In is invaluable!
• I enjoyed having the top doctors on hand to present, being able to talk to other adults with the same disease that I have and receiving the “MitoFirst” handbook and the Mito 101 CD to give to my doctors. I was glad to find information about CoQ10 and receive a sample. Thank you UMDF for all of your hard work in planning our conference. I appreciate all that you did!
• It was all fascinating and a welcoming opportunity to talk with people who have experienced things that we have.
• There was a lot of great information and I had the chance to meet several mito adults. I also learned more from some of the mito parents. I loved the poster room!

(continued on page 8)

OTHER NOTABLE EVENTS

• June 21, 2008. Friends and Family of Norma Gibson gathered for the 15th annual Gibson Pot Luck BBQ in Ukiah, CA. The evening included laughter, great food and a silent auction. The event is held each year in memory of Heidi Daniels and raised $4,430 for the UMDF this year. Thank you Norma for your continued support!

• July 19, 2008. Local auto-crossing drivers gathered in the parking lot by Captin’s Stadium in Eastlake, OH to compete in an Auto-X to benefit the UMDF. The race featured a controlled car course in which cars “raced” through a maneuverability course of cones and competed for the fastest time.

• July 19, 2008. Musicians from across the country converged at Donovan’s Reef in Sea Bright, NJ for a fundraising event called “Dunesday.” The event featured such national acts as Brian Kirk and the Jirks, Drama Rama, and Colin Hay from Men At Work. This year, partial proceeds from the all-day concert benefited the UMDF!

• August 2, 2008. The first annual Run 4 Raley was held at the Philo Ball Park on Harrison Street in Philo, IL. The 5K run and 1-mile walk was held in memory of Raley Kirby, who passed away at seven weeks old from a mitochondrial disorder. Thank you to all of those who honored her memory.

• August 9, 2008. The second annual Brew at the Zoo was held at the Pittsburgh Zoo & PPG Aquarium. The event featured more than 25 national, local and home brewers as well as live entertainment by Here and Now and French Blue and complimentary food. Over 1,400 beer enthusiasts attended the Brew at the Zoo to raise more than $45,000 for the UMDF.

• August 7, 2008. Splishin Splashin for the UMDF was held at the Crooksville Pool in Crooksville, OH. Attendees participated in fun contests such as race the lifeguard and highest splash. The event was held in honor of Baylee Thompson.

• August 16-17, 2008. Softball teams competed in Baylee’s Ball Bash in Cannelville, OH in honor of Baylee Thompson. This charity softball tournament was sanctioned by the ASA and raised both funds and awareness of mitochondrial disorders.

Sacred Heart Academy students discuss their poster presentation with the scientific community

Baylee Thompson
For more information about a chapter, group or ambassador near you, contact the UMDF office at 888-317-UMDF!
Ken Graham was living a fairly ‘normal’ life. He and his wife had settled down in Ontario, Canada with their only son, and he was working for a major multi-national aircraft engine manufacturer. Although he had some health issues, including diabetes, ulcerative colitis, bilateral ptosis, astigmatism, strabismus and Dupuytrens Disease, none of these affected his every day life, and he had them under control.

Things started to change in December of 1995. Ken came down with a flu bug that seemed to last forever. The most serious issues that came from the sudden decline in his health were constant general malaise, generalized muscle weakness, chronic fatigue, diarrhea, multiple cognitive problems, muscle and joint pain, and problems adjusting to temperature change - and the list grew daily. By February of 1996, Ken went from working 12 hour days and being able to take two stairs at a time, to being on full disability from work and barely able to climb the stairs at all.

Ken recalls the doctors thinking that he was a hypochondriac. “To be completely honest, it was not uncommon for me to think that of myself,” Ken said. Under his own will, Ken went to a psychiatrist, which was of no help. He was not a hypochondriac, but what was wrong?

Discussions with his PCP, gastroenterologist and diabetes specialist only lead to the gastroenterologist putting the blame on his diabetes, and the diabetes specialist stated the problems were due to his bowel disease. Since the symptoms were many and diverse, Ken’s PCP diagnosed him with Chronic Fatigue Syndrome.

It was not until March of 2002 that Ken would finally receive an accurate diagnosis for what had been ailing him for six years. The diagnosis came almost by accident and was the result of a multi referral search for a cause of his bilateral ptosis. He was referred to a neurologist who suggested that he have a muscle biopsy done. Ken’s response was “This seems to be much ado about some droopy eyelids.” He decided to go through with the procedure. Years of doubts and questions came to an end. ‘It’ had a name. He was diagnosed with non-genetic Mitochondrial Cytopathy with CPEO.

In addition to his diagnosis, the only other information he received was that “it would only affect your eyes and possibly your heart; you should have an EKG done annually.” No follow-up plan, no treatments, no suggestions, Ken was on his own. As soon as he got home, he did an internet search on “Mitochondrial Cytopathy” and the UMDF’s website appeared at the top of the list. Ken spent the next four hours reading everything he could on the subject. What he did not learn from the UMDF website directly, he did from the links he found on the site. “I have a very high degree of appreciation for the UMDF website,” Ken said. “I feel that it is an extremely valuable resource to every mito patient.”

