

The UMDF's Mitochondrial Disease Congressional Caucus kicks off with its first hearing on Capitol Hill



Elizabeth Kennerley speaking at the Mitochondrial Disease Congressional Caucus.

It was standing room only for the first ever meeting of the "Mitochondrial Disease Congressional Caucus" on September 20, 2012, when the UMDF presented the first of a four part series on mitochondrial disease and its implications on human health. The session, entitled 'Mitochondria 101 – How Something So Small is So Important to Human Life', attracted representatives from nearly 20 congressional offices and supporters from the medical and biomedical communities.

The briefing began with a welcome from the caucus co-founders, Rep. Anna Eshoo (D-CA-14) and Rep. Tim Murphy (R-PA-18). Both house members emphasized the importance of the role of the caucus in serving as a platform to educate other members about mitochondrial disease, its impact on those affected and their families, and the implications on human health. Vamsi Mootha, M.D., Professor of Systems Biology and Medicine at Harvard Medical School and the Department of Molecular Biology - Massachusetts General Hospital, gave an overview of mitochondrial disease and dysfunction for those attending the briefing. But it was the presentation of Elizabeth Kennerley, 25, of Solebury, Pennsylvania, that gave those attending a glimpse into the life of a person affected by mitochondrial disease.

Kennerley, an affected adult, walked the audience through her disease from diagnosis to how she lives with her illness daily. "Every day is different with some variation in symptoms and severity," she said. "Every day is a surprise and some days are better than others. Basically, having mito is like a box of chocolates. You never know what you're gonna get." Kennerley told the audience that when she was born, she suffered from low muscle tone and developmental delays that she later outgrew. When she was 18 months old, Kennerley was admitted to the hospital for an infection, was placed on antibiotics, and had her first stroke two weeks later. Doctors told her parents to take Elizabeth home and treat her normally because "lightning never strikes twice." But it did.

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Every dollar counts! To contribute to research, go to www.umdf.org and click on "Give Today."

EPI-743 Trial Begins in Patients with Leigh Syndrome

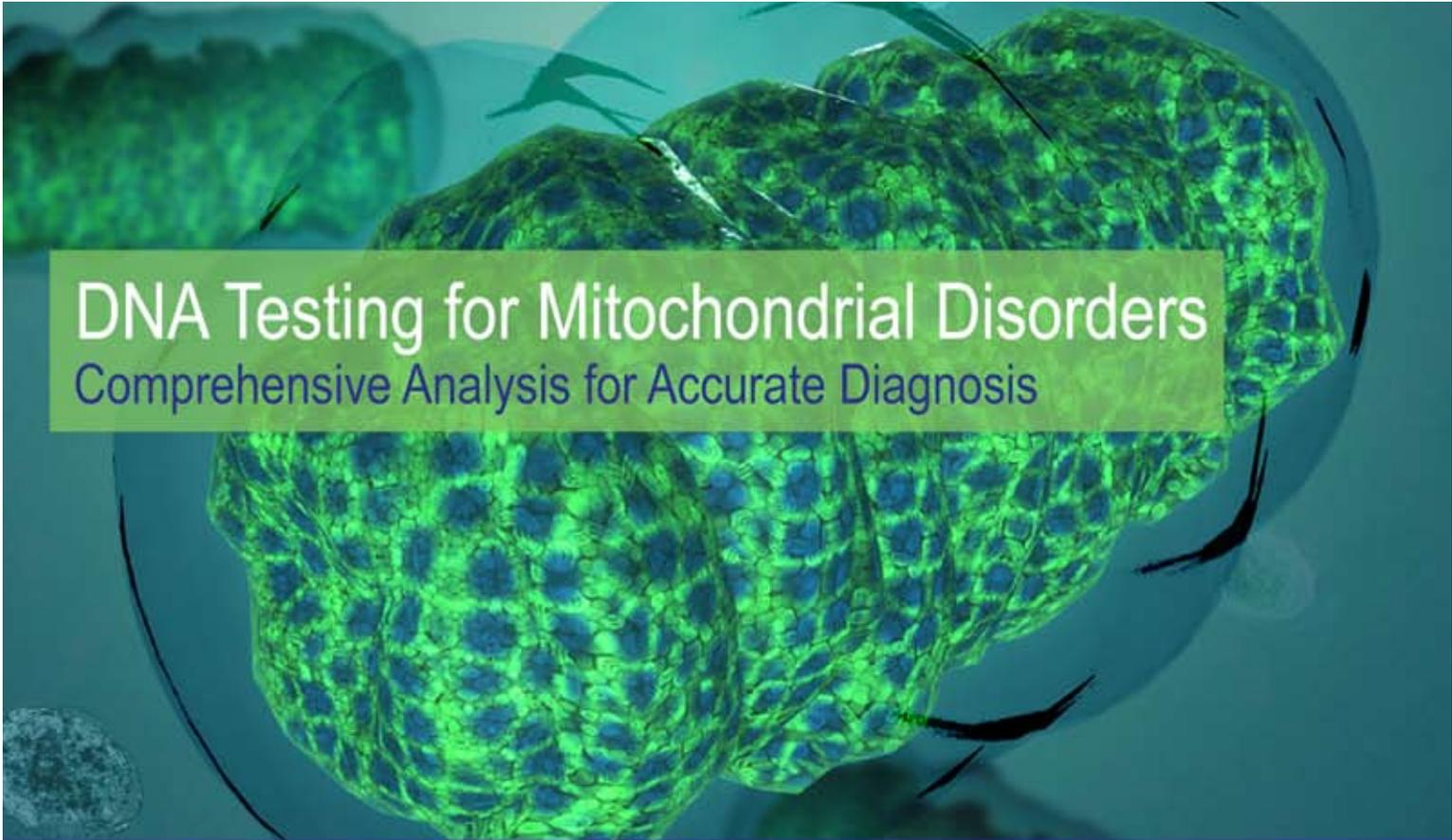
Edison Pharmaceuticals has announced the start of a phase 2B study entitled, "A Phase 2B Randomized, Placebo-Controlled, Double-Blind Clinical Trial of EPI-743 in Children with Leigh Syndrome." The trial is a placebo-controlled study lasting six months, and then extending an additional six months, during which time all subjects will receive EPI-743. Subjects must be between one and twelve years old, possess genetic confirmation of Leigh syndrome, and meet certain disease severity criteria. More information on the study specifics is available on clinicaltrials.gov. Four clinical trial sites have been selected in the United States: Lucile Packard Children's Hospital, Stanford University Medical Center – Palo Alto, California; Akron Children's Hospital – Akron, Ohio; Seattle Children's Hospital – Seattle, Washington; and Texas Children's Hospital, Baylor University – Houston, Texas.

The start of the trial follows the publication of a study entitled, "Prospective Open Label Study of

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From the Chairman



The month of September was an important month for affected individuals and their families. Not only was it the month in which thousands of awareness activities occurred around the country, but it was also a month for some very exciting developments that have had an important impact on our community. It is easy to see this progress by referring to the UMDF's mission - *To promote research and education for the diagnosis, treatment, and cure of mitochondrial disorders and to provide support to affected individuals and families.* **Note the highlighted words below.**

We received some very exciting news when Edison Pharmaceuticals announced that the Committee for Orphan Medical Products (COMP), European Medicines Agency, granted orphan designation to EPI-743 for the **TREATMENT** of Leigh disease. According to Edison, this is the first time a positive opinion has been issued on an orphan designation for the **TREATMENT** of Leigh syndrome, for which no authorized **TREATMENT** exists in the European Union. Edison also announced positive results in their study, "Prospective Open Label Study of EPI-743 in Children with Leigh Syndrome." I would invite you to learn more about this study, what it means for patients in the United States, and upcoming clinical trials by visiting www.umdf.org/epi743. From this page, you can click on the link to listen to all of the latest information about EPI-743 that was presented by Dr. Guy Miller of Edison Pharmaceuticals and Dr. Greg Enns from Lucille Packard Children's Hospital and Stanford University.

On September 21, more than 50 people filled a congressional briefing room on Capitol Hill for the inaugural meeting of the "Congressional Mitochondrial Disease Caucus." The caucus was formed because UMDF members made its creation part of the 'ask' when we all participated in "Day on the Hill" back in June. To date, 15 members of Congress are members of the caucus. Because the caucus serves as a

platform for the **EDUCATION** of mitochondrial disease, potential **TREATMENTS**, and possible **CURES**, we need more members of Congress to sign up and become members. I encourage you to visit www.umdf.org/ legislation to see if your congressman is a member. If they are not, follow the links on the page, send them a letter, or call them, and ask them to join.

