

PHASE 3 TRIAL OF COENZYME Q10 IN MITOCHONDRIAL DISEASES



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What is a “Clinical Trial”? A clinical trial is an experiment in which the test subjects are human beings, not rats or cells in tissue culture. A clinical trial tests hypotheses, or the beliefs of scientists and clinicians that the particular treatment under investigation will be well tolerated and will benefit patients who are affected by a certain disease. For a clinical trial to even begin, much less succeed, there must be a strong bond of mutual trust between the physicians and other clinical researchers and the patients who voluntarily choose to participate in the trial. Such a decision by a subject, or by the parent or guardian of a child too young or ill to give their own consent, must be based on a frank and thorough discussion of the expected risks and benefits associated with participation in the trial, whether

out-of-pocket expenses, hospitalizations, special diets or procedures will be incurred and what safeguards are in place to ensure the maximum possible protection of subjects against harm during the course of the study.

How might CoQ10 help patients with genetic mitochondrial diseases? Mitochondria represent the “powerhouses” responsible for converting the foods we eat into the energy that allows all cells and tissues to function normally. Cells suffer and die if their mitochondria cannot meet their energy demands, which can be due to one or more genetic defects in the enzymes involved in energy metabolism.

There are several potential benefits for such patients in taking CoQ10. First, CoQ10 is a normal part of the mitochondrial respiratory (electron transport) chain (RC) that is required for conversion of food into energy. Therefore, people born with genetic defects in the RC might benefit by increasing the amount of CoQ10 available for normal RC function. Second, some children are born with a primary deficiency in the ability to synthesize their own CoQ10. In such cases, giving CoQ10 replaces a vital substance that the patient’s body cannot make on its own. Third, CoQ10 is a good “antioxidant”, meaning it has the ability to detoxify harmful “free radicals” that may accumulate when the RC is malfunctioning.

For those individuals already taking some form of CoQ10 because they have a proven or suspected mitochondrial disease, the need to conduct a trial might seem unnecessary. However, here is an unsettling fact: there has never been a scientifically or ethically rigorous test of the safety or efficacy of any dose or formulation of CoQ10 in patients with genetic mitochondrial diseases. Consequently, no one knows 1) which mitochondrial diseases are benefited and which are not by supplemental CoQ10; 2) to what extent CoQ10 helps those it might benefit; 3) how much CoQ10 should be taken; and, most importantly, 4) whether CoQ10 is safe, especially at higher doses?

(Continued on page 7)

CONTENTS

Ask The Mito DocSM
3

Chapter Activities
4-9

A Day in the Life of Perri Miologos
11

News from Atlanta, GA
14

Advocacy
16

Announcements
18



Photos from the DelVal Chapter Energy for Life: Walkathon - Employees from Endo Pharmaceuticals, Flagship Sponsor of the walkathon and Lucy Marlett putting on her shades at the walkathon. (Photos by Thomas Pohlig of Thomas Studios.) For more details on Energy for Life Walkathons, see pages 8 and 9!



**Volume 15
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FROM THE CHAIRMAN

As I write this column, 2010 is rapidly drawing to a close. For those of us caught up in the daily battle towards a treatment and a cure for mitochondrial disease, this is always a good time to reflect on the past year and look at some of the tremendous progress that has been made.



By participating in the NAMDC Clinical Patient Registry, patients will provide researchers with a large database of information that will be used for research at clinics around the nation and the world. Shortly after the new year, NAMDC hopes to sign up patients so continue to watch the UMDF website and newsletters for information.

In February, we welcomed the news that the Mayo Clinic in Rochester, MN, established the first mitochondrial disease biobank in the United States. This news was significant because having this facility will make it much easier to conduct research studies about mitochondrial diseases. Researchers have access to blood and tissue samples, along with patient data, from hundreds of people all in one place. The Biobank is also a place for scientists to share the information that they collect. What a tremendous advancement in mitochondrial medicine and for those who are affected. UMDF promoted the opening of this biobank through our website and by webinar and we are told that the Mayo Clinic is very pleased with the response.

April brought news that Doug Turnbull, PhD and his colleagues at Newcastle University in the U.K. successfully genetically engineered embryos from parents who would have passed on mitochondrial DNA mutations by conceiving the old-fashioned way.

Throughout the year, we reported to you the important developments surrounding the North American Mitochondrial Disease Consortium (NAMDC). Through participation by UMDF members who are affected or who are the parents of an affected child, NAMDC will collect important medical information to enroll patients in all of the available clinical research studies. The UMDF serves as a collaborative partner with NAMDC, who will fill the role of liaison between NAMDC and the affected community.

In June, UMDF awarded researchers more than \$315,000 towards a cure. While these three projects are still in their early stages, it is our hope that they will help investigators determine the role played by mutated mitochondrial DNA-repair enzymes in the development of an inherited disease that causes progressive loss of coordination and mobility in humans, discover the cellular defects that two diseases have in common providing important insights into metabolic impairments that may be common to a number of mitochondrial diseases, and investigate the underlying vascular pathology of the stroke-like episodes experienced by individuals with the mitochondrial disease known as MELAS.

The coming year looks even brighter. There are developments ahead on new clinical trials and potential treatments as well as a special presentation on this topic that is scheduled for our Symposium in Chicago. The joint session is designed for families as well as clinicians and researchers. It is being organized by Peter W. Stacpoole, PhD., MD. Dr. Stacpoole is based at the University of Florida at Gainesville and is a member of the UMDF's Scientific and Medical Advisory board. Mark your calendars and plan to be with us in Chicago June 15-18, 2011!

We can't wait to see what successes the New Year brings!

Energy to all,



W. Dan Wright, UMDF Chairman



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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.

Responders for this issue: Russell P. Saneto, DO, Ph.D. of Children's Hospital and Regional Medical Center, Seattle, WA and Jerry Vockley, M.D., Ph.D. of Children's Hospital in Pittsburgh, PA.

THE QUESTION IS...

Why isn't an NADH supplement prescribed for patients with Complex I deficiency?

RESPONSE FROM RUSSELL P. SANETO, DO, PH.D.:

There is no data that NADH capsules have any benefit in mitochondrial disease. In fact therapeutically, the problem is distal to NADH anyway. Complex I uses NADH to transfer 2 electrons to coenzyme Q10. If complex I is defective, then all the NADH in the world is not going to help, unless there is a Km mutation that alters NADH binding. This has never been found. The better treatments are riboflavin, uridine, and coenzyme Q10.

THE QUESTION IS...

I have read some recent articles about patients' alarmingly high increase in exposure to radiation via scans, multiple x-rays, etc, and the potentially harmful effects this may cause in the future, such as cancer. (The articles were about patients in general, not mito patients.) I am concerned for myself and especially for my young daughter who has mito and has had several scans already. Should I be worried?