Ken thinks so much of the UMDF website that just hours before his heart bypass surgery, he provided the link to his anesthesiologist so that he could gather information on mitochondrial disease and the complications that could arise. The doctor spent the next half hour on the UMDF website looking at the information that would be important to him.

Ken credits his wife, Helen, for helping him get through all of his frustrations and down days. “She believed I was sick from the very beginning, and stuck with me 24/7, 365 days a year. I honestly don’t know what I would have done without her.” Ken also has the support of a loving son, Matthew and his wife Heather, who acts as a fill-in chauffeur for his doctor appointments.

Ken is currently serving as a Mito Ambassador with the UMDF for the Toronto, Canada area. Ken was looking to volunteer for something and wanted to keep in touch with the reality of his health situation without it being all self-centered. He was also looking for something that wouldn’t zap all of his energy. “What better organization could I get involved with?” he said. “The UMDF is aware of the limits that mito imposes.”

“I simply want to give back,” he said. “Knowing that others were out there who could use some kind of help, people who felt alone and lost in the maze of a relatively unknown, under-diagnosed and often misdiagnosed illness. Any information and resources I can either provide or point them to is obviously a bonus, and the UMDF is able to help me provide the necessary information and resources.”
Despite what the Gregorian calendar says, the UMDF celebrated a ‘New Year’ on July 1, 2008. It was the start of our new fiscal year. At our symposium in Indianapolis, I realized the great strides the UMDF has made over the past year and continues to make in education and awareness.

A year ago, I don’t think any of us could have imagined that current and former members of our Scientific and Medical Advisory Board along with our CEO and Executive Director, Chuck Mohan, would be called to represent the UMDF and participate in a discussion on the potential relationship between mitochondrial diseases and autism spectrum disorders. That is what happened the day after our symposium in Indianapolis concluded. The National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Mental Health (NIMH), the Centers for Disease Control and Prevention (CDC), the Food and Drug Administration (FDA), and the Department of Health and Human Services (DHHS), scheduled a workshop to discuss how the neurology of mitochondrial disorders might affect autism research. The time and place of the meeting were no coincidence. Without the UMDF bringing together the top mitochondrial disease medical experts under one roof for our annual symposium, the follow-up meeting with the governmental agencies would not have occurred.

I want to especially thank all of the participants who went out of their way to make this event happen. I was very proud to see Dr. Bruce Cohen of the Cleveland Clinic and Dr. Doug Wallace from the University of California, Irvine, interviewed by ABC’s Good Morning America about the workshop and mitochondrial disease.

Other examples of the public’s recognition of the mitochondria seem to come every day. In research for Alzheimer’s and Huntington’s diseases, an old Russian drug, Dimebon, is getting new coverage for its effect on the mitochondria. This research states, “the most potent activity identified for Dimebon is enhancement of mitochondrial function in the presence of cellular stress. Much literature has implicated mitochondrial dysfunction in aging and neurodegenerative diseases like Alzheimer’s disease.” The UMDF-funded research project, “Pathogenic Mitochondrial DNA Mutations Are Common in the General Population” proves that mitochondrial mutations occur in at least 1 in 200 individuals. This project implies that mitochondrial dysfunctions are not rare and are, in fact, quite common. As these facts are more widely understood, pharmaceutical companies should begin to invest more money, which will bring more treatments and more cures.

I am tremendously proud of the positive feedback we’ve been getting on “Indy 2008- Setting the Pace in Mitochondrial Medicine.” More than 500 families and members of the medical community attended the sessions. The symposium sets the UMDF apart because we work very hard to provide educational opportunities for members of the medical community and for patients and families. With Indy now behind us, we must go forward to 2009. Our next symposium will be held in the Washington, DC area June 24-27, 2009. Along with exciting scientific and family sessions, our 2009 symposium will have a unique component. We will schedule for our members to meet with their congressional and senatorial representatives in an effort to call for increased federal spending for primary mitochondrial disease research. The UMDF may have awarded $6 million in research grants over the past decade, but government-funded research can take us further down the road in our mission to find a cure. The UMDF has created an advocacy toolkit that will help you add your voice to the effort. This toolkit, which you can find on the UMDF website under ‘Advocacy,’ has been designed to help you start the dialogue with your elected officials today. Even if you can’t be in D.C. next summer, there are things you can do now that will have a tremendous impact.

With your help and support, we’ve come a long way in one short year. I can’t wait to see what the next 12 months bring.

Energy to all,

W. Dan Wright, UMDF Chairman

Volunteer Spotlight

A volunteer is one who enters into any service of his own free will. When 13 year old Nathan Weinrauch of New Jersey was looking for a good deed to do for his bar mitzvah project, he decided he would do just that - he would volunteer. Just volunteering was not enough for Nathan; he wanted the experience to be meaningful to someone and to change someone’s life for the better. That is when he decided to volunteer to be a big brother, not just any big brother, but a big brother to a young boy who suffers from Leigh’s Disease. This opportunity enabled Nathan to do his mitzvah project and focus on mitochondrial disease.