Our strategic plan continues to advance. Our goal was to pilot a program that would create a regional coordinator position in each of seven regions across the United States to improve **SUPPORT**. Last year, Margaret Moore joined us to be our Regional Coordinator in the Southeast Region. Because of the tremendous progress Margaret is making in her region, we have decided to expand our **SUPPORT** with additional Regional Coordinators. Anne Simonsen will be serving as our Regional Coordinator in the Great Lakes Region and Cassie Franklin will be serving as our Regional Coordinator in the Central Region. We are very excited to have them on board, and I hope you get to meet them soon. We plan to increase our staff to the four other regions of the country very soon.

And finally, we welcomed a new Board Member to the UMDF this fall. Debra Schindler-Boultinghouse, a longtime Houston Chapter Officer, joined the UMDF Board of Trustees in September. We welcome Deb to the board as she continues her service to mitochondrial disease patients and families.

Fall definitely seems like an energizing time at the UMDF with developments and progress that we all can be excited about.

Energy to all,

W. Dan Wright, UMDF Chairman



HOPE. ENERGY. LIFE.

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UMDF's Mitochondrial Disease Congressional Caucus

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When Kennerley was 14, she suffered another stroke. Doctors speculated that her illness was the result of a blood clotting issue, Lyme disease, or that her illness was in her head. It was not until she turned 16 that Kennerley would receive her diagnosis of Complex I mitochondrial disease. Further illustrating her point, Kennerley outlined the myriad of issues she has to battle with her health insurance company and she spoke of the others that she knows who face similar battles.

Dr. Danuta Krostoski, Ph.D., Special Assistant to the Deputy Director at the Eunice Kennedy Shriver National Institute of Child Health and Human Development at the National Institutes of Health, wrapped up the session. Dr. Krostoski outlined the need for patient registries and repositories, clinical trials, and collaborative partnerships as a pathway to move patients toward effective treatments. She highlighted the work being done by the North American Mitochondrial Disease Consortium (NAMDC) and the newly formed Mitochondrial Disease Sequence Data Repository Consortium (MSeqDR) as pathways towards better treatments and potential cures. MSeqDr was initiated at the UMDF Symposium in Washington, D.C. Dr. Krostoski told the audience that MSeqDr calls for a common, genomic data repository with more than 100 experts participating

globally and will interface with already existing global genomic databases. She stated that the end result could be an increase in the ability to diagnose primary mitochondrial diseases, provide greater opportunity to design research projects to understand the mechanisms underlying these disorders, facilitate identification of genetic links to "secondary" mitochondrial conditions, and increase potential for new treatments.

These congressional briefings would not be possible without the help of our UMDF members who either participated in the 2012 Day on the Hill or phoned their congressman/ congresswoman and asked him/her to attend this session or any of the upcoming sessions planned in 2013. To date, the Congressional Mitochondrial Disease Caucus has 15 members. If you would like to see if your congressman is a member, visit www.umdf.org/legislation. Midway down the web page is a link that will tell you the current members of the Caucus.

If you want your congressman to join – you need to ask. Call your congressman today and ask them to join the Mitochondrial Disease Congressional Caucus or send them a letter at www.umdf.org/legislation.

EPI-743 Trial Begins in Patients with Leigh Syndrome

(Continued from page 1)

EPI-743 in Children with Leigh Syndrome (Subacute Necrotizing Encephalomyelopathy)," was conducted at the Ospedale Pediatrico Bambino Gesù– the Vatican's Children's Hospital, Rome, Italy. The results of the clinical trial were published online, September 10, 2012, in the journal, "Molecular Genetics and Metabolism."

With the announcement by Edison Pharmaceuticals, the United Mitochondrial Disease Foundation stated that the news is another step towards the development of potential treatments for mitochondrial diseases. "As the largest advocacy group representing mitochondrial disease patients, we are pleased to see this new development," said Charles A. Mohan, Jr., CEO and Executive Director of the UMDF. "The news of the first patient participating in this trial is not only important for patients who are suffering from Leigh disease. It also gives hope to those who suffer from the multiple variations of mitochondrial disease that research can help us move closer to a cure."

According to Edison Pharmaceuticals, ten children with seven differing subtypes of Leigh syndrome, ranging in age from 1-13 years, were treated with EPI-743 in the Italian study. All ten children exhibited reversal of disease progression as measured by four different disease-relevant metrics. The clinical response was durable over 180 days. No significant safety events were observed. Edison reports that the findings confirm previous clinical results obtained in the United States and in Europe.

Leigh syndrome is an inherited lethal, progressive, predominantly pediatric, neuromuscular disorder for which there are no approved treatments. Initially described in 1951, the hallmarks of the disease include bilateral necrosis (death) of central nervous system regions responsible for the control of breathing and other neurologic functions. Leigh syndrome belongs to a large family of disorders identified as "mitochondrial disease." The disorders share a common biochemical feature: defects in cellular energy metabolism. EPI-743 is an orally bioavailable small molecule being developed by Edison Pharmaceuticals for the treatment of Leigh syndrome and other inherited mitochondrial diseases.

"The UMDF is anxious to help Edison recruit patients for this promising U.S. trial," said Mohan. "As you know, we have a large patient database and working with the North American Mitochondrial Disease Consortium (NAMDC), we will educate the patient community about this exciting development and encourage participation in this very important upcoming trial."

On October, 5, 2012, the UMDF and MitoAction conducted a joint conference call with Dr. Guy Miller and Dr. Greg Enns of Lucille Packard Children's Hospital at Stanford University. Several hundred people joined the call to hear the latest information about the upcoming trial. Doctors Miller and Enns also answered some of the questions generated by the patient community. You may listen to the call by visiting www.umdf.org/epi743. The page also contains the latest information about EPI-743.

UMDF Board Members Welcome New Additions

The United Mitochondrial Disease Foundation (UMDF) Board of Trustees is pleased to welcome the addition of three new members: Marni Falk, M.D., Norma Gibson, and Debra Schindler-Boultinghouse.



Marni Falk, M.D.

Marni Falk, M.D.

Marni Falk, M.D., is the Scientific and Medical Advisory Board (SMAB) Representative. She is also the Chair of the SMAB and has been a member of it since 2011. She lives in Philadelphia, Pennsylvania.

She is an Assistant Professor in the Division of Human Genetics, Department of Pediatrics at The Children's Hospital of Philadelphia (CHOP) and University of Pennsylvania Perelman School of Medicine. Board certified in Pediatrics and Clinical Genetics, Dr.

Falk directs the CHOP Mitochondrial-Genetics Diagnostic Clinic to aid in the evaluation and management of individuals of all ages with suspected mitochondrial disease. She is actively involved in developing improved diagnostic approaches for mitochondrial disease, including whole exome sequencing approaches in affected families.

Dr. Falk is also the Principal Investigator of an NIH-funded translational research laboratory at CHOP that investigates the global metabolic consequences of mitochondrial disease, and targeted pharmacologic therapies, in *C. elegans*, mouse, and human tissue genetic models. She has authored 40 publications in the areas of human genetics and mitochondrial disease, and served in 2010 as guest editor of a Developmental Disabilities and Research Reviews special issue on "Emerging Research in Mitochondrial Disease."



Norma Gibson

Norma Gibson

Norma Gibson is the Chapter Liaison. Gibson of Ukiah, California, joined UMDF in 1997, along with her daughter, Heidi Marie Daniel. Heidi, who lost her battle with mitochondrial disease in 2001, was an inspiration to everyone she met and she worked very hard to educate the public and the medical community about mitochondrial disease.

Gibson is the President of the UMDF California Chapter and is the Event Co-Chair for the 2013 Energy

for Life Walkathon in San Francisco. The first Energy for Life Walkathon in San Francisco, led by Gibson, drew approximately 425 people and raised more than \$66,000. She has initiated and directed numerous fundraisers throughout the years, including selling raffle tickets and holding wine tastings. Her donations to the UMDF have exceeded \$37,000!

She received the Stanley A. Davis Award at the UMDF's 2012 Symposium. This Stanley A. Davis Leadership Award is the most prestigious UMDF National Award honoring a UMDF Leader who best represents the selfless dedication and commitment to the UMDF Mission as that of its namesake.



Debra Schindler-Boultinghouse

Debra Schindler-Boultinghouse

Debra Schindler-Boultinghouse is a Trustee. She lives in Houston, Texas, with her husband, Dr. Oscar Boultinghouse, and both of them support the efforts of the UMDF. She is the mother of three children, Kyle, Kat, and Chris, and stays active in their lives. Chris, her youngest child, died from mitochondrial disease in 2004 at age 11.

Schindler-Boultinghouse has been active in the Houston community in multiple efforts over the last 28 years. She is the founder and President of the Houston Chapter of the UMDF.