RESPONSE FROM RUSSELL P. SANETO, DO, PH.D.:

In testing for possible medical problems, there is always a balance between testing to find the answer (to the medical question) that leads to a diagnosis and subsequent directed treatment, and the invasiveness of the test. A major problem with our bodies is that we have no window to look inside and see what the problem may be. The use of X-rays, CT scans, and isotope tests unfortunately requires a certain exposure to ionizing radiation. There are risks for almost every test that we do in the medical field. So, the balance of risk and benefit lies in what can be gained from the test. I do not think that any of us in the medical field would expose our patients to testing unless the benefit outweighed the risk. Ionizing radiation has risks. Unnecessary testing should always be avoided. Using methods that limit the risk should always be used. However, when illness strikes and the diagnosis is questionable without testing, testing is warranted.

It is good to know that there are limits placed on radiation exposure. For the most part, exposure is limited to below these limits. So, there are safety guidelines in place. These guidelines are enforced for both patients and those doing the testing. I hope this helps.

THE QUESTION IS...

I am diagnosed with Mitochondrial Myopathy with Ragged Red Fibers found on muscle biopsy in 2008. Because they haven't found a mutation in my mitochondria DNA, my doctor believes it's probably in the Nuclear DNA. I have Gastric and Bladder Stimulators to help my system work properly....which it does help. I have been experiencing EXTREME muscle weakness all over and it can happen in a matter of minutes without warning, making me fall to the ground because I am so severely weak. Once I have rested on the floor after 20 minutes or so, I can crawl to a chair, but I still feel weak in my arms and legs. I do suffer from muscle weakness on a daily basis even without attacks. My heart has been checked and everything is fine besides having low blood pressure. My doctor doesn't know what is causing this weakness. Have you seen this

before and know what is the cause? I also recently found I have hearing loss and have been suffering from vertigo too. A test showed no response for my vestibular nerve in the left ear. In addition, I have chronic Migraines and Dysautonomia. What do you think this sudden muscle weakness could be related to? Thank you for your time.

RESPONSE FROM JERRY VOCKLEY, M.D., PH.D.:

Mitochondrial myopathies can present with many different symptoms and the symptoms can change significantly over time. Muscle weakness, dysautonomia, migraine headaches, hearing loss, and vertigo are all common problems in this group of disorders. Progression of muscle disease with weakness is certainly a part of your mitochondrial disease, but it is important to realize that any underlying other illnesses can make muscle disease worse. You should have your primary care doctor check you carefully for any other problems such as infections (bladder and sinus infections can often be otherwise asymptomatic), anemia, or salt and mineral imbalance in your blood. Also be sure that your nutritional status is good and that you are sleeping well at night. If no other underlying problems can be found, then it is likely that your mitochondrial disease itself is at fault. You should be seen by your metabolic physician to see if your supplements need to be adjusted or changed. Sometimes, a short hospitalization for IV fluids can be helpful. Regardless, keep in mind that symptoms can wax and wane in mitochondrial disease, and so taking care of yourself now is important with the hope that the symptoms will reverse with time.

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 19, 2010.** A lunch buffet, a motorcycle ride, and a silent auction were all held at Higgy's Pizzeria in McDonough, GA in honor and memory of Andrew Caleb Radney. All proceeds went to fund The UMDF Andrew Radney Research Fund. This was the second lunch buffet that Higgy's owners, Tim and Debbie Higdon, have held to benefit Andrew's Research Fund. Thank you to the Higdons and Bill and Michelle Cummings for organizing the motorcycle ride, Robi Smith for coordinating the silent auction, and to the many business donors, and all that participated in this event. The raised funds totaled over \$4,000. Andrew Radney went to Heaven on May 11, 2010 at age 9 and is missed greatly by all who knew him.

• **September 25, 2010.** The fourth Annual Music for Megan and Family Fest was held at Wills Park Equestrian Center in Alpharetta, GA. The benefit concert and family fun festival was inspired by Megan Sheridan, a little girl affected by mitochondrial disease. The event featured The Return, an authentic Beatles tribute band, and it included moonwalks, pony rides, face painting, games, a climbing wall, and food. This year's event raised more than \$46,000, and over the past four years, the event has raised over \$200,000 for UMDF! Thank you Laura and Trey Sheridan, and thanks to all those people who have supported this fundraiser over the past four years!



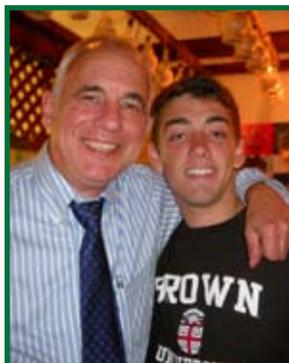
Megan Sheridan

• **October 30, 2010.** Sandy Riggan ran for research and raised over \$700. Sandy, an inspirational adult affected by a mitochondrial disorder, ran the half marathon for a second year in a row. Way to go Sandy!

CALIFORNIA CHAPTER

• **September 23, 2010.** Through the outstanding footwork of Linda Wilkinson, one of our UMDF Chapter Board Members, more than 40 Chevys Fresh Mex restaurants helped to raise awareness about mitochondrial disease, raise funds for the UMDF. A big thank you to Linda, the Wilkinson family, California Chapter members, and Chevys Fresh Mex restaurants! More than \$1,200 was raised for the UMDF!

• **September 27, 2010.** Nate Charney, a Napa High School senior who has mitochondrial disease, organized a UMDF Dine and Donate fundraiser at Filippi's Pizza Grotto. He raised over \$600. Thank you Nate!



Dr. Robert Maddox and Nate Charney at Filippi's Pizza Grotto.

CENTRAL OHIO CHAPTER

• **October 3, 2010.** The 10th Olivia Steele Memorial Golf Outing took place at The Players Club at Foxfire Golf Club in Lockbourne, OH. The event raised about \$1,700. Thank you so much!

• **October 17, 2010.** Scott Hammond participated in the Columbus Marathon and ran in memory of his son, Teddy. He helped to raise over \$4,000 for UMDF! Way to go Scott!

DC/BALTIMORE/NORTHERN VIRGINIA CHAPTER

• **September 21, 2010.** In honor of Mitochondrial Disease Awareness Week, three Chili's Grill and Bar restaurants in Maryland donated a portion of their proceeds on September 21, 2010 to the UMDF. A special thank you to Kathleen King for arranging the awareness event. Approximately \$430 was raised for UMDF!

• **October 23, 2010.** The second annual Fall into a Cure Gala was held at Belle Haven Country Club in Alexandria, VA and raised almost \$40,000! Event Chairs, Anne Tuccillo and Sharon Goldin, with the help of numerous volunteers planned an enjoyable evening of food, entertainment, and phenomenal auction items. Thanks for all of your hard work!



Sharon Goldin and Anne Tuccillo at the Fall into a Cure Gala.

DELAWARE VALLEY CHAPTER

• **September 22, 2010.** The Delaware Valley Chapter held a Mitochondrial Disease Awareness Night at the Philadelphia Phillies. Three Hundred people came to Citizens Bank Park on a rainy night and watched a thrilling 1-0 victory over the Atlanta Braves. In addition to raising awareness for mitochondrial disease, almost \$400 was raised for UMDF. Plans are already in the works to make next year's awareness game bigger and better!