Mitochondrial disease is very near to Nathan’s heart, as his six year old cousin, Brandon Leach of Maryland, is also suffering from a mitochondrial disease. “The disease affects Brandon’s life by limiting his daily activities,” Nathan said in his Bar Mitzvah speech. “He becomes tired very easily and has difficulty fighting infections.” With Brandon in Maryland and Nathan in New Jersey, they have limited opportunities to spend time together. Since distance kept Nathan from being a big brother to his cousin, he decided to get in contact with a family who lives nearby and has a child with a mitochondrial disease. He made the commitment to be a big brother to the family’s son.

Nathan began visiting the young boy several times and would keep him company by reading to him. “I hope to make a difference in his life by making him smile.” Nathan says. Although Nathan has since finished his mitzvah project, he has plans to continue the visits with the young boy. “I look forward to spending more time with him.”

Thank you, Nathan, for making a difference!
SUPPORTING OUR CAUSE

UMDF ADOPTS SEASONAL FUNDRAISING APPEALS STRATEGY

Starting this fiscal year, the United Mitochondrial Disease Foundation's national office will conduct four seasonal appeals – fall, winter, spring and summer. Each appeal will be targeted to specific donors, thanking them for their past support and encouraging them to donate again. In the past, fundraising appeals sent by the National Office may have occurred around the same time as a promotion for a special chapter event. In some instances, prospective donors were even confused as to whether the appeal was part of the upcoming chapter event or something entirely separate.

The UMDF is working with chapter representatives to supplement, not supplant, local events. To avoid donor confusion, the National Office will coordinate with chapters to ensure the success of local events that may overlap with a seasonal appeal. We will include language in each of our appeal letters that directs the prospective donor to the Calendar of Events on our website. The UMDF will encourage prospective donors who receive the appeal to support their local chapter events while also considering making an additional gift through the national appeal.

The next scheduled national appeal will occur in September to promote Mitochondrial Disease Awareness Week activities throughout the country. In November, the UMDF’s annual Holiday appeal will be mailed. Donors will be given the opportunity to purchase UMDF holiday cards specially designed by a young contest winner. The entire UMDF family of members, friends, and past donors will receive this mailing.

In March 2009, the spring appeal will target donors who have not made a gift in several years. The mailing will feature both an affected child and an adult, describing how a gift to UMDF can help support those affected by mitochondrial disease. The June 2009 summer appeal will target our consistent annual donors and promote our partnership with Plates for a Purpose. Donors at certain levels through this appeal will be eligible to receive the specially designed plate.

The UMDF will be working with its chapters, mito groups and ambassadors throughout the year to coordinate our appeals with local fundraising events. We encourage our members and friends to support their local programs.

National appeals do not replace the need to support the many walk/runs and other special events hosted by our chapters and ambassadors.

The UMDF’s national appeals are meant to remind all about the need to support mitochondrial research and education efforts as we move toward a cure.

DON’T FORGET THE MATCHING GIFT

Do you or your spouse work for a company that offers a matching gifts program?

If you do, you can double or even triple the value of your next gift to the United Mitochondrial Disease Foundation. All it takes is a quick call to your company’s Personnel or Human Resources Department.

Many corporations match the gifts their employees give to non-profit and charitable organizations. These matching programs help to extend the reach and impact of corporate giving and to encourage employees to be actively involved in supporting their communities and their favorite charitable organizations.

Through a matching gifts program, companies will provide a dollar-for-dollar match of gifts made to the United Mitochondrial Disease Foundation by their employees. Some even offer a 3:1 match, tripling the value of an individual’s gift. Companies may also match the gifts of retirees or spouses of employees.

Check with your Personnel or Human Resources Department to obtain a matching gift form that you fill out and send along with your gift to the UMDF. We verify the receipt of your gift and return the form to your company. They, in turn, send UMDF a check that matches your donation. To reduce paperwork, many companies have turned to an electronic system for matching employees’ gifts, making the process even easier.

Your company’s Human Resources Department can help answer any of your questions regarding their policy on matching gifts. Please take that extra step when you make your next gift to the UMDF.

CONTACT THE DEVELOPMENT TEAM

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Hannah Pallas, 4 year old with Mitochondrial Proliferation
ATLANTA CHAPTER
• September 27, 2008. The second annual Music for Megan Charity Benefit Concert will be held at Wills Equestrian Park in Alpharetta, GA. More than 1,000 people attended the inaugural event last year and raised more than $58,000 in honor of Megan Sheridan. Visit www.meganshope.org for more information.

• October 6, 2008. The fifth annual Fore-A-Cure Golf Tournament hosted by the Atlanta Chapter will be held at the Standard Club in Duluth, GA. For more information contact, Chris Swinn at atlchapter@umdf.org or visit www.foreacuremito.org.