She started this group locally in 2005 and it became a chapter of the national group in March of 2007. The Houston Chapter's efforts include fundraising through an Energy for Life Walkathon, in which she is the Co-Chair, and Mito is a Mess, which has raised over \$600,000 at this point. The Chapter also has an all family annual facilitated support group, an annual mito family fun day in Texas, and a leadership seminar to educate and develop future UMDF leaders.

In addition to her efforts at the UMDF, Schindler-Boultinghouse began GenesisBCS in 1983 and serves as President and is majority stockholder. Genesis provides communication solutions to Houston and surrounding metroplex businesses. They have sold about 3,500 solutions and received multiple awards from manufactures, peers, Ernst and Young, and the Houston technology community. She has also held positions in the following organizations: the Houston Better Business Bureau, the Houston Livestock Show and Rodeo, The Professional Group (a 200+ women entrepreneur group), and St. Cecilia's Advisory Board. She is a graduate of Ohio State University, is a Certified Stephens Minister, and a recent Goldman Sachs 10,000 Small Businesses graduate.

Become a UMDF Volunteer!

Volunteering on the Board of Trustees is just one way you can get involved with the UMDF.

Look for other ways to volunteer by going to the UMDF website, www.umdf.org, and clicking on "Get Involved."

How To Let People Who Care, Help You

Have any of your family and friends ever asked you, "What is that organization you spend so much time talking about and what is it that they do?" You may not have known what to say or how to respond. Yet, if they were the ones that had a serious illness, wouldn't you want more information about their struggles and a way to help them?

We may not know how to engage those that care about us. Having an Ask Event is one way to allow people to help you. It gives them a chance to make a financial gift to the United Mitochondrial Disease Foundation (UMDF) and partner with them to further the UMDF's mission of supporting those with mitochondrial disease and supporting research towards a cure. It also gives those that care about you a chance to connect with you and the UMDF by providing them with the opportunity to learn more about your situation, mitochondrial disease, and the strides being made by the UMDF.

There have been several of these events sponsored already. Fred Durham of Nashville, Tennessee, hosted an Ask Event at a local restaurant where 8 - 10 people from the UMDF community

attended. He shared with those in attendance about why the UMDF is important to him and staff from the National Office gave an update on what's been happening at the Foundation. An Ask Event was also recently held in Pittsburgh, Pennsylvania, in which Dr. Amy Goldstein spoke to those in attendance sharing her perspective of the importance of treating those affected with a mitochondrial disease.

Anyone can hold an Ask Event, and typically, these events are small so the conversation can be tailored to what attendees want to know more about. Some people may want to connect with the UMDF and learn more about how they provide support and education to those affected, while others may want to hear about the latest news in the area of research.

There are currently two Ask Events planned, one in Houston, Texas, and one in Boston, Massachusetts. If you are interested in hosting your own Ask Event, contact Cindy Shafer, UMDF Director of Development, by telephone, toll-free, 1-888-317-8633 or via e-mail at cindy.shafer@umdf.org.

Estate Planning for Future Generations

If you are looking for a way to ensure that future generations benefit from UMDF, you may want to consider an estate gift. UMDF's staff will work closely with you and your financial advisor or legal counsel to assist with choosing the best option for you. Estate giving vehicles offer a variety of tax benefits and can accomplish your long term giving goals.

Estate giving can appear to be complicated, but some important facts to know are:

- You do not need to be wealthy to make an estate gift.
- Anyone can make an estate gift at any point in his/her life.
- Estate gifts can benefit a specific aspect of our mission or can help fund general operating expenses.
- Estate giving vehicles come in all shapes and sizes to meet the donor's needs.
- An estate gift is a great way to show your appreciation to UMDF and acknowledge the difference it has made in your life or the life of a loved one.

For more information about how you can include UMDF in your estate plan, please contact Cindy Shafer, Director of Development, by telephone, toll-free, at 1-888-317-8633 or via e-mail at cindy.shafer@umdf.org.



Will you leave a legacy?

Planned giving means that you make plans today to make a gift to UMDF either now or in the future. Typical planned gifts are wills, endowments, gifts of property, insurance policies or investments you own.

For more information Call Cindy Shafer at 888.317.UMDF

 UNITED MITOCHONDRIAL DISEASE FOUNDATION. HOPE. ENERGY. LIFE.

UMDF Hires Two Regional Coordinators

In September, the United Mitochondrial Disease Foundation (UMDF) hired two Regional Coordinators. Anne Simonsen of Minneapolis, Minnesota, is the Regional Coordinator for the Great Lakes Region, and Cassie Franklin, of Texas, is the Regional Coordinator for the Central Region.

Simonsen will work with patients and families who live in the states of Kentucky, Minnesota, Wisconsin, Illinois, Michigan, Indiana, and Ohio. Franklin will work with patients and families who live in Texas, Louisiana, Mississippi, Arkansas, Oklahoma, Kansas, Missouri, Nebraska, Iowa, South Dakota, and North Dakota.

Simonsen brings to the UMDF over a decade of management experience leading projects in a number of different capacities. She has a Bachelor's degree from the University of St. Thomas in St. Paul, MN. Simonsen said, "The UMDF has been an important part of my family's life for the past two years, and I am honored to work with others dedicated towards a cure!" Feel free to contact her by telephone at 651-271-4313 or through e-mail at anne.simonsen@umdf.org.

Franklin joins the UMDF with more than six years of non-profit experience in the museum and education fields. She

has a Bachelor of Arts degree from Texas A&M University and a Masters of Arts degree from Tufts University. Franklin said, "I am so proud to be working toward such a great cause, finding a cure and treatment for mitochondrial disease, but I am even more grateful to be serving, supporting, and connecting such great people." She can be reached by telephone at 979-571-2147 or via e-mail at cassie.franklin@umdf.org.

As part of the UMDF's strategic plan to better focus on the needs of its members, the organization has developed a plan that will create seven regions across the country. With these latest additions, the UMDF now has three full-time regional coordinators across the country. In addition to Simonsen and Franklin, Margaret Moore oversees the Southeast Region. Four more regions are planned as the UMDF continues to follow its strategic plan.



Anne Simonsen



Cassie Franklin

In their new roles, Simonsen and Franklin will be responsible for helping the UMDF identify members interested in participating in support and social activities, as well as, patient, family, medical education, advocacy, and development activities. Once those individuals are identified, they will work with the UMDF National Office to facilitate the various activities within the region.

Are you looking for a Mitochondrial Physician?

The United Mitochondrial Disease Foundation (UMDF) has a fairly extensive physician list, which contains several hundred names of doctors throughout the United States who manage the care of mitochondrial patients. We have a list of Canadian and overseas physicians as well. The best way to obtain this information is to contact the UMDF National Office by calling the toll-free phone number, 1-888-317-8633, or by sending an e-mail through the www.umdf.org/umdfconnect form.

The physician world is constantly changing. Our staff is updating the physician list regularly based on physicians who complete our "Do You Manage Mito" form. Some physicians have requested that their contact information not be included on a published list on the website but are comfortable with the UMDF providing information upon request. The UMDF

strives to serve our mitochondrial community with the most up-to-date information as well as provide tips on navigating some of the offices, and we feel the best way to serve you is through direct contact by phone or e-mail. Please contact us...we are here for you!

In addition to offering helpful suggestions about specific physician office practices, the UMDF staff can also share information about local UMDF support groups and activities that may be of interest to you and your family. And, we always love to hear from our patients and families.

Do you already have a physician managing your care and would recommend him/her to others? Please contact us by phone at 1-888-317-8633 or e-mail info@umdf.org. With your help, we can make a difference to others in your area!

UMDF Celebrates Awareness Week 2012

The National Office staff of the United Mitochondrial Disease Foundation (UMDF), along with many of you, celebrated Awareness Week, September 16-22, 2012. If you are not familiar with it, Awareness Week takes place the third week in September every year across the globe. It's a week where those who are affected by mitochondrial disease can educate others about the disease since it's not as commonly known about as diseases such as cancer or diabetes.

Jody Thompson of Crooksville, Ohio, was one of the many people who ordered collateral from the UMDF. She set up a booth at a high school football game and distributed information about mitochondrial disease to attendees. Since her daughter, Baylee, was chosen to receive a bedroom makeover by Special Spaces, Thompson arranged to have it done during Awareness Week to capitalize on awareness, and the story was picked up by a local TV station and newspaper in Thompson's hometown.