(CHAPTER EVENTS CONTINUED ON PAGE 5)

CHAPTER EVENTS (CON'T)

HOUSTON CHAPTER

• **September 15, 2010.** The Houston Chapter helped organize a fundraising event with Dr. Mary Kay Koenig, Director of the UT Mitochondrial Clinic at the University of Texas Medical School, Houston. Mito is a Mess was held at the Grove at Discovery Green and included cocktails, hors d'oeuvres, and a silent auction. The event raised about \$3,000 for the UMDF! Thanks to all who participated in this wonderful event.

• **October 28, 2010.** Chapter Members Laura Jackson and Leanne Donelson organized a Gleannloch Farms Holiday Market Show at

the Gleannloch Pines Golf Club in Spring, TX in honor of Curtis Jackson, a 10-year-old boy with mitochondrial disease. More than \$1,200 were raised! Thanks to all who participated and a special thank you to Laura and Leanne for all of their hard work planning the event.



Curtis Jackson



Devin L. Torrez creating the "Mito is a Mess" artwork.

INDIANA CHAPTER

• **September 7, 2010.** Jennifer Greenlee of Indianapolis, Indiana held a violin recital in honor of her husband, Kevin and her daughter, Grace. Jennifer is a professional violinist and decided to use her talent to raise funds for the UMDF. The violin recital raised over \$2,000 and an unmeasurable amount of awareness. Thank you Jennifer for your hard work!

• **September 19, 2010.** Kristine Miller participated in the Cancun 70.3 mile triathlon. While training, she asked for donations in honor of her two daughters, Zoe and Eliana. Kristine raised almost \$2,000. Thank you Kristine!

KANSAS CITY CHAPTER

• **October 11, 2010.** The Kansas City Chapter sends out a big thank you to Precision Roofing and the owners Mike Weber and Rich Hoffman. On a very rainy morning, they presented the second annual Precision Roofing Golf Classic at the Lakewood Golf Course. Everyone showed up knowing the event would still move forward even in the rain. There were many of the KC Royals' greatest participating in the event. With the hard work of Mike & Rich, they raised \$7,500 for the UMDF. Way to go Mike & Rich!

NEW ENGLAND CHAPTER

• **September 15, 2010.** The Publick House Cooks event for the UMDF raised awareness and funds. Dinner guests enjoyed Thanksgiving themed foods while learning more about mitochondrial disease and the UMDF. The people who worked the night of the buffet dinner are all volunteers who work in various departments of the Publick House. Thanks to the Publick House for raising awareness and \$1,000.

• **October 2, 2010.** The New England Chapter hosted the 2010 Mito Walk and Masquerade Parade at the LEGO campus in Enfield, CT. The event raised more than \$5,700. About 100 people came to participate, and many got in the Halloween spirit a bit early with costumes! There were LEGO building activities and displays, music, refreshments, raffles, and prizes for the best costumes! A big thank you to the New England Chapter members!



Participants in the New England Chapter 2010 Mito Walk and Masquerade Parade at LEGO.

NEW YORK METRO CHAPTER

• **September 24, 2010.** Sarah Rogers and a group of her friends, Team Frozen Burrito, traveled to Washington, DC to participate in the Ragnar Relay in support of UMDF. In addition to having a wonderful time the team raised over \$4,000 for mitochondrial disease. Thank you Sarah!

• **September 18, 2010.** Darleen (DeDe) Agar Lawrence held a family festival at her home in Middletown, NJ, which included silent auction baskets, food, and fun. Darlene has three children that are affected by mitochondrial disease: Shannon, Hayley, and Brett. The event raised \$20,000 for the UMDF! Way to go DeDe!

• **October 16, 2010.** The New York Metro Chapter hosted the first ever Helping on the Hudson dinner and auction event. Kim Zuzzolo chaired the event and everyone had a wonderful evening. The event raised over \$2,000 for UMDF. Thank you Kim!

OHIO CHAPTER

• **October 30, 2010.** The Student Occupational Therapy Association (SOTA) from Brown Mackie College in Akron, OH held a fundraiser at Legend Lanes in Cuyahoga Falls to help support the UMDF. The SOTA raised nearly \$400 for the UMDF. This event was held in honor of the members of the Northeast Ohio Chapter. Debra Fleming, who is an affected member, spoke to the SOTA class in December 2010 to educate them on the disease.

NOTABLE EVENTS

- **July 17, 2010.** Greg & Carolyn Martin organized the sixth annual Carter Martin Golf Outing in Iowa. Each year, family and friends are invited to the event in honor and memory of Carter's birthday which is on July 18th. About \$260 was raised for the UMDF. Thank you Greg & Carolyn!

- **September 4, 2010.** The Gillen Family of Pittsburgh, PA held the Incredible Ice Cream Extravaganza for mitochondrial disease in honor of Merritt Gillen. Merritt celebrated her 9th birthday with a sundae bar, tons of games, and a silent auction. The Gillen Family and their friends raised over \$6,610 for the UMDF! Thank you for your support and Happy Belated Birthday Merritt!



*Merritt Gillen
with her sister, Paige*

- **September 12, 2010.** A fundraiser called Bowling for Mito was held at Tampa's Pin Chasers in the Tampa Bay Area, Central Fla. About 20 bowlers participated and raised over \$500 for research. Thank you Jennifer Slaughter for coordinating the event!



Elena Welhouse

- **September 17, 2010.** Mindy Welhouse hosted the fourth Elena's Hope fundraising dinner in Kimberly, WI. Attendees enjoyed a delicious dinner and fun auction, raising over \$10,000. UMDF appreciates Mindy's ongoing commitment to raise research dollars.

- **September 18, 2010.** Rolland and Willie Bagby organized the third annual Savannah's Hope Mito Walk in memory of their daughter, Savannah Elizabeth. The event was held at Adventure Life Reformed Church in Altoona, IA and included several family, friendly activities. The event raised more than \$2,500. Thank you Rolland and Willie!

- **September 18, 2010.** Jane Gurley of Monroeville, PA planned a Monroeville Rotary Golf Outing in Western Pennsylvania that raised \$1,500 for the UMDF. Thanks Jane for all your hard work in planning such a successful event!

- **September 25, 2010.** A special thank you goes to the Idaho Mito Group, led by Jennifer Pfefferle, for holding their annual Energy Bowl-a-Thon. Not only did the group have a great time celebrating mitochondrial disease awareness week, they raised over \$800 to support research. Thank you Jennifer!



*Racers from
Payton's Race for a Cure -
Payton's dad, Andy is #309!*

- **September 25, 2010.** The second annual Payton's Race for a Cure in Western Michigan was held in honor of Payton DeWitt, the daughter of Andy and Michelle. The motor cross event raised nearly \$4,000 for the UMDF! A big thank you to the DeWitt family and all members of the Payton's Race for a Cure non-profit organization!

- **October 8, 2010.** Patti Bauer held a Trivia Night & Auction at the Knights of Columbus hall in Springfield, IL. The registration included drinks and had pizza and baked goods for sale. The great night raised over \$6,000 for research! Great job!