CENTRAL OHIO CHAPTER
• October 5, 2008. The eighth annual Olivia Steele Memorial Golf Outing will be held at Kyber Run Golf Course in Johnstown, OH. The outing is brought to you by Performance Site Co., Shelly Material and the Steele Family. For more information, contact JR Steele at 614-206-6237 or email jr.steele@performancesitecompany.com.

DELAWARE VALLEY CHAPTER
• September 27, 2008. Jamming with Jamie and Friends, a dinner and auction fundraiser, will be held at the Ramblewood Country Club in Mount Laurel, NJ from 7-10pm. The event is held in honor of Jamieson Smith, youth ambassador for the UMDF and a board member of the Delaware Valley Chapter.
• October 4, 2008. An outdoor Family Fun Fest event will be held at the Cannstatter Volksfest in Philadelphia, PA. For more information, contact Tinna Donnelly at 267-240-2393 or email tinna211@comcast.net.

HOUSTON CHAPTER
• October 14, 2008. The first annual Golf Tournament will be held at the Forest Hills Course at the Clubs of Kingwood. For more information, contact houstonchapter@umdf.org.

INDIANA CHAPTER
• October 4, 2008. The first annual Walk and Family Fun day will be held at Forest Park in Noblesville, IN. Family Fun activities include a clown, balloon artist and bounce houses. For more information, visit www.umdf.org/indianawalk.

MINNEAPOLIS/ST. PAUL CHAPTER
• September 20, 2008. The third annual MITO 5K Walk/Run will be held at Thomas Lake Park in Eagan, MN. For more information and to register online, visit www.umdf.org/minnesotarace.

NEW ENGLAND CHAPTER
• September 27, 2008. The annual Mito Walk and Family Fun day will be held at the LEGO Campus in Enfield, CT. Family activities begin at 9am and the 5K walk begins at 11am. For more information, visit www.umdf.org/legowalk.
• Fall, 2008. New England artist Marjorie Olson will be selling her watercolor artwork, with 100% of the proceeds benefitting the UMDF in honor of her niece Rachel Varriano. Marjorie will be in Vermont in October and in Massachusetts in November and December. For more information, visit the UMDF Calendar of Events at www.umdf.org and click on “Art for Rachel” or email molson4000@comcast.net.

IDAHO MITO GROUP
• September 20, 2008. An Energy Bowl-a-Thon will be held at the Meridian Bowling Lanes in Meridian, ID. The fee is $25 per bowler or $100 for a family of four or more. For more information, contact Jennifer Pfefferle at 208-863-9403 or email mitogroupofidaho@yahoo.com

AROUND THE COUNTRY
• September 26, 2008. The third annual Elena’s Hope Charity Dinner will be held at Liberty Hall in Kimbery, WI. Proceeds will benefit the UMDF through Elena’s Hope Research Fund in honor of Elena Welhouse. For more information, contact Mindy Welhouse at mwelhouse@new.rr.com.
• October 11, 2008. The second annual Kure for Kat will be held at South Lakes Park in Denton, TX. Kure for Kat is held in honor of Katherine Dickerson, and proceeds benefit the UMDF through the Katherine Dickens Research Fund. Register or donate online at www.umdf.org/kureforkat.
• October 16, 2008. The annual Chris Schindler Memorial Celebration will be held at The Brisco Manor in Richmond, TX. The evening will include live & silent auctions, a delicious dinner and much more. Go to www.chrisschindlermemorial.com for more information!
FUNDRAISING HIGHLIGHTS

GIFTS FROM THE HEART

- Thirteen year old Ashlyn Snyder of Allentown, PA held an auction at her family’s yard sale. Ashlyn sold energy bands and green ribbon lollipops, as well as handed out brochures to spread awareness. She was able to raise $208 for the UMDF! Thank you Ashlyn for your hard work!

- Collin Bruce turned two years old this year, and in lieu of gifts, the family asked that donations be made to the UMDF in memory of Collin’s cousin Riley Patterson. Happy Birthday, Collin! At the party, his sister Rachel held a lemonade stand and donated the proceeds to the UMDF. A total of $85 was donated to the UMDF from the birthday party and the lemonade stand! Thank you for your support!

- Jane Wessel and Tony Lang of West Lake, OH were married on June 28, 2008. In lieu of wedding gifts, they asked that donations be made in memory of Alexandra Elios.

- Chuck and Adrienne Mohan of Monroeville, PA held their annual Mohan’s 4th of July party in memory of their daughter Gina. The 4th of July was Gina’s favorite holiday! Thank you to the Mohan Family and Friends for your continued support!

- Interstate Companies in Iowa donated $449 to the UMDF in honor of Autumn Hoekstra. The organization held a Jeans for Dollars day in June.

- Six year old Jack Blaine of Ohio held a Coins for a Cure campaign in honor of his good friend Ellie Kovalcik. Jack was able to raise $51.64 for the UMDF in honor of Ellie. Great job, Jack!