Austin Angeloff, a five-year-old with mitochondrial disease, from Kingsford, Michigan, took the initiative to raise awareness and funds for the UMDF by holding numerous fundraisers. Angeloff asked his mother, Genevieve, if he could sell lemonade during her garage sale to raise money for research. During Awareness Week, he sold Mito Awareness ribbons at First Presbyterian Church in Kingsford and gave out cards explaining how the disease affects him.



David Porter distributing information about mitochondrial disease at an Awareness Night event.

David Porter, an affected adult who lives in Flowery Branch, Georgia, held an Awareness Night in Buford, Georgia, at the Hamilton Mill Chick-Fil-A. The event was also a Spirit Night and Chick-Fil-A donated 5% of the total proceeds from 5:00 p.m. - 8:00 p.m. that night. Cheryl Porter, David's mom, said, "We had a large turnout and it was lots of fun!"

Sara Brown of Winnsboro, Texas, kicked off Awareness Week with an Emery Hope Brown Benefit, a benefit auction for her daughter, Emery and the UMDF. Dan Wright, UMDF Chairman of the Board, spoke, and there were more than 500 people in attendance. Throughout the week, Interact Club, a

group of high schoolers at Winnsboro High School, decided to make mitochondrial disease awareness a priority, made presentations to the community, had raffles, and sold t-shirts to benefit the UMDF. On Friday, September 21, which happened to be the high school's Homecoming, a



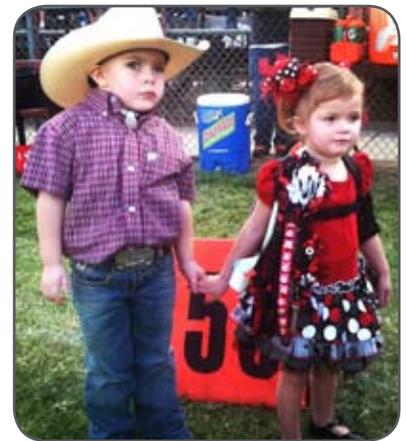
Austin Angeloff with a Mito Awareness ribbon and card about mitochondrial disease. Photo used with permission from the Iron Mountain Daily News.

pep rally was held in which Interact recognized Emery and Jake

Warren, who also has Leigh's disease, and made a presentation to the students about mitochondrial disease. Emery and Jake rode in the Homecoming parade and helped crown the Homecoming Queen at the football game. More than 500 balloons were released before the game to remember those who are fighting mitochondrial disease and those who passed away too soon.

Christina Whaley, a Spanish Teacher at Steele Canyon Charter High School in San Diego, California, talks to her students about mitochondrial disease on a regular basis. Since May of 2012, she has talked to about 250 students because that is when she found out her daughter, Kailyn, had the

disease. During Awareness Week, Whaley sent out an e-mail to a staff of 250 people, to inform them about both of her daughters, who have mitochondrial disease, and educate them about it. In addition, she posted her story on Facebook to 370 friends in a private message and distributed the UMDF's bookmarks, which were a big hit. Whaley said, "This awareness has led to students interested in researching mitochondrial disease for their junior year research projects, senior year awareness projects, and students starting a club on campus called the Action for Mito Club." In addition to these awareness efforts, Whaley helped the UMDF by getting approximately 500 friends to "Like" the Chase Community giving page and choose UMDF. She also spread the word to friends about fundraisers, such as the Halloween costumes. com 5 Minute FUN-raiser that UMDF held this fall.



Jake Warren and Emery Brown at Winnsboro's Homecoming.



Christina Whaley's daughters: Charis, age 1.5 and Kailyn, age 3.5, who both have mitochondrial disease.

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Missy Leone, an affected adult who lives in Farmington Hills, Michigan, manned a table at the Detroit Metropolitan Wayne County Airport where she educated a lot of people about mitochondrial disease because many of the people whom she spoke with had never heard of it before. Leone also sold Dairy Queen ice cream sandwiches at the table to raise money for the UMDF. Since Awareness Week, she has continued her efforts and sold ice cream sandwiches at her church and at a hockey tournament.

Spreading awareness about mitochondrial disease was the passion and mission of Leslie Cora Whitt-Williams. Diagnosed at the age of 20, Whitt-Williams dedicated the last few years of her life distributing information about her illness to everyone she met.

Just before Awareness Week started in September, Whitt-Williams was reading about Japanese legends. The large, white crane is revered in Japan because of its graceful and majestic beauty. Whitt-Williams continued her research. According to the legend, a crane is said to live 1,000 years. It promises that anyone who folds 1,000 origami cranes will be granted a wish. Other variations of the legend state that the person may be granted good luck, or recovery from illness or injury.

Whitt-Williams wanted to spend Awareness week folding paper into 1,000 origami cranes. Her older sister, Megan Sheehy, knew the task would demand something that Whitt-Williams was lacking - energy. Sheehy knew her sister would need help. She created an event on Facebook, in honor of Whitt-Williams. Sheehy told the world about her sister's desire of folding cranes; she asked others to make cranes out of origami paper for Leslie. The event spread worldwide across social media and people were not only making origami cranes, but they were learning more about mitochondrial disease, which was Whitt-Williams' dream in the first place. Whitt-Williams received over 5,000 cranes. Sadly, on October 21, 2012, Whitt-Williams lost her battle with mitochondrial disease and left us far too soon at the age of 24.

Whitt-Williams lived her life like the beauty and majesty of the crane. A huge Cincinnati Reds fan, she lived in Cincinnati, Ohio, with her husband, Jeff, and in close proximity to her mom, Allisa Whitt. Before Leslie became sick, she was an athlete; she played soccer during her elementary and middle school years, and she was involved with swimming in her high



Leslie Whitt-Williams with some of the many origami cranes she received.

school years. Whitt-Williams graduated from New Richmond High School in New Richmond, Ohio, as valedictorian with a 4.43 GPA, and she was able to accomplish this while missing most of her sophomore year because of being in the hospital. She attended Case Western University with the intentions of studying pre-med, but she was unable to finish because of her health. Then, she went home to Cincinnati where she attended Xavier University; she only lasted one semester due to her deteriorating health.

Whitt-Williams wanted to raise awareness for those who battle mitochondrial disease because she wanted more doctors, nurses, and hospitals to know more about mitochondrial disease and wanted them to take patients more seriously who say they have it. She also wished there were more definitive diagnosis and treatment options. She wanted others who have mitochondrial disease to keep on fighting and battle until their last breath.

You don't have to wait until Awareness Week to raise awareness about mitochondrial disease. You can raise awareness about the disease all year long. If you are looking for some ideas on how to educate others, the UMDF has a number of suggestions on its "Awareness Week" web page at www.umdf.org/awareness.

Crystal Evans-Pradhan Helped Leslie Make her Wish Come True

Crystal Evans-Pradhan, who has Mitochondrial Myopathy, promoted Leslie's wish for 1,000 cranes by posting information about Leslie, her wish, and mitochondrial disease on her website.

So many people learned about mitochondrial disease as a result of Leslie's wish. Leslie received more than 5,000 origami cranes.

What can you do to raise awareness about mitochondrial disease? For ideas, go to the UMDF website and look under "Get Involved, Awareness Week."



Crystal Evans-Pradhan

Getting Connected with the UMDF

Interested in networking with other UMDF members who understand the challenges of living with mitochondrial disease? Need the names of physicians near you who are familiar with the diagnosis and/or treatment of mitochondrial disorders? Can't find the information you are looking for on the UMDF website? Let the UMDF help get you connected. You can call the UMDF office toll free at 888-317-UMDF and a member of our friendly staff will be happy to assist you. If you prefer, you can complete our new contact form at www.umdf.org/umdfconnect.

Jean Bassett and Melinda O'Toole have worked in the Member Services Department for more than ten years and respond to the information requests received by UMDF. When

you send a request, a staff member will respond with appropriate basic information, provide physician names, or suggest possible resources. If additional assistance is needed, your inquiry will be forwarded to a member of our network of volunteers or one of our Regional Coordinators. Our volunteer Support Ambassadors offer a listening ear, information on local resources, and an understanding of life with mitochondrial disease.

UMDF offers in-person support groups in many locations, as well as educational meetings, social activities, annual meetings, webinars, clinical trial information, quarterly newsletters, and many other ways to get connected. Be sure that you stay connected and learn about local opportunities by registering with UMDF at www.umdf.org/join. It's free!

Become a Part of the United Mitochondrial Disease Foundation Support Volunteer Team

Caring individuals interested in becoming a part of the UMDF support team are needed. UMDF offers support through Support Ambassadors, local support groups, and one-time meet and greet events. Volunteers are vital for all of these and other efforts. UMDF Support Ambassadors provide a listening ear for newly diagnosed patients and families whose situations have changed. They engage members who are interested in networking with others affected by mitochondrial

disease. In an effort to allow volunteers to concentrate their energy on activities that they find rewarding, we have recently revised our UMDF Ambassador role to be primarily a support contact. If you are interested in learning more about this or other UMDF volunteer opportunities, please go to www.umdf.org/volunteerops and complete the online form. Upon receiving your completed form a member of the UMDF staff will contact you.