*Adam, Phil, David, Brian, and Brad
Bauer at the Trivia Night & Auction.*

- **October 9, 2010.**

Maggie Dickens organized the fourth annual Kure for Kat was held at South Lakes Park in Denton, TX. It offered all participants a fun-filled experience with entertainment, refreshments, and mitochondrial disease resources. In total, the event raised nearly \$14,000 for the UMDF research in honor of Katherine Dickens. Way to go Maggie!



Katherine Dickens

- **October 9, 2010.** Greg Wellman of Huntersville, NC participated in the *Swim for Them 10K Swim* event in honor of Adam and Braeden Rogers of Jonesborough, TN. The Rogers boys

are friends of Greg's family, and they both have mitochondrial disease. Greg raised more than \$2,100 for the UMDF! A huge thank you to Greg for taking on such a feat and to all who helped support him!



Adam & Braeden Rogers

- **October 10, 2010.** The Double Wide Grill in Pittsburgh, PA held an All-You-Can-Eat Pancake Breakfast in honor of the UMDF. The event raised nearly \$500 for the UMDF. Thank you to the Double Wide Grill for your support of the UMDF!

- **October 16, 2010.** Thanks to our members across the nation for purchasing Macy's Shop for a Cause passes and helping the UMDF raise about \$1,800!

- **October 23, 2010.** Bruster's Ice Cream lovers got the chance to discover UMDF's mission at the annual Bruster's Ice Cream of Ingomar's costume contest in Pittsburgh, PA. About \$120 was raised for the UMDF. Thank you Bruster's!



*Participants in
Bruster's Ice Cream of
Ingomar's costume contest.*

- **November 6, 2010.**

Amber Ferrell held her second annual Photos for Mito day in Central Florida. She shoots and edits pictures for families and donates her time in support of the UMDF. Amber and all of the great mito families involved helped to raise over \$1,200 for research! Thanks Amber!

PHASE 3 TRIAL (CONTINUED FROM PAGE 1)

All the above questions concerning CoQ10 are addressed in the ongoing clinical trial of CoQ10. It is called a "Phase 3" trial because it represents the most definitive test of the potential safety and therapeutic benefit of CoQ10 in mitochondrial diseases. If the results of the trial demonstrate significant clinical benefit and good tolerability of CoQ10, such information could be submitted to the Food and Drug Administration for consideration of approving CoQ10 for certain genetic mitochondrial diseases. Insurance companies generally require FDA approval to pay for drugs and other therapies.

The Phase 3 Trial of CoQ10 is being conducted at 4 sites in North America:

- Shands Hospital at the University of Florida, Gainesville, FL (Dr. Peter Stacpoole, Principal Investigator)
- Cincinnati Children's Hospital Medical Center, Cincinnati, OH (Dr. Ton DeGrauw, P.I.)
- Rainbow Babies and Children's Hospital, Cleveland, OH (Dr. Douglas Kerr, P.I.)
- Sick Children's Hospital, Toronto, ON (Dr. Annette Feigenbaum, P.I.)

Children who are eligible to participate in the trial must meet the following criteria:

- Age: 12 months to 18 years at time of entry
- Definite biochemical or genetic diagnosis of a genetic mitochondrial disease involving the RC
- No major other diseases, such as heart or kidney failure
- Capable of holding head up against gravity

The duration of the trial for each participant is one year. During the first six months, each patient receives either CoQ10, at an oral dose of 10 mg per kilogram of body weight, or placebo. After the first six months, the treatment is reversed, and the same patient is "crossed over" to the other treatment. Both the patient and the treating physician are "blinded" as to whether the patient is receiving CoQ10 or placebo at any given time. Such a "double-blind, placebo-controlled" study design is required by the FDA to ensure that the trial's data can be obtained and analyzed as objectively as possible.

Many safeguards are built into Phase 3 trials to ensure the maximum possible safety of the participants. These include both lay and professional members of various review boards who conduct continuous review of all ethical and scientific aspects of the trial and can know at any time the particular treatment a patient is receiving.

Children who participate in the CoQ10 trial undergo one - two days of tests every three or six months at one of the study sites. These tests include evaluation of muscle strength, neurological status, quality of life and overall health, which includes obtaining blood and urine samples. The CoQ10 is provided free by the Tishcon Corporation. When necessary, free round-trip air transportation is facilitated by Mercy Medical Airlift, a nationwide charitable air transport association, and by the U.S. military branches for families stationed overseas. Funding for the trial is provided by a grant from the Food and Drug Administration.

For more information about the Phase 3 Trial of CoQ10 in Mitochondrial Diseases, contact:

Courtney Yates, RN
Study Coordinator, CoQ10 Clinical Trial
University of Florida College of Medicine
Phone: (352) 273-9016
Email: courtney.yates@medicine.ufl.edu
Fax: (352) 273-9013

UPCOMING EVENTS

ATLANTA CHAPTER

- **April 30, 2011.** The Energy for Life: All Aboard for a Cure Walkathon will be held at Thrasher Park in Norcross, GA. Please visit www.energyforlifewalk.org/atlanta for more information.

CENTRAL OHIO CHAPTER

- **April 2, 2011.** The seventh annual Bet on Baylee Casino Day & Night Auction to benefit the UMDF will be held at the Roseville Community Center in Roseville, OH from noon to midnight. Three bands will play after the auction: Vision, Familiar Stranger, and Fast Freddy. Fast Freddy will sing a special song, entitled "Baylee's Eyes" at the event that will be dedicated to Baylee Thompson and others affected with mitochondrial disease. For more information, contact Jody Thompson at: 740-704-2994.

HOUSTON CHAPTER

- **February 5, 2011.** The first annual Houston Energy for Life Walkathon/ Fifth Annual Christopher's Heart Fun Walk will be held at Sam Houston Park in downtown Houston, TX. Last year, nearly \$110,000 was raised for the UMDF. For more information, visit www.energyforlifewalk.org/houston.

INDIANA CHAPTER

- **April 16, 2011.** The Energy for Life Walkathon: Indiana will be held at the Indiana University - Purdue University Indianapolis Campus in Indianapolis, IN. Stay tuned for more information!

MIDDLE TENNESSEE CHAPTER

- **April 2, 2011.** The Energy for Life Walkathon: Middle Tennessee will be held at The Nashville Zoo at Grassmere in Nashville, TN. Please visit www.energyforlifewalk.org/midten for more information.

NEW YORK METRO CHAPTER

- **February 5, 2011.** For the Love of Ted, a fundraiser for the UMDF will be held at the South Nassau Unitarian Universalist Congregation at 4:00 p.m. Participants will be able to express themselves through art by participating in a guided spiritual collage journey and stamping activity to make unique valentine cards. Stamping activities will be provided by Paula Rosenberg, who has over 15 years of experience. There will also be a dinner at 6:00 p.m., a speaker, and an open microphone from 8:00 p.m. - 10:00 p.m. Admission is \$20. This fundraiser is in honor of Ted Tiller, a 19-year-old man with mitochondrial disease. Please RSVP to corinaism@aol.com or call: 516-579-4711 for more information.