- Sholar and Maddie Petit of Ohio sold “Ellie Bellie Jewelry” in honor of their cousin Ellie Kovalcik. The girls homemade jewelry raised $60 for the UMDF! Thank you girls for your creativity!

- Olivia and Lauren Petit of Ohio held a lemonade stand and raised $16.65 for the UMDF in honor of their cousin Ellie Kovalcik. Way to go, girls!

- Congratulations to David Havrilak and Michelle Yenchik on their July 12, 2008 wedding. A donation of $500 was made to the UMDF in memory of Kevin Blosky. The donation was made in honor of all the wedding guests.

- St. Austin Catholic School in Austin, TX held a non-uniform day and donated $413.30 to the UMDF. Thank you for your support!

- The National Honor Society at Fayetteville High School in Ohio held a fundraiser in honor of Jenny Schnitzler. The event raised over $350 for the UMDF! Thank you to the students of Fayetteville High School!

- Emma Stewart at her Birthday Party

- Emma Stewart of Greensburg, PA celebrated her second birthday on July 19, 2008. In lieu of gifts, family and friends donated $350 to the UMDF in Emma’s honor. Happy Birthday to you, Emma!

- A bake sale was held at Maurice Hawk School in honor of Sara Ward. A donation of $800 was made to the UMDF!

- A donation was made in the amount of $100 from the JM Family “Dollars for Doers” program. Tara Desmet of Florida is an employee at JM Family and did volunteer work. The donation was made on her behalf for her volunteer time.

- A bake sale was held at the 2008 Fine Arts Night at East View Elementary School in Chicago, IL. The event raised $1,337 for the UMDF.

- The Lark & Loon, LLC in Georgia held a fundraising event in honor of Ellie Green. The event raised $480 for the UMDF.

ONGOING FUNDRAISERS

COINS FOR A CURE℠

The following families participated in the Coins for a Cure℠ campaign and sent in funds raised in the months of May, June and July:

- Jack Blaine 
in honor of Ellie Kovalcik
- The Gerke Family 
in honor of Ruth Gerke
- The Mantooth Family 
in honor of Jacob Mantooth

TEA FOR MITO℠

The following families participated in Tea for Mito℠ and sent in funds raised in the months of May, June and July:

- The Trottier Family 
in honor of Ian Trottier
- The Wasielewski Family 
in honor of Lora Wasielewski

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

For information about how you can become involved, contact the special events department at 888-317-UMDF or events@umdf.org.
**FRIDAY NIGHT BANQUET AND AWARD PRESENTATIONS**

Scientific and family attendees came together on Friday night to celebrate all of the UMDF’s accomplishments and the volunteers who helped make them possible. The evening started with a presentation from keynote speaker Stephen G. Marriott, EVP of Culture with Marriott International. Awards were presented to the 2008 Research Grant Recipients as well as the LEAP and Heartstrings Award winners. The Heartstrings winner, Emily Swinn presented the first Stanley A. Davis Leadership Award to her father Chris Swinn of Atlanta. The evening was wrapped up with a special presentation by comic-magician Sam Simon in “Sleep! The Power of Suggestion…The Magic of the Mind!”

**LEAP AWARD**

*Living, Encouraging, Achieving & Persisting*

The LEAP Award was designed to recognize an individual, 14 years or older, living positively with mitochondrial disease, highlighting the person’s accomplishments and volunteer service. The individual should demonstrate a positive attitude, hope for a brighter future, and an enthusiasm that inspires others.

This year we are recognizing Therese Garvin, Delaware Valley Chapter President and mother of three. Therese was diagnosed with mitochondrial disease in 2001 after five years of symptoms that included seizures, fainting spells, digestive problems, night sweats, stroke-like episodes, fatigue and weakness that necessitated the use of a walker and wheelchair. Although Therese continues to struggle with many of these issues since her diagnosis and treatment, she is now able to walk without assistance.

Volunteering seems to have been a way of life for Therese. She has worked with local theater groups and other civic organizations for many years. Fortunately for the UMDF, two years ago Therese decided to focus her efforts on behalf of the UMDF. As chapter president, Therese’s positive attitude and uplifting spirit have helped the Delaware Valley Chapter achieve a new level of member participation. Working with a strong chapter board, Therese’s leadership has resulted in regular opportunities for support, new fundraising events, increased sharing of information and a bright outlook for the future.

Sarah Slack, a member of the Delaware Valley Chapter Board recently said “Therese is a great candidate for this award; she is living proof that we can do anything we put our minds to.” We couldn’t agree more!

**HEARTSTRINGS AWARD**

*Recognizing a youth commitment that tugs on the heartstrings.*

The Heartstrings Award was created to recognize the efforts of an individual under the age of 18 who has donated or raised funds for the UMDF, enabling the UMDF to continue its mission. The winner is chosen based on the criteria of age, time invested, talents demonstrated, effectiveness and generosity.