Have you joined the RDCRN and NAMDC?

If not, you should. By signing up for both patient contact registries, you are furthering research and potential cures and treatments. Patients who participate in research make it possible for researchers to create new studies and work for the improvement of all our lives.

The Rare Disease Clinical Research Network, or RDCRN, provides a Contact Registry that is patient-populated. The registry collects contact information and registers people with rare diseases via the Internet. It is a useful tool for researchers for recruitment for clinical trials and other projects.

The North American Mitochondrial Disease Consortium, or NAMDC, is more in-depth. In order to participate in the

NAMDC Patient Data Registry and Biorepository, patients have to sign an informed consent form that allows researchers to enter information from the patients' medical records in a database. This database will be used, among other things, to refine the techniques used for patient diagnosis of mitochondrial diseases, and is a far more powerful tool than a contact registry alone.

Do you want to make a contribution to mitochondrial disease research? The absolute best thing you can do is participate in both registries. For information on the RDCRN and details on how to join, visit www.umdf.org/rdcrn. For information on NAMDC and details as to how to join, visit www.umdf.org/namdc.

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 www.umdff.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 include: Mark Tarnopolsky, M.D., Ph.D., FRCP (C), McMaster University, Hamilton, Ontario, Canada; Russell Saneto, D.O., Ph.D., Seattle Children's Hospital, Seattle, WA, and Jerry Vockley, M.D., Ph.D., Children's Hospital of Pittsburgh, Pittsburgh, PA.

The Question is...

My daughter is now 16 and has been on the DepoProvera shot for over one year to control heavy painful periods. She is now looking to change methods. We were wondering if the birth control patch is a safe option. She has an unspecified form of mitochondrial disorder with a secondary carnitine deficiency. If it helps her younger brother has complexes I, III and V (found with a muscle biopsy). We are just beginning other testing for her to see if we can get more specific.



Russell Saneto, D.O., Ph.D.

Response from Russ Saneto, D.O., Ph.D.

Birth control is a personal choice and efficacy and side effects are often dependent on the particular patient. If you mean, "safe option" being not causing exacerbation of a possible mitochondrial disease, likely the patch would be safe, as was the DepoProvera shot. We have had patients who used this without significant side effects. We have also had patients use the progesterone IUD, birth control pills, etc. If your

daughter is taking other medications, I would strongly encourage you to discuss this with your physician. Also, she should be taking folic acid supplementation.

The Question is...

My daughter was diagnosed with a mitochondrial disease (Complex II-III) through a muscle biopsy (frozen tissue sample). She has muscle weakness, seizures, developmental delays, auditory neuropathy, and cortical vision loss. I know that mitochondrial disease affects muscles, but her internal organs (heart, liver, and kidney) are functioning properly. Is this normal for someone who is diagnosed with a mito disease? We are happy she does not have any issues with these organs, but are concerned that maybe we are dealing with some other disease altogether.

ASK THE MITO DOCSM

Response from Jerry Vockley, M.D., Ph.D.

Mitochondrial disease can affect any organ in the body and in any combination. The exact expression of disease varies considerable from patient to patient. The problems your daughter faces are certainly seen in great frequency in mitochondrial disease. Heart and kidney can be affected at any age, so even if they are working properly now, they should be monitored on a regular basis. You

don't mention how old your daughter is. For younger children (<5 years) testing every six months is usually sufficient. After that, yearly testing is more typical. Most patients with mito disease and liver problems typically experience this in the first year or two of life. Beyond that, it is less common and testing on the same interval as for heart and kidney is reasonable. There is no reason to question your daughter's diagnosis based on her combination of symptoms.



Jerry Vockley, M.D., Ph.D.

The Question is...

I have complex 1 disease and my local physician has suggested N-acetylcysteine. Would this be any benefit to me?



Mark Tarnopolsky, M.D., Ph.D., FRCP (C)

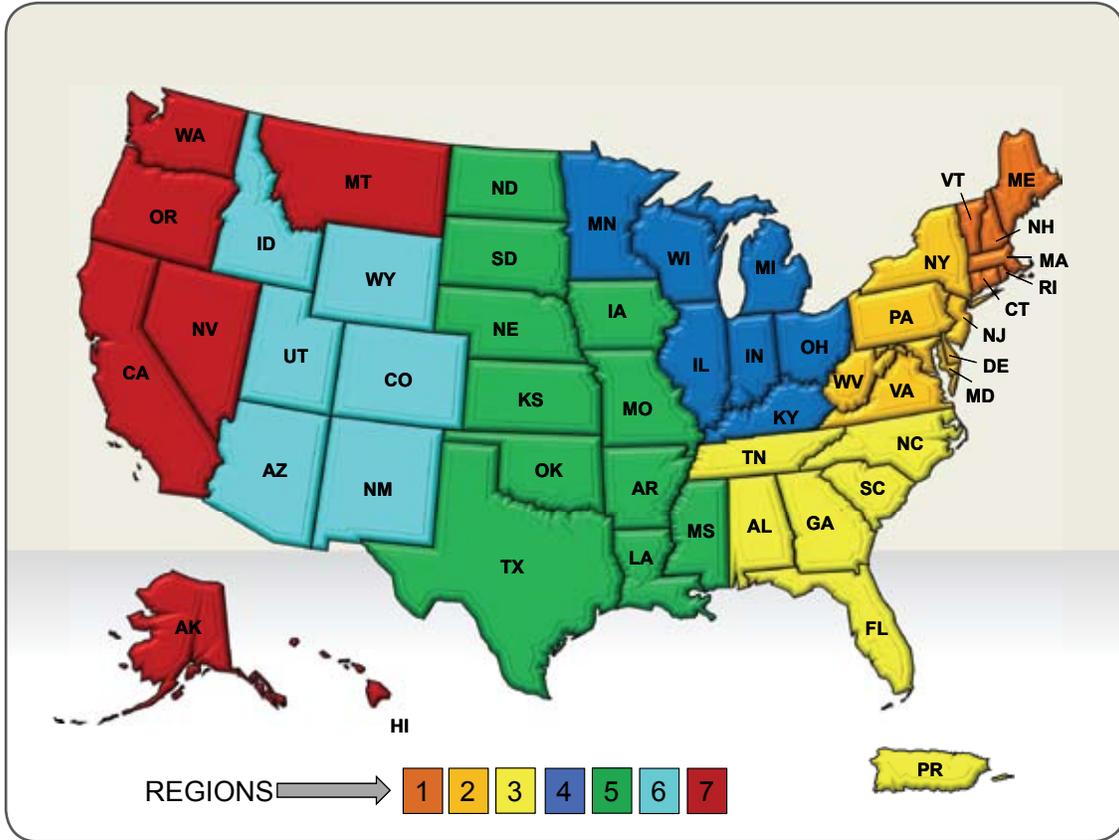
Response from Mark Tarnopolsky, M.D., Ph.D., FRCP (C)

N-acetylcysteine (NAC) is an antioxidant. Yes, many patients with mito will have an increase in oxidative stress. My comment would be that there are no randomized clinical trials (RCT) using NAC in mito disease and it only targets one of the final common pathways in mitochondrial disease. That is why we use a cocktail – In our RCT with creatine, coenzyme Q10,

alpha lipoic acid and vitamin E lowered oxidative stress and lactate. In the future we may consider NAC but the other anti-oxidants we used were shown to work (lower oxidative stress) in an RCT so why switch to an unproven therapy?



In addition to the support staff at the UMDF National Office, help is available to you across the United States and around the world. To reach a state contact for support and/or if your state is not listed and you would still like to connect, simply e-mail to connect@umdf.org. When sending the e-mail, please include the leader's name or city/state in the subject line for us to better serve your needs. Interested in getting involved? Visit www.umdf.org/volunteeropps or call 1-888-317-8633!