OHIO CHAPTER

- **May 7, 2011.** The Wild for a Cure Walk will be held at the Cleveland Metroparks Zoo. The event will include a 1 mile walk through the zoo so you can enjoy the wildlife! For more information or to register, please visit www.wildforacure.org.

AROUND THE COUNTRY

- **March 26, 2011.** The second annual Jackson-Culley Mito-What5K will be held in Millington, TN at USA Stadium. For more information please contact Angie Hayes at angie.hayes07@gmail.com or visit www.mitowhat5k.blogspot.com.
- **March 27, 2011 (tentative date).** The Kindbom family is planning a wine tasting event, "Cheers to You, Hope for Others", at Lakeside at the Medford Clubhouse in Medford, NJ, in honor of their daughter, Rachel. For more information, please contact Sharon Kindbom at chrisnsharonk@verizon.net.
- **April 9, 2011.** The Energy for Life Walkathon: St. Louis will be held at New Baden Village Park in New Baden, IL. Please visit www.energyforlifewalk.org/stlouis for more information.

ENERGY FOR LIFE WALKATHONS

CAROLINA FOOTHILLS CHAPTER

• **September 18, 2010.** The inaugural Energy for Life Walkathon: Carolina Foothills was held in Freedom Park in Charlotte, NC. The fundraiser exceeded the original goal by over \$40,000 with all funds going to the UMDF. Thirty-four teams and a total of 644 walkers participated in the event. The walkathon raised about \$74,000. Thank you for your support!



Olivia's Fireflies participated in the Energy for Life Walkathon: Carolina Foothills in memory of Olivia Paige Goldberg.



Kara Strittmatter from the UMDF National Office and Rachael Pipp at the Chicago Area Chapter Energy for Life Walkathon.

CHICAGO AREA CHAPTER

• **September 19, 2010.** Led by co-chairs Cherie Lawson, Gail Wehling and Patrick Kelley, the Chicago Area Chapter staged their first ever Energy for Life Walkathon in Pottawatomie Park in St. Charles, IL. Twenty-six teams came together for a great day at this beautiful park. Team Patrick was the top team, and Team Loftus, from Wisconsin was runner-up. With more than 230 participants, the walkathon exceeded last year's totals by more than \$10,000. Not only did the walk raise awareness for mitochondrial disease, but it raised more than

\$57,000 towards a cure. A big thank you to all who helped make this day successful!

DELAWARE VALLEY CHAPTER

• **September 25, 2010.** The DeVal Chapter celebrated their first Annual Energy for Life Walkathon at Campbell's Field in Camden, NJ. Over 300 walkers joined the Chapter on a warm, sunny day to walk through Rutgers University and along the river front near the Aquarium. Many new teams joined including the top fundraising team, Sydney's Shining Stars, and runner-up, For the Love of Lucy. The Flagship Sponsor, Endo Pharmaceuticals also came out to support the walk. Close to \$45,000 was raised for research. Thanks to all who participated!



Sydney's Shining Stars, the top fundraising team at the DeVal Chapter Energy for Life Walkathon. (Photo by Thomas Pohlig of Thomas Studios)

KANSAS CITY CHAPTER

• **September 19, 2010.** The Energy for Life Walkathon: Kansas City was held at the Community America Ballpark. The walk included a fish fry, kids games, face painting, and mitochondrial disease resources. In total, the event raised over \$19,000 for the UMDF. Thanks to everyone who participated and a special thank you to Precision Roofing of Lee's Summit, MO and the help of former Royals' player Al Fitzmorris.



Team Joey at the Kansas City Chapter Energy for Life Walkathon. Joey Atchley is the little boy being held in the front row.



Sonora's Explorers at the Energy for Life Walkathon: Minnesota. Sonora Wendt is the little girl in the pink tights in the front row.

MINNEAPOLIS/ST. PAUL CHAPTER

• **September 11, 2010.** The Energy for Life Walkathon: Minnesota was a huge success with more than \$86,500 raised for the UMDF! More than \$49,000 was raised in memory of Leo James Chapman-Neseth. A special thank you to every member of Leo's team who came out to support the walk, go Leo's Lions! Also, thank you to everyone who participated or donated to the walk – we couldn't have done it without you!

(ENERGY FOR LIFE WALKATHONS CONTINUED ON PAGE 9)

ENERGY FOR LIFE WALKATHONS (CONTINUED)

AROUND THE COUNTRY

- **September 11, 2010.** The first annual Energy for Life Walkathon in Western New York was a huge success. More than 244 walkers turned out for the event and over \$24,000 was raised for the UMDF. Thanks to everyone for their support!

Sherri and Rich Schultz at the Energy for Life Walkathon in Western NY.



- **September 25, 2010.**

The Energy for Life Walkathon: Northwestern Pennsylvania was held in Sugar Grove, PA, hometown of 4-year-old Cooper Groves who has surf 1/leigh's disease. More than \$21,200 was raised for the UMDF thanks to the support of family and friends in this small community. The Nanni family from Indiana, PA was a wonderful addition to the event. We can't wait to see everyone next year!



Cooper Groves laughs with Terri, his grandmother.

GIFTS FROM THE HEART

- The Friends and Family of Ally Brunk held the seventh annual Ally Brunk Memorial 5k Run on June 12, 2010. Through their efforts and the support of their community in Grand Ledge, MI, they were able to raise \$2,500 for the UMDF. Thank you to the Brunk Family and Friends!

- The 2011 Class at St. Angela Merici School in Ohio conducted a Fun Fair for the students to raise money for the UMDF. The students raised over \$350. Thank you to the student body for your fundraising and awareness efforts!



Kaya and Bode Knake with supportive friends

- The Vasilich Family of Pittsburgh, PA held their annual Karaoke for Kate fundraiser in memory of Kaitlin Vasilich. The annual event raised \$1,500 for the UMDF and continues to be an awareness building event. Thank you to the Vasilich Family for your continued support!

- Rachael Pipp of Grafton, WI, placed a "Coins for a Cure" box at her local dentist office and raised over \$100 for research! Thank you, Rachael for your continued support to the UMDF Mission. Also, Rachael Pipp will ride her stationary exercise bike to raise money and get the message out about mitochondrial disease. She hopes to raise awareness and funds to find a cure. To make a donation to Rachael please visit <http://www.umdf.org/marathonformito>.



*Ben Stewart
(Photo by Patricia Murrell & Anna Stewart with MurrellStewart Photography)*

- Anna Stewart, a UMDF Ambassador in Bossier City, LA organized a Dress Down Day at five local schools during awareness week. The events were held in honor of Anna's 6-year-old son, Ben and raised over \$3,400 for the UMDF. Thank you Anna for your hard work!

- A Casual Day was held at Upper Saint Clair High School, PA, in honor of the Gillen Family. The employees raised more than \$220 for the UMDF. Thank you to those who participated in the Casual Day.