This year’s honoree, Emily Swinn, was diagnosed with mitochondrial disease when she was five years old. She celebrated her 12th birthday this year. Working with the Atlanta Chapter, Emily’s contributions to the mission of the United Mitochondrial Disease Foundation, despite her limitations, have been both heartwarming and remarkable. She has participated in, attended, volunteered, or acted as a spokesperson for numerous fundraising events including Fore-a-Cure Golf Tournament, Row for Mito, Ty’s Trot, Race for Riley, Music for Megan and Mito Madness. She helps her family keep the Atlanta Chapter moving, assisting with mailings and meeting set-up.

Perhaps Emily’s own words sum it up best. Several years ago Emily asked her mother, Mary Swinn, “Mom, have you found it yet?” When Mary asked her what she meant, Emily responded “You know, a cure for my disease. Isn’t that what you are doing with the UMDF?” With the help of inspirational individuals like Emily, we know that we will.

**STANLEY A. DAVIS LEADERSHIP AWARD**

The Stanley A. Davis Leadership Award is the most prestigious UMDF National Award honoring a UMDF Chapter President that best represents the selfless dedication and commitment to the UMDF Mission as that of its namesake.

The first recipient of the Stanley A. Davis Leadership Award is Chris Swinn, President of the Atlanta Chapter. Chris and his wife, Mary, joined the UMDF in 2002 after their daughter, Emily, was diagnosed with a mitochondrial disease. Under his leadership, the Atlanta Chapter has grown from a few families to over 80 in the Chapter’s membership directory and many more who have some involvement in education, awareness or fundraising. Chris and the Atlanta Chapter Board strive to bring mitochondrial disease to the forefront of the general and medical community in the Metropolitan Atlanta area. Chris has chaired the annual Fore-a-Cure Golf tournament for five years. Chris has recently accepted the role of Chapter Liaison with the UMDF and is honored to work with the leaders of all UMDF chapters to assist each to further the mission of the UMDF.
Andy is now in his twenty's. Andy summed it all up in one sentence, it was simple to him. I walked over to Andy's wheelchair, at first I did not understand that he had already typed out what he had wanted to say through his voice computer. He had done this as he sat patiently for two hours listening to all of us talking. I put the microphone in front of his face and he pushed it down towards his voice computer, then his computer told us what was on his mind. His one piece of advice, “live life to the fullest because you never know what could happen next.” The room went quiet then we all started clapping for Andy, clapping for each other, clapping for the courage that we face each day. In spite of our own suffering, the power of the group is that it helps to get us outside ourselves to connect with another.

There is something to be said about the power of a group. Over 40 adults came together during our second annual Adult Gathering at the UMDF annual Symposium in Indianapolis on June 27, 2008. Mitochondrial disease may rob us of our power (energy), but on that day, for those two and half hours I believe there was a feeling of empowerment. I don’t often get the chance, other than at our symposium, to mingle with so many other mitochondrial patients. Adults representing the many faces of mitochondrial disease shared their experience, strength and hope with each other during an open mike format.

Although no two mitochondrial patients are exactly alike, most everyone expressed experience in dealing with a long list of varied symptoms, a lack of energy and a struggle getting a proper diagnosis. It seemed we had all become best friends with persistence and patience, a true testimony to the human spirit. A wide range of profiles were present, confirming the importance and crucial effects the mitochondria play in the body. What amazed me the most was the tone in the room; yes, there were tears but mostly solutions offered. One lady talked about how, despite her muscle weakness, she stuck to a daily physical workout. Many expressed the importance of support from family and friends, and others shared about how to deal with day-to-day routines and doctors. There is a healing that takes place on an unconscious level when one mitochondrial patient listens to another, as if to say “I have been there, I have been through that too, I understand.”

The last two adults that shared were truly inspirational, leaving a memory in my heart and mind. Amanda had made it to our symposium despite the fact she was facing her 35th surgery, most had involved her heart. She said all she had wanted was to be here with other mitochondrial patients, and how this had meant the world to her. Then there was Andy who was diagnosed with Leigh’s Disease at age four.

There is a saying that is dear to me, “I complained because I had no shoes until I met a man that had no feet.” The Adult Advisory Council is here to serve you; look for new updates on the UMDF website.

Yours in Service and Towards a Cure,
Sharon Shaw
Chairman of the Adult Advisory Council Team (A.A.C.T.)
Vice Chairman of the UMDF Board of Trustees

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

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
Pam Johnson, MD, Kansas City
Cynthia Rosen, New Mexico
Gregory Yellen, Maryland

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

AACT MISSION
To ensure equal representation and service of the affected adult community to the affected pediatric community -- and to better represent, serve and assist adults with mitochondrial disease.
CAPITOL HILL VISITS - JUNE 25, 2009