New England Region (1)

MAINE
Amber Taylor, Bangor

VERMONT
MaryBeth LeFevre

CONNECTICUT, MASSACHUSETTS, NEW HAMPSHIRE, RHODE ISLAND
Contact the National Office to Connect

Northeast Region (2)

DELAWARE
Judy Weeks, Dover

DC – See Virginia

MARYLAND
Dawn Murphy, DC/Baltimore/Northern Virginia Chapter

NEW JERSEY
Laurel Smith, Delaware Valley Chapter

Northeast Region (2)

NEW YORK
Kim Zuzzolo, NY Metro Chapter
Linda Roesch, Buffalo, Western NY Mito Group
Jennifer Schwartzoff, Buffalo, Western NY Mito Group
Erica Beyea, Buffalo, Western NY Parents Mito Group
Sandy Sallaj, Buffalo, Western NY Parents Mito Group
Jacqueline Perrotta, Albany
Lori Piccirilli, Binghamton
Kimberly Dedrick, Utica

PENNSYLVANIA
Daria Grabowski, Erie
Jessica Myers, Erie Mito Group
Kim Olenderski, Central Pennsylvania
Heather Pallas, Pittsburgh (children)
Karen Wilson, Pittsburgh (adults)

VIRGINIA
Heather Meyer, Lynchburg
Judi Bartle, Central Virginia Mito Group
Sharon Hoffert, Central Virginia Mito Group
Molly McCaffrey Adams, Richmond

Northeast Region (2)

Sharon Goldin, DC/Baltimore/Northern Virginia Chapter
Anne Tuccillo, DC/Baltimore/Northern Virginia Chapter

WEST VIRGINIA

Contact the National Office to Connect

Southeast Region (3)

Margaret Moore, Regional Coordinator

ALABAMA

Margie Slempp, Huntsville, North AL Mito Group

FLORIDA

Amber Ferrell, Gainesville, Central FL Mito Group
Garry Krueger, North Central Florida
Joan Morris, Titusville, FL
Denise Richardson, Fort Lauderdale
Holly Schneider, Coconut Creek
Jennifer Slauter, Orlando, Central FL Mito Group
Sophie Szilagyi, North East Florida

GEORGIA

Hannah Bossie, Athens
Sebastien Cotte, Atlanta
Gail LaFramboise, West Central Georgia
Shelly Lorenzen, Sugar Hill
Wendy Clegg Loyd, Columbus
Mary Beth Morris, Atlanta area
Cheryl Porter, Atlanta
Tiffany Tuggle, Stockbridge

NORTH CAROLINA

Heather Baudet, Raleigh Durham
Jenny Hobbs, Winston-Salem
Terry Holeman, Fayetteville
Christy Koury, Charlotte
Kris Shields, Charlotte
Adriana Smith, Raleigh Durham

SOUTH CAROLINA

Christine Goldin,
Greenville/Spartanburg
Karis Mott, Chapin

TENNESSEE

Emily Culley, Memphis area
Courtney Fellers, Nashville area
Nancy Garrison, Nashville
Brandalyn Henderson, Nashville
Karrie LaCroix, Memphis area
Nancy and Jeffrey Rubio, Knoxville

Great Lakes and Midwest Region (4)

Anne Simonsen, Regional Coordinator

ILLINOIS

Cherie Lawson, Chicago Area Chapter
Luke or Leslie Kirby, Philo
Patti Bauer, Springfield
Victoria Helms, St. Louis Area Mito Group

INDIANA

Jackie Parrish, Indiana Chapter

MICHIGAN

Julie Scott, Eastern Michigan Mito Group
Missy Leone, Eastern Michigan Mito Group
Suzanne Arends, Western Michigan Mito Group
Carrie Gervasone, Fraser
Holly Worden, Lakeview

MINNESOTA

Stacey Pieper, Minneapolis/St. Paul Chapter

OHIO

Darcy Zehe, Ohio Chapter
Ruth Gerke, Central Ohio
Jody Thompson, Central Ohio
Amanda & Jason Salensky, Cincinnati Mito Group
Chris & Alisa Rawski, Toledo

WISCONSIN

Jaqueline Bohne, Harshaw
Karen Loftus, Milwaukee
Terilyn Musser, LaCrosse/Eau Claire
Mindy Welhouse, Kimberly

KENTUCKY

Krystena Richards, Mt. Sterling

Central Region (5)

Cassie Franklin, Regional Coordinator

ARKANSAS

Lacie Moore, Rogers

IOWA

Ronda Eick, Northern Iowa
Kim Novy, Des Moines, Iowa Mito Group

LOUISIANA

Chantel Wooley, Covington
Mandy Poche, Baton Rouge
Anna Stewart, Bossier City

MISSOURI (see also Illinois)

Keli Stone, St. Louis Area Mito Group

TEXAS

Deb Schindler-Boultinghouse,
Houston Chapter
Shawna McElveen, Dallas/Fort Worth
Joshua Brewer, Dallas/Fort Worth
Manuel Castro, Austin
Shamayn Kennedy, Wichita Falls

NORTH DAKOTA & SOUTH DAKOTA

Marty Campbell, Beach, ND

Contact the National Office to connect to Kansas, Mississippi, Nebraska, and Oklahoma

Western Region (6)

ARIZONA

Gina Blair, Peoria

IDAHO

Jennifer Pfefferle, Boise, Idaho Mito Group

NEW MEXICO

Stephanie Cassady, Albuquerque

UTAH

Laura McCluskey, Orem

COLORADO, WYOMING

Contact the National Office to Connect

Pacific and Northwest Region (7)

CALIFORNIA

Norma Gibson, California Chapter
Cheryl Burge, Inland Empire
Cory Greenlee, La Verne

HAWAII

Kimo Phan, Honolulu

OREGON

Kimberli Freiling, Monmouth

WASHINGTON

Joy Krumdiack, NW Washington

ALASKA, MONTANA, NEVADA

Contact the National Office to Connect

INTERNATIONAL

Rob Ryan, Australia
John Carreiro, British Columbia
Nilam Agrawal, India
Saijad Haider, Pakistan
Anne Hansen, Norway
Vidar Hunstad Vik, Norway
Rowland Dicker, United Kingdom
Keely Schellenberg, Winnipeg

YOUTH AMBASSADORS

Joe Wise, California
Emily Swinn, Georgia
Briana Garrlido, Hawaii
Haley Wroth, Massachusetts/
Connecticut
Alexandra Simonian, New York
Tyler Liebegott, Pennsylvania
Colleen Powell, Pennsylvania
Devin Shuman, Washington
Jordan Schmeer, Virginia

Adult Corner

The Adult Advisory Council Team (AACT) - Representing, Serving, and Supporting Affected Adults

Since 2007, the Adult Advisory Council Team (AACT) has been working closely with the UMDF to enhance your experience at the UMDF's annual symposium.

The AACT wants to remind you that if you weren't able to attend the 2012 symposium, you can view most of the family sessions on your computer. Twenty of them were posted as videos on the UMDF website. The videos and transcripts are available at www.umdf.org/2012symposiumvideos.

Gail Wehling, Co-Chairman of the AACT, said, "We hope to see you in June 2013 in Newport Beach, California, joining hundreds of others to learn more about mitochondrial disease, to meet with some of the finest doctors in the field, and to meet others who are on the same journey."

If you want to contact one of the AACT members regarding an issue that pertains to adults with mitochondrial disease, please e-mail them at act@umdf.org.

Adult Advisory Council Team Gains New Members



Jennifer Schwartzott

The Adult Advisory Council Team welcomes Jennifer Schwartzott, Joy Krumdiack, and David McNeas.

Jennifer Schwartzott, who was diagnosed with Mitochondrial Myopathy in 1990 and lives in Western New York, joined the Adult Advisory Council Team (AACT) in June. Sharon Shaw, Chairman of the AACT, invited Schwartzott to be a member of the AACT at the 2012 UMDF Symposium. Shaw said, "I heard of her

reputation from the UMDF staff and her dedication with her chapter in New York. Jennifer also mentioned that she was able to identify more than 300 adult mitochondrial patients through her networking in the New York area."

Schwartzott is a volunteer leader for the UMDF New York Chapter and leads the support group meetings in the Western NY area, which serves a large number of adult members. She is

also the Co-Chair of the Energy For Life Walkathon in Western New York. Schwartzott said, "I am looking forward to participating in the Adult Advisory Council Team."

Information about Joy Krumdiack of Bellingham, Washington, and David McNeas of Chardon, Ohio, will be in the next newsletter.

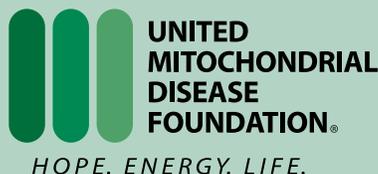
AACT is not a support group, but an advisory council. The purpose of the AACT is to represent and serve the unique needs of the affected adult community and to ensure that those needs are adequately represented to the United Mitochondrial Disease Foundation (UMDF) resulting in enhanced services to the affected adult population. AACT is a liaison to the UMDF Board of Trustees and will assess and evaluate, provide advice and guidance, and make recommendations to UMDF on adult-related issues.