- Twelve-year-old Kaya Knake of Canton, MI and her friends participated in a 5k run and collected pledges for the UMDF. The group of friends ran in honor of Kaya's four-year-old brother, Bode who has a mitochondrial disease. The group raised \$2,200 for the UMDF in Bode's honor! Thank you to Kaya and her friends for your generous support!

- Alyssa Rogers held a lemonade stand fundraiser in honor of her brother, Carson and donated all of the proceeds to the UMDF. She raised about \$60. Thank you Alyssa for your contribution!

- A special thanks to the Memphis Area Mito Group! On September 21, 2010, a Chick-fil-

A fundraiser was held in honor of Asa Wilson of Medon, TN. Thanks to everyone who participated, a total of \$450.00 was donated to the UMDF. The group also organized a McAlister's Deli night fundraiser on September 24, 2010. A total of \$410.00 was raised and donated to the UMDF!

- On September 24, 2010, Matt Kovalcik and Steve Geraghty hosted the Champions of Hope Annual Gathering for Giving. (The event was previously known as the KGWP Charity Outing.) Special thanks to the Kovalciks for donating \$1,000 to the UMDF. The event raised money in honor of Ellie Kovalcik and all those affected by mitochondrial disease.
- A Never Lose Hope 5K Run and Fun Walk was held on September 25, 2010 in memory of Gavin Owens. UMDF received a donation of \$500 from the event. Thanks to the Cusick and Owens families for helping to find a cure for mitochondrial disease.
- Congratulations to Jenn Heatly who completed the ING NYC Marathon on November 7, 2010. Thanks to generous donations, over \$300 was donated to the UMDF.
- Gwen Abele held a birthday party for her son, Austen Abele-Castro, who turned 14 and has had mitochondrial disease since birth. In honor of Austen's day, \$150 was donated to the UMDF. Thank you Gwen and Austen!
- Laura Perreault of Lansing, IL has put her sewing talents to use to support the UMDF and has already raised over \$200. Laura, with the help of her family, creates baby bibs, burp cloths, and tutus to sell at craft fairs and online at www.SewWonderful4ACause.com.

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UNITED MITOCHONDRIAL DISEASE FOUNDATION

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LOVING THE LIFE SHE LIVES

A Day in the Life of Perri Elaine Miologos



Perri Elaine Miologos

Perri Elaine Miologos of Chicago, IL was first diagnosed with Kearns-Sayre Syndrome when she was a freshman in college in 2004. For a couple of years after her diagnosis, she went to numerous doctors for check-ups and routine tests without any new answers. According to Perri, “it became very tiresome very fast and seemed to be more fun for the doctors than it was for me.” She said, “My mitochondrial disease has not progressed over the past six years; in fact, some say it has improved but know one really knows. I believe this is not just by chance, but because I make it a priority to take care of myself.” For the past year and a half, her mitochondrial disease has not had a significant effect on her daily life. She said that she is more than the mitochondrial disease she is diagnosed with, and she doesn’t let it define her or take over her thoughts or her life.

A couple of years ago, her immune system was weak and she was getting sick often. Her body was not healthy enough to recover on its own and she was taking prescription drugs from her doctor to help her get well. She kept getting one sickness after another. Perri said, “My frustration grew until I decided I needed to change my lifestyle in order to give my body what it needed to take care of itself on its own once again.”

She was introduced to a naturopath and a theory of healing from within that focused on the health of the mind and body. “I always thought my diet was relatively healthy, but I soon realized it was not at all,” she said. A lot of the foods that she ate and thought were healthy, were not. Since then, Perri has eliminated junk food from her diet, minimized sugar to barely any, eats more quality protein,

fruits, vegetables, and dairy products and avoids foods that come out of a box or bag. She admits that she does cheat on holidays and on special occasions when she eats a piece of cake at work or a slice of frozen pizza at her friend’s house.

She made what she put into her body a focal point because she began to believe that what you put into your body becomes a part of you. Perri decided to stop taking synthetic drugs, over the counter medicine, and prescription drugs. Instead of taking synthetic vitamins, she now takes pure, whole food supplements that serve the same purpose. She began using herbal remedies and started educating herself on alternative medicine. Perri takes a yoga class twice a week, and feels that yoga has not only helped her with her strength and balance but has also managed her stress levels.

As a result of her new lifestyle, Perri said that her health has improved in many ways, and she has not been sick or to the doctor in over a year. She said, “I no longer get the four o’clock low at work, random headaches, colds and sniffles that I can’t shake off, or mood swings, and I have a lot more positive energy. Life is short and I refuse to let mitochondrial disease prevent me from living it up. I do not want to let myself be sick through it and this is a fundamental part of my belief.”

Perri continues, “I am not urging people to stop taking their medicine or abandon treatments. I am encouraging people to be more conscience of their thoughts, beliefs, and their health. We often think of our mind and body as separate, but I feel both are very important to your quality of life. Your beliefs are important and have a profound manifestation on your body. The bottom line is, whatever works for you, keep doing it as long as you are happy.”

She has one priority in life: to be happy. She said, “A wise friend of mine gave me a silver ring. The outside of the silver band read ‘live the life you love’ and the inside of the band that hugs your finger read ‘love the life you live.’”

Perri finished college in May 2008 and has been working in market research in the food and beverage industry ever since. She said she really enjoys her job, the people she works with, and the company she works for. She sits on the UMDF Chicago Chapter Board as Co-Vice President, and she helped to plan the chapter’s annual holiday party. She enjoys traveling and yoga. She says she loves to travel because you never know who you might meet that might change your life, and she enjoys yoga because it brings strength, focus, and calmness to her life.

It is no surprise that Perri won the UMDF’s LEAP Award in 2009. Her optimistic attitude inspires many people around her; she embodies the spirit of the LEAP Award.



Perri and her brother, Kevin

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 website 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).

Nominations may be submitted online at: www.surveymonkey.com/s/Heartstrings2011 or type your essay and attach it to the nomination form.

Mail the nomination by April 14, 2011 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, 2011 to info@umdf.org.

Person Nominating

Name: _____

Address: _____

Phone: _____

E-mail: _____

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 website 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.

Nominations may be submitted online at: www.surveymonkey.com/s/LEAP2011 or type your essay and attach it to the nomination form.

Mail the nomination by April 14, 2011 to:

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

Or fax to 412-793-6477 or e-mail the nomination by April 14, 2011 to info@umdf.org.

Person Nominating

Name: _____

Address: _____

Phone: _____

E-mail: _____

Nominee for the Award

Name: _____

Address: _____

Phone: _____

Diagnosis (if known): _____

Age (must be at least 14 years old): _____

NATIONAL OFFICE UPDATE

UMDF STRATEGIC PLAN PROGRESS

The UMDF Staff continues to work towards the goals in our three year strategic plan. The three year plan is ambitious and will help guide the foundation to continue to fulfill our mission of promoting research and education for the diagnosis, treatment, and cure of mitochondrial disorders and to provide support to affected families and individuals.