As the staff at the UMDF continues to lay the groundwork for our symposium in Washington D.C. on June 24-27, 2009, we are hoping that you are making plans to join us for this very important session. As you know, we have scheduled a day on Capitol Hill for Thursday, June 25, 2009, and we would like to have as many people as possible attend. There is much that needs to be done before we can schedule a Capitol Hill visit with your congressional representative or senator, and the UMDF has put together an Advocacy Toolkit to help you with this process. The toolkit is a free, valuable resource that helps you become an advocate for additional federal funding for mitochondrial disease research. Inside the toolkit, you will find tips on writing letters to your congressional representative or senator, sample letters, and talking points that the UMDF would like you to use in this effort. Making this initial contact on the local level with your elected federal officials must be the first step in your advocacy mission. After writing a letter, your next step would be to try to set up a meeting with the staff of your federal officials. The ultimate goal is to schedule a meeting between you and your elected official on Thursday, June 25, 2009 in Washington, D.C. Even if you cannot make it to the nation’s capitol, you can still advocate by following the toolkit and engaging your representatives on the local level. The toolkit has directions and examples for writing letters and editorials to your local media. We encourage your participation in this very important effort and we hope that you start making plans now for our visit to Washington, D.C. in June. If you would like an advocacy toolkit, please email info@umdf.org to request one today!

MEMBER RESOURCES

DISABILITY & INSURANCE RESOURCES

The United Mitochondrial Disease Foundation occasionally receives calls regarding the struggle that our members often have with their insurance companies. We have compiled a list of some helpful online resources to help you in this struggle.

FATTY OXIDATION DISORDERS (FOD)

Fatty Oxidation Disorders Family Support Group has a page on their web site devoted to insurance rights and information. On this page, you will find links to other various organizations related to insurance, disability, and advocacy issues. Visit www.fodsupport.org/insurance.htm to view this information.

CARING VOICE COALITION

Caring Voice Coalition is dedicated to helping those who suffer from serious, chronic illnesses. The CVC offers the following programs:
- Financial assistance program, providing financial support to help patients keep and use health insurance coverage.
- Insurance education and counseling, helping patients get the most from their healthcare coverage.
- Patient support program, linking patients and caregivers to needed services and resources.
To learn more about CVC, visit their web site at www.caringvoice.org or contact them at 1-888-267-1440.

FAMILIES USA

Families USA is a national nonprofit, non-partisan organization dedicated to the achievement of high-quality, affordable health care for all Americans. On this web site you can find information about Medicare, Medicaid, Children’s Health, Prescription Drugs, Uninsured, Private Insurance, Minority Health and Global Health. To see what Families USA has to offer, visit their web site at www.familiesusa.org or contact them at 202-628-3030.

REFLEX SYMPATHETIC DYSTROPHY SYNDROME ASSOCIATION

The RSDSA’s web site has a page devoted to writing appeals to your insurance company when you are denied coverage. The page details the steps you will need to take to make the appeal successful. The page can be viewed at www.rsds.org/4/resources/when_a_carrier_says_no.htm.

FIRST HAND FOUNDATION

First Hand Foundation is a nonprofit organization that helps children with health-related needs when insurance and other financial resources have been exhausted. To see if you qualify, visit www.cerner.com/firsthand or contact them at 816-201-1569.

UNIVERSITY HEALTHCARE CHILDREN’S FOUNDATION, INC.

Children who have medical needs are sometimes not insured comprehensively to provide coverage for all of their medical treatments. There are few places for families who have gaps in their commercial health benefit plan coverage to turn to for funding medically necessary services for their children. Children may go without necessary treatment, or they receive the care but the families assume a large amount of debt. The University Healthcare Children’s Foundation understands these needs and is willing to help fill this void.
To learn more about what the University Healthcare Children’s Foundation can do for you, visit www.uhccf.org or contact them at 1-800-328-5979.
MITOCHONDRIAL DISEASE AWARENESS WEEK - SEPTEMBER 21-27

The United Mitochondrial Disease Foundation’s Chapters, Mito Groups, Ambassadors and Members will be holding fundraising and awareness 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.

ALABAMA

- **Dauphin Island.** Information will be distributed at the Ladies Club Meeting.
- **Hazel Green.** Peggy Rhoden will sell Energy for Life Bands and t-shirts.

ARIZONA

- **Prescott Valley.** Information will be distributed at local grocery stores and at a local zoo along with “Coins for a Cure” collections

CALIFORNIA

- **Clovis.** Brittany Wilkinson will hold UMDF Rallies at local schools.
- **Fresno.** The third annual Steps to a Cure Walk will be held at Woodward Park on September 14, 2008. For more information, contact Linda Wilkinson at 559-299-1767 or dotoheven@aol.com.
- **Los Angeles.** Information will be distributed at Children’s Hospital of Los Angeles.
- **Tracy.** Information will be distributed at local physicians’ offices, schools and churches.

CONNECTICUT

- **Enfield.** The New England Chapter will hold its annual Mito Walk and Family Fun day at the LEGO Campus on September 27, 2008. For more information, visit www.umdf.org/legowalk.

GEORGIA

- **Acworth.** Information will be distributed at a men’s outing at Stacy Cochran’s church.
- **Alpharetta.** The Atlanta Chapter will hold the second annual Music for Megan Charity Benefit Concert at Wills Equestrian Park on September 27, 2008. Visit www.meganshope.org for more information.
- **Kathleen.** Information will be distributed at various physicians’ offices and to the medical community.