The group convenes on a conference call about four to five times per year and meets in person once a year at the UMDF's annual symposium. If being a member of AACT sounds like something that you would be interested in, contact Sharon Shaw by telephone at 602-692-0001 or via e-mail at shshaw@aol.com.

Adult Advisory Council Team (AACT)

Sharon Shaw, AACT Chair, California
Gail Wehling, AACT Co-Chair, Illinois
Bob Brieff, New York
Linda Cooper, California
Whit Davis, Pennsylvania
Rev. David Hamm, Maryland
Pam Johnson, M.D., Kansas
Joy Krumdiack, Washington
Debra Makowski, Arizona
David McNeas, Ohio
Jennifer Schwartzott, New York
Gregory Yellen, Maryland

Medical Advisors:
Bruce H. Cohen, M.D.
Amy Goldstein, M.D.



PURPOSE OF AACT

To represent and serve the unique needs of the affected adult community and to ensure that those needs are adequately represented to UMDF resulting in enhanced services to the affected adult population.

AACT is a liaison to the UMDF Board of Trustees and will assess and evaluate, provide advice and guidance, and make recommendations to UMDF on adult-related issues.

Healthy Recipes for Winter

The three recipes below are from "Minding My Mitochondria 2nd Ed. - How I Overcame Secondary Progressive Multiple Sclerosis and Got Out of My Wheelchair," a book written by Terry Wahls, M.D., which was suggested to the UMDF.

Chili Pie

Ingredients:

- 1 cup chopped onion
- 1/2 teaspoon coconut or olive oil
- 1-2 teaspoons chili powder
- 1 teaspoon ground cumin
- 1/2 teaspoon garlic powder
- 1/4 teaspoon salt
- 15 oz. can red kidney beans, well drained
- 1 1/2 cups cooked brown rice
- 1/2 cup brewers yeast
- 1 1/2 cups coconut or nut milk
- 1/2 cup ground flax seeds placed in 1/2 cup boiling water
- green pepper, onion rings and salsa for garnish (optional)

Instructions:

In a large saucepan, cook onion in oil until softened. Stir in chili powder, cumin, garlic powder, and salt, cooking 1 more minute. Stir in beans, rice, brewers yeast, milk, and flax seed in boiling water combination. Spread in a 10-inch pie plate and bake uncovered, at 350 degrees for about 20 minutes or until center is just set. Allow it to sit for 10 minutes before serving. Garnish with green pepper and onion rings and salsa, if desired. (Serves 6)

Autumn Bean Soup

Ingredients:

- 2 cups white kidney beans (Cannellini) (include any liquid from canned beans)
- 1 - 2 cups kidney bean or red beans (canned or cooked dry)
- 1 1/2 - 2 cups chickpeas (garbanzos, canned or cooked from dry)
- 2 - 3 cups spinach or escarole, washed drained, and chopped or 10 oz. frozen chopped spinach
- 4 cups chicken broth (read ingredients to be sure gluten free)
- 2 onions, chopped
- 1 large clove garlic, minced
- 1 teaspoon dried basil
- 1 tablespoon dried parsley
- 1 teaspoon dried oregano
- pepper to taste
- brewers yeast for garnish, optional

Instructions:

Combine all ingredients and simmer until onions are soft, about 45 minutes. Serve immediately, garnished with brewers yeast, if desired. Substitute bone broth for chicken broth for a boost for your bones. (Serves 6)

Nutrition is just one of topics to be discussed at the UMDF's annual symposium.

**Join the UMDF for
Mitochondrial Medicine 2013
at the Newport Beach Marriott Hotel & Spa
in Newport Beach, California!**

**Scientific Program: June 12 - 15
Family Program: June 14 - 15**

**Upcoming details will be posted on
www.umdff.org/symposium.**



Blueberry Banana Muffins

Ingredients:

- 2/3 cup mashed ripe banana
- 1 egg
- 1 tablespoon flax seed in 2 tablespoon boiling water
- 1/2 cup oat, almond, or rice milk or apple juice
- 1/3 cup coconut oil (cold pressed preferred)
- 2 cups rice flour
- 1 teaspoon baking soda
- 1 teaspoon baking powder
- 1 cup fresh or frozen blueberries
- 1/4 teaspoon salt

Instructions:

Beat the mashed banana and egg together until creamy. Mix in milk and oil and beat well. Combine dry ingredients, stirring just until moistened. Gently mix in blueberries. Spoon batter into oiled and floured muffin pan, filling 2/3 full. Bake 15 minutes at 350 degrees or until lightly browned. (Makes 12 muffins)

NOTE: Diet and nutrition needs vary from patient to patient in mitochondrial disease. If you like the recipes and they meet your dietary requirements set by your physician or dietitian, enjoy!

The Symposium Doesn't Have to End in June

Margaret Moore, UMDF Regional Coordinator-Southeast, wanted to bring the 2012 UMDF Symposium to people in her region who could not attend so she asked several attendees to hold a Symposium Synopsis. There were three held: one in Durham, North Carolina, one in Nashville, Tennessee, and one in Atlanta, Georgia.

On July 28, 2012, Jenny Hobbs, Christy Koury, Dr. Tim Koves (2012 Mitochondrial Medicine Abstract Cash Award Winner), and Adriana Smith held a Symposium Synopsis at St. Luke's Episcopal Church in Durham, NC. Dr. Koves talked about his research while Hobbs spoke on the UMDF's advocacy efforts on Day on the Hill. Koury gave an overview about Dr. Wallace's talk on living with mitochondrial disease, and Smith talked about nutrition. Smith said, "It was not in any way challenging to coordinate this event." In order to prepare for it, she secured the venue, made handouts, and organized her thoughts before speaking to the group.



Kristi Cole, Mary Beth Morris, Cheryl Porter, and Sebastien Cotte at the Symposium Synopsis in Atlanta, GA

On August 25, 2012, Dr. Tyler Reimschisel and Sonya Murray held their recap of the 2012 Symposium at the Vanderbilt Children's Hospital in Nashville, Tennessee. While Dr. Reimschisel focused more on a review of the scientific sessions, Murray told attendees what she learned in the family sessions. Murray said, "I would encourage everyone to attend the symposium." She found it extremely beneficial in many different ways. This past year, she learned about supplements and nutrition, among other things, and was able to use her newly found knowledge to help her care for her daughter, Taylor. Murray is grateful for the scholarship she received from the UMDF to attend. She went on to say, "What was so special to me about attending the symposium is that there are famous doctors right in front of you, and you can talk to them. It's not like seeing a superstar in Nashville and not being able to talk to them because you want to respect their privacy. These doctors are superstars to us, and yet they are there to talk to us."

On September 15, 2012, Kristi Cole, Sebastien Cotte, Dr. Fran Kendall, Mary Beth Morris, and Cheryl Porter held their recap of several of the presentations that they attended during the symposium in June. The event included 24 attendees, many of whom were new to the mitochondrial community. The group hopes to offer the Symposium Synopsis again next year. The topics that they presented included: general information about the United Mitochondrial Disease Foundation, an overview of Day on the Hill 2012, upcoming local events, information about Dr. Parikh and his talk on what mitochondrial disease is and potential therapies, information about Dr. Greg Enns and his talk on EPI-743 and clinical trials, the mito cocktail, an overview of Attorney Kelly Thompson and Special Needs Financial Planner James Ibach's talk on financial and legal issues, information about Dr. David Thorburn and his talk on genetics and next generation sequencing, a scientific sessions review by Dr. Kendall (via video presentation), and a summary of Mitochondrial Medicine 2012.



Sebastien Cotte speaking to the attendees.

Would you like to coordinate a Symposium Synopsis in your community?

Contact your UMDF Regional Coordinator or the UMDF Member Services Department for assistance, toll-free, at 1-888-317-UMDF or at connect@umdf.org.

UMDF Encourages Future Scientists

Do you remember learning about biology in high school? Some of the high school girls who attend the Sacred Heart Academy in Hamden, Connecticut, are not just learning basic biology. Some girls take classes with Sr. Mary Jane Paoella, ASCJ, who founded the school's biotechnology program in the early 1990s. In order to take classes under this program, students must be honor students and have a background in the life sciences. They must also be focused and precise, according to Sr. Mary Jane.

In June of 2012, the United Mitochondrial Disease Foundation (UMDF) held their annual symposium in Bethesda, Maryland, and the event drew 284 scientists and clinicians. Nineteen students, consisting of juniors and seniors, from the Sacred Heart Academy attended the symposium and were the youngest presenters. These girls presented two posters involving the Actin gene. In September of 2012, the Academy was informed that their 16th to 18th DNA sequences were published by Genbank, the U.S. Government's National Genetic Database. Students at the school have been studying gene sequencing since 1996 and began having their work published in 2005.