The UMDF's Member Services department has been working on the preliminary work to restructure our current chapter model to help support the future growth of the foundation. You will be hearing more about this as we make more progress towards aligning the roles

of our volunteers towards their unique gifts and talents as we seek to grow the foundation's member base across the country.

Our Development Department has made progress in recruiting new board members and is working towards a plan that connects donors to the UMDF.

With awareness and education, the strategic plan is moving forward as we have identified the 50 largest population centers within the United States. Having this task completed, we are now in a better position to create the educational and awareness plans in place across the country.

DID YOU KNOW?

In addition to providing support to UMDF members, the Member Services department offers information and assistance to those who are newly diagnosed with a mitochondrial disease. They are often the first point-of-contact to many people who call in to the UMDF National Office. Physician contact information, local chapter information, literature, and a listening ear are just some of the resources offered to first-time phone and e-mail contacts by the Member Services team. Thanks to Jean Bassett, Melinda O'Toole, Nicole Shanter, and Kara Strittmatter for all of their hard work!

2011 SYMPOSIUM

The United Mitochondrial Disease Foundation, Mitochondrial Medicine Society, Mitochondria Research Society, Mitochondrial Physiology Society (MiP2010) and the Northeastern Ohio Universities College of Medicine & Pharmacy present

Mitochondrial Medicine 2011: Chicago

June 15-17, 2011 –
Scientific Meetings

June 17-18, 2011 –
Patient/Family Meetings

June 18, 2011 –
Special Clinical Mitochondria &
Diabetes Meeting

Location: Renaissance Schaumburg
Convention Center Hotel
Schaumburg, Illinois

Global Learning Objectives:

1. Define the current state of knowledge of mitochondrial DNA mutations and nuclear DNA mutations as they result in human disease.
2. Review the current state of knowledge of the pathogenic mechanisms of mitochondrial diseases.
3. Review the current state of knowledge of the role of mitochondrial function in Diabetes and Metabolic Syndrome.
4. Review current state of knowledge on mitochondrial biochemistry, physiology and dynamics and relate this to the pathophysiology of mitochondrial disease.

For further information visit www.umdff.org/symposium
or contact the UMDF at 888-317-8633 or symposium@umdff.org

Call for Abstracts is open at:
www.umdff.org/callforabstracts



save the date

Mitochondrial Medicine 2011: Chicago

June 15-18, 2011

JUNIOR YOUTH AMBASSADORS HELP RAISE AWARENESS ABOUT MITOCHONDRIAL DISEASE

By Lisa Higgins, Atlanta Chapter Board Member and Walk Chair

The Atlanta Chapter of the United Mitochondrial Disease Foundation started a new program to help highlight the wonderful “mito kids” in our area and try to bring more publicity to mitochondrial disorders. Our Junior Youth Ambassador Program is a spin-off of the national one, but on a smaller scale and only with local children.

In April of 2010, two Junior Youth Ambassadors were chosen to serve for one year. Katie Parsons of Marietta, GA and Dakota Baty of Carnesville, GA were chosen. Both Katie and Dakota are affected with mitochondrial disease and their families are very involved in trying to raise funds and awareness of the disease.



Katie Parsons of Marietta, GA

Katie is an amazing 7-year-old girl from Marietta, GA who does not let her mitochondrial deficiency slow her down. Katie suffers from low blood sugar issues, balance impairment, and cardiac issues, just to name a few. Katie has embraced her position as a Junior Ambassador in so many ways – she has inspired another child she knows to raise money for

UMDF, spoken at UMDf events, and been interviewed by the media to help bring mitochondrial disease to the forefront. Despite battling fatigue that is the “norm” with mito, Katie loves to play with her dolls, go to school, and listen to Hannah Montana. She participates in multiple therapies every week and especially loves to ride horses in therapeutic riding!



Dakota Baty of Carnesville, GA

Dakota is an adorable 5-year-old little boy from Carnesville, GA. He began having seizures at four months old. Many tests and hospital stays later, he was diagnosed with complex 1 mitochondrial disease. Even after two VNS implants, dozens of ICU stays and ER visits, multiple EEGs, brain surgery, and continual multiple therapies, he doesn't give up. He continues to “wow” his parents and other family members with his sweet demeanor and charming smile. He was even befriended by a 13-year-old girl who got to know him after she spotted his picture on the UMDf website. She worked odd jobs to raise money to support the UMDf cause in his honor. Dakota loves big rig trucks, the Wonder Pets, and swaying his hips to any kind of music.

The Atlanta Chapter has seen a great response to the Junior Youth Ambassadors, with both Katie and Dakota being recognized on stage at Music for Megan in September 2010. Katie even prepared and gave a small speech to the crowd! In addition, their official titles have helped increase awareness of mitochondrial disease by getting more media attention, including a recent article written by a writer at a local Marietta, GA newspaper that was subsequently picked up by the Associated Press and distributed nationwide!

We would like to thank Katie and Dakota for their hard work so far this year and look forward to their continued efforts. They still have about five months left to serve before they will hand over the reins to two new Junior Youth Ambassadors on April 30, 2011 at the fourth annual Atlanta Energy for Life Walk: All Aboard for a Cure!

WE WANT YOUR STORIES!

Please consider submitting an article on your experiences with a specific topic that would be of interest to others with mitochondrial disease.

Contact Alison Cooley at alison.cooley@umdf.org with your story or story idea!

We look forward to hearing from you!

ADVOCACY

H.R. 3502 AND S.2858

LEGISLATION MUST BE REINTRODUCED IN 2011

On January 3, 2011, the 112th Congress will begin its first session. If you have been watching the news, you saw that there will be many changes ahead in the political makeup. In the House, the Republican Party gained a majority of seats, while the Democratic Party will maintain a majority in the Senate, albeit reduced from the 111th Congress.

So what does all of this mean for H.R. 3502 and S. 2858? H.R. 3502 gained the support and co-sponsorship of 47 members of Congress. The bill managed to acquire co-sponsorship because of the efforts of UMDF members who worked hard to schedule meetings, make phone calls, and write letters to their members of the House of Representatives. H.R. 3502 was referred to the Energy and Commerce Committee. That

committee determines if the bill will advance. They chose not to take any action on H.R. 3502. The bill expires at the end of 2010.

S.2858 received the support and co-sponsorship of seven Senators, all Democrats. The bill was referred to the Health, Education, Labor and Pensions Committee in the U.S. Senate. Like its house companion measure, S.2858 did not make it out of the committee. The bill expires at the end of 2010.

So what is next? In January, we will return to Washington, D.C., to have both bills reintroduced. We believe in both pieces of legislation. We will work harder than ever to make sure that they move out of committee and onto President Obama's desk before December 2013. We need the UMDF membership to muster the same support and enthusiasm displayed over the past year and a half to garner co-sponsors for the new bills. Will you help us get them passed?