IDAHO

- **Meridian.** The Idaho Mito Group will hold an Energy Bowl-a-Thon at the Meridian Bowling Lanes on September 20, 2008. For more information, contact Jennifer Pfefferle at 208-863-9403 or mitogroupofidaho@yahoo.com

ILLINOIS

- **New Baden.** Information will be distributed at local physicians’ offices and businesses.

INDIANA

- **Bainbridge.** The Indiana Chapter will hold a Family & Friends Day at Hope’s Way on September 27, 2008. For more information, contact Jackie at 317-839-7800.

IOWA

- **Altoona.** Savannah's Hope will hold a Mito Walk at the Altoona Campus on September 20, 2008. For more information, visit www.savannahshope.weebly.com.
- **Rock Valley.** The second annual “Plants for a Purpose” will be held on September 24, 2008.

LOUISIANA

- **Sulphur.** The Greater Jackson Mississippi Mito Group will hold Jude’s Fais Do Do for Mito at the Jubilee Center on September 20, 2008. For more information, visit www.judesmitojourney.com.

MINNESOTA

- **Eagan.** COPT will hold a Denim Day on September 26, 2008.
- **Eagan.** The Minneapolis/St. Paul Chapter will hold the third annual MITO 5K Walk/Run at Thomas Lake Park on September 20, 2008. For more information, visit www.umdf.org/minnesotarace.

NEW JERSEY

- **Hamilton.** Information will be distributed at a local Chick-fil-a store and at a local hospital information desk.
- **Mount Laurel.** The Delaware Valley Chapter will hold Jamming with Jamie and Friends at the Ramblewood Country Club on September 27, 2008.
- **Randolph.** A Blood Drive will be held on September 21, 2008 at Bethlehem Church in memory of Connor Millard.

NEW YORK

- **Latham.** Information will be distributed at an event held for Amanda Perrotta on September 20, 2008.

OHIO

- **Columbus.** The Central Ohio Chapter will hold the third annual Kovalcik & Geraghty Wealth Partners Charity Golf Outing at Worthington Country Club on September 22, 2008. For more information, visit www.umdf.org/KGWP.

TENNESSEE

- **Nashville.** Presentations will be made at Children’s Hospital Vanderbilt.

WEST VIRGINIA

- **Huntington.** Information will be distributed in the lobby area of Marshall University Medical Center.

WISCONSIN

- **Kimberly.** The third annual Elena’s Hope Charity Dinner will be held at Liberty Hall on September 26, 2008. For more information, contact Mindy Welhouse at mwelhouse@new rr.com
**UMDF MERCHANDISE**

UMDF merchandise is a great way to raise awareness and to support the UMDF and all those affected with mitochondrial diseases. The UMDF’s new logoshop opened up over the summer! Check out all the new merchandise and old favorites available at http://umdf.promoshop.com.

**THE LIFE YOU LONGED FOR**

Author Maribeth Fischer, the executive director of Writers at the Beach, a biannual writers’ conference that benefits the United Mitochondrial Disease Foundation, and the president of the Rehoboth Beach Writers’ Guild, has agreed to offer her latest book, “The Life You Longed For,” in an autographed edition through the UMDF web site.

Fischer’s book was warmly received at the UMDF’s Indianapolis Symposium and quickly sold out. In the book, Fischer tells the touching story of Grace – a woman who, after her son is diagnosed with a mitochondrial disease, must beat all odds to protect her son’s life, her marriage, and her own reputation. Much of her son’s progress is attributed to his mother’s self-sacrificing and dedicated care. But Grace’s world is shattered when she is accused of Munchausen Syndrome by Proxy, a strange psychological disorder where a mother makes her otherwise healthy child sick or purposely fakes her child’s illness in order to gain attention and approval for herself. As Grace battles the suspicions of those around her, she must also deal with the other private secrets in her life—secrets that threaten to destroy her marriage and upend her world.

Fischer lives in Rehoboth Beach, Delaware. Check the UMDF web site for this opportunity to purchase an autographed copy of “The Life You Longed For.”

**HOLIDAY CARD ART CONTEST**

The UMDF will hold the third annual Holiday Card Art Contest this winter. The winning artwork will be featured on the 2009 holiday card appeal and the artist will receive a special gift. The UMDF will also have blank holiday cards available for purchase.

Participants can be up to 18 years old and do not have to be diagnosed with a mitochondrial disease to enter, but they are required to write a short explanation about what their drawing means to them and how they are affected by mitochondrial disease. Participants may enter more than once. The theme of the drawing(s) should be holiday or winter spirit, rather than reflect a specific holiday. Submission deadline is January 30, 2009.

Contest rules and entry form will be available on the UMDF website in October. If you need a copy of the contest rules and entry form to be mailed to you, contact the UMDF National Office at 888-317-UMDF.

**SUBMISSION DEADLINE FOR ISSUE 4 IS OCTOBER 31, 2008!**