Every year, the girls choose a disease gene to study. In the past, they studied five genes most implicated in osteoporosis. The students will continue to learn about gene sequencing this year, and they are studying the PINK1 and PTEN genes that are associated with mitochondrial disease, Parkinson's disease, and breast and prostate cancer.

The nineteen girls who recently had their work published experimented on a nuclear gene, which if mutated, could possibly be implicated in mitochondrial disease. Their focus was on the Actin gene in horseshoe crabs, endangered bay scallops, and tunicates. Some of these girls will go on to study biotechnology and health sciences in college.

Sr. Mary Jane said, "The students were very impressed by the families they met at the symposium and they were so pleased to be part of the advocacy team who went to Capitol Hill. In fact, both Connecticut Senators responded positively to their request. The girls have been interested in both mitochondrial and nuclear genes implicated in mitochondrial diseases because one of their classmates lost a brother last year, to mitochondrial disease."

The young scientists from Sacred Heart Academy were able to present at the 2012 Symposium by submitting an abstract to the UMDF, which went through a review process. In fact, students from the school have experienced the UMDF's review process twice and their work was accepted as posters for the UMDF's Symposium in 2008 and in 2012. In June of 2012, the Abstract Review Committee did a special question and answer time with them during the poster sessions and were quite impressed with their projects and knowledge base.



Sr. Mary Jane Paoella with some of her students at the 2012 symposium.

The UMDF takes pride in its abstract review process for the international symposium. It begins with a Call for Abstracts in October/November and scientists/researchers (including students) from all over the world submit using the online form at www.umdf.org/callforabstracts. Each year, we receive more than 100 submissions and our Abstract Review Committee, which is made up of the Scientific Program Planning Committee and several other researchers from around the world, has to determine if the abstract is acceptable for the program – either as a Poster or as an Oral Presentation. The symposium scientific program typically has between 25-28 slots for oral presentations and the Committee does a thorough review of all submissions to determine oral versus poster presentation.

The Call for Abstracts closes on March 31, 2013, and each reviewer is given between 10-20 abstracts to review with specific criteria to measure and score – originality, significance, relevance, conclusion justified, and clarity. For an unbiased review, all identifiers, such as names and institutions, are removed from each abstract prior to the reviewers receiving it. Reviewers are not assigned any abstracts with which they may have a conflict, such as an affiliation with the same institution. After all scores are combined, a conference call takes place with the Committee to go through each and every abstract to determine Oral versus Poster Presentation as well as triage any abstract with low scores. Cash Awards are also determined at this time based on highest ranking scores.

All accepted abstracts are published in the course syllabus, which is provided to attendees and in the journal *Mitochondrion* post conference. The 2013 Call for Abstracts is open and we look forward to another successful year of submissions!

Call for Abstracts - Oral and Poster Presentations for the 2013 Symposium

All abstracts must be submitted electronically online at: www.umdf.org/callforabstracts by March 31, 2013.

Travel scholarships are available for new researchers. Visit www.umdf.org/symposium.

Family Meetings and Grand Rounds for Health Care Providers

The United Mitochondrial Disease Foundation (UMDF) has made Grand Rounds a top priority to reach out to physicians through introducing and/or broadening the knowledge base on mitochondrial diseases. The primary purpose of our Grand Rounds program is to provide continuing education to health care providers on topics specific to mitochondrial disorders, which also furthers the 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.

With the generous support from Transgenomic Labs, the UMDF hosts approximately 12-15 Grand Rounds per fiscal year throughout the United States. These meetings have received nothing but positive feedback from the medical community.

In addition to Grand Rounds, the UMDF also schedules a special family meeting with our members during this time to not only help educate patients/families about mitochondrial disease but to allow them to speak one-on-one with a mitochondrial specialist. These family meetings are also suitable for outreach to nurses, therapists, educators, and various allied health professionals.

Please see the schedule below for family meetings and Grand Rounds. Perhaps you can get a health care provider to attend or you may want to go to a family meeting.

Contact Janet Owens, UMDF Executive Administrative Assistant for more information. She can be reached at the National Office, toll-free, at 1-800-317-8633, ext. 107 or at janet@umdf.org.

Upcoming Family Meetings and Grand Rounds

<u>Date</u>	<u>Type of Meeting - Presenter</u>	<u>Location</u>
12/19/12	Grand Rounds - Bruce Cohen, M.D.	John Hopkins Medicine, Baltimore, MD
12/20/12	Family Meeting - Bruce Cohen, M.D.	Georgetown University Hospital, Washington, DC
12/21/12	Grand Rounds - Bruce Cohen, M.D.	Georgetown University Hospital, Washington, DC
2/7/2013	Family Meeting - Bruce Cohen, M.D.	(location to be determined - Tampa, FL area)
2/8/2013	Grand Rounds - Bruce Cohen, M.D.	University of South Florida, Tampa, FL
2/12/2013	Grand Rounds - Bruce Cohen, M.D.	Egleston, Atlanta, GA
2/12/2013	Family Meeting - Bruce Cohen, M.D.	(location to be determined - Atlanta, GA area)
2/13/2013	Grand Rounds - Bruce Cohen, M.D.	Scottish Rite, Atlanta, GA
3/6/2013	Family Meeting - Bruce Cohen, M.D.	(location to be determined - NYC Metro area)
3/7/2013	Grand Rounds - Bruce Cohen, M.D.	St. Barnabas Hospital, Bronx, NY
4/15/2013	Family Meeting - Bruce Cohen, M.D.	East Tennessee Children's Hospital, Knoxville, TN
4/16/2013	Grand Rounds - Bruce Cohen, M.D.	East Tennessee Children's Hospital, Knoxville, TN
5/2/2013	Family Meeting - Bruce Cohen, M.D.	University Medical Center, Las Vegas, NV
5/3/2013	Grand Rounds - Bruce Cohen, M.D.	University Medical Center, Las Vegas, NV
5/19/2013	Family Meeting - Bruce Cohen, M.D.	(location to be determined - New Orleans, LA area)
5/20/2013	Grand Rounds - Bruce Cohen, M.D.	Tulane Univ. School of Medicine, New Orleans, LA
7/24/2013	Family Meeting - Bruce Cohen, M.D.	Texas State University, San Marcos, TX
7/25/2013	Grand Rounds - Bruce Cohen, M.D.	Texas State University, San Marcos, TX

For complete meeting details, visit the UMDF calendar on the UMDF website: www.umdf.org.

Special Resource for Expectant Mothers

Often times, the UMDF Member Services Department receives questions about mitochondrial disease and pregnancy. We found a resource that we would like to share with you. "Newcastle Mitochondrial Disease Guidelines: Pregnancy in Mitochondrial Disease" is now included in Mito 101 on the UMDF website. For more information, visit www.umdf.org/mito101revised and scroll down to the pregnancy article.

In the Clinic

The UMDF is happy to kick off a new, newsletter feature we call "In the Clinic..." In this edition, we take you to the Wayne State University Mitochondrial Disease Program. The program is working to build an active collaboration between basic researchers and clinicians that will advance both research and patient care. The Wayne State University Mitochondrial Medicine Program is composed of individuals drawn from clinicians, researchers, and other allied health professionals, who work in a highly collaborative environment and are seeking to improve research and treatment of mitochondrial disease. We are "in the clinic," staffed by John Kamholz, M.D., Ph.D. Dr. Kamholz is a Professor of Neurology and of Molecular Medicine and Genetics, and a member of the Graduate Group in Genetics and Molecular Biology at Wayne State School of Medicine in Detroit, MI.



John Kamholz, M.D., Ph.D.

1. Tell us how you became interested in mitochondrial disease patients?

Several individuals at the University of Pennsylvania, where I did my medical school and residency training, were working on basic and clinical studies of mitochondria, so issues of mitochondrial function in health and disease were a common topic of discussion at seminars and rounds. At one of our Grand Rounds we saw a movie of a patient with Luft's disease, the first identified mitochondrial disorder, in which mitochondria are "uncoupled," causing significant generation of heat and profuse sweating, even at rest. This patient and the excitement of the research community toward basic mitochondrial biology piqued my interest in mitochondrial disease and led to the establishment of our current mitochondrial clinic.

2. Does your clinic accommodate children and adults?

Our clinic accommodates both adults and children.

3. Does your clinic diagnose patients and provide follow up care?

Our clinic is involved in both the diagnosis and treatment of patients and provides follow up care.

4. Do patients need referrals?

Patients will be seen in the clinic either with or without referral.

5. What types of research are you doing right now?

Our clinic is associated with a group of basic scientists focused on the regulation of mitochondrial function who work in the Center for Molecular