MARK YOUR CALENDAR

SOCIETY OF GENERAL PHYSIOLOGISTS PLAN FALL 2011 MEETING

The Society of General Physiologists (SGP), dedicated to cutting-edge research in physiology, is holding its 65th annual symposium at the Marine Biological Laboratory in Woods Hole, Massachusetts, September 7-11, 2011. This conference, "Mitochondrial Physiology and Medicine", is especially timely due to recent major scientific advancements in discovering the central role of mitochondrial signaling in controlling human health and disease.

Dr. Shey-Shing Sheu (University of Rochester) is putting together this conference, assisted by an organizing committee of eminent scientists including Drs. Robert Balaban (NHLBI), Paolo Bernardi (University of Padova), Robert Dirksen (University of Rochester), Roberta Gottlieb (San Diego State University), Gyorgy Hajnoczky (Thomas Jefferson University), and Brian O'Rourke (Johns Hopkins University). The keynote speakers are Drs. David Clapham (HHMI, Harvard Medical School) and Douglas Wallace (Children's Hospital of Philadelphia, University of Pennsylvania),

both international leaders in the field of mitochondrial physiology and disease.

This meeting will provide a multidisciplinary platform for presentation of the most recent developments in this evolving field. SGP meetings are intimate gatherings of 125-225 people, ideally formatted to promote interactive exchange of new ideas and recent research findings.

This symposium will have a unique theme, focusing on mitochondrial physiology and its relationship to the pathogenesis of human diseases, and highlighting several key areas of research where the progress has been most extraordinary and innovative. These areas are: (1) mitochondrial morphology, movement, and dynamics; (2) system biology of mitochondria; (3) mitochondrial ion channels and transporters; (4) mitochondrial communication, signaling, Ca²⁺, and reactive oxygen species; and (5) mitochondria in cell death and disease.

Information on registration, abstract submission, awards, etc. may be found on SGP's website: www.sgpweb.org

MEMBER RESOURCES

RESOURCES FOR ADAPTIVE DEVICES

ABLEDATA

This resource provides objective information about assistive technology products and rehabilitation equipment. It also has do-it-yourself designs. To learn more, view: [website: www.abledata.com/](http://www.abledata.com/).

Adaptive Access

Accessibility resources are available from Adaptive Access on information, products, and services. Their website also includes favorite web links for the elderly and people with disabilities. Click on their website: www.adaptiveaccess.com/resources.php for more information.

Adaptive Technologies & Research, Inc.

For information on daily living aids for those with no hand function, check out this website: www.adapt-technologies.com/.

Assistive Technology Solutions

This resource provides plans for do-it-yourself devices for assisting persons with disabilities. Go to their website: www.atsolutions.org/folders/solutions.htm.

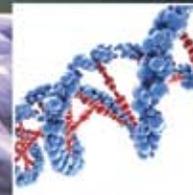
Family Village Accessibility Shopping Mall

To find resources for adaptive products and assistive technology, go to this website: www.familyvillage.wisc.edu/mall.htm.

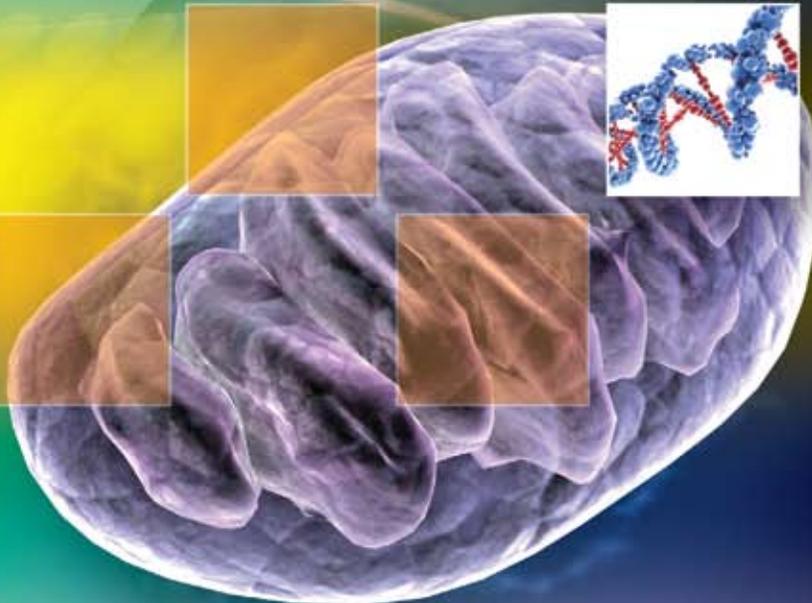
Muscular Dystrophy Family and Friends Foundation (MDFF)

The MDFF provides adaptive equipment such as: wheelchairs, hospital beds, van lifts, ramps for family homes, shower chairs, bath chairs, lift systems, breathing machines, clinic services, communication devices, braces and social outings. Contact them by phone at 317-923-6333 or 800-544-1213 or view their website: www.mdff.org.

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- Low-cost family member testing available

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ANNOUNCEMENTS

CHUCK MOHAN WINS AWARD

On November 4, 2010, Chuck Mohan was recognized as Monroeville Citizen of the Year by Total Trib Media at the Monroeville Area Chamber of Commerce ROCs Awards. Every year, the Monroeville Area Chamber of Commerce recognizes organizations, individuals, and companies that shine in the community.

During the event, Chuck was one of a handful of people who were recognized. Chuck was honored for founding UMDF and for all of the work he has done for the organization.



Chuck Mohan stands between Chad Amond, Monroeville Area Chamber of Commerce President and Edith Hughes of Trib Total Media.

(Photo by Keith Brown of Mirage Advertising.)

STAFF PROMOTIONS AND ADDITIONS

The National Office of the UMDF is pleased to announce that Tania Hanscom has been promoted and taken a new role in the organization as Special Events Coordinator. Tania has been with the UMDF for five years and while she has enjoyed her most recent work in communications, she is excited to be in the Special Events Department again. Tania will be working with the entire UMDF staff and hopes to take the Energy for Life Walkathons to new heights. Congratulations Tania on your new position!

Nicole Shanter has worked in the Membership Services Department for the past two years. Nicole has recently taken on a more active role with the Special Events Department and will be assisting our volunteers with all UMDF events, including the Energy for Life Walkathons. Join us in congratulating Nicole on her new position!

Alison Cooley joined the staff at UMDF on November 29, 2010 as Communications Assistant. Alison brings more than eight years of communications experience with her. She has a Bachelor of Arts degree in Communications and has worked in various public relations positions where she was successful in promoting people, places, and events through the media. She also gained experience writing and designing various pieces of collateral, including newsletters, brochures, flyers, and fact sheets.

The UMDF would like to wish you a healthy, happy holiday season and a wonderful new year!

SUBMISSION DEADLINE FOR VOLUME 16 ISSUE 1 IS JANUARY 31, 2011!



IN THIS ISSUE:

Phase 3 Trial of Coenzyme Q10 in mitochondrial diseases
See page 1!

What's new in my area?
Check out pages 4-9!

Heartstrings and LEAP Award applications on pages 12 & 13!

2011 Symposium details
See page 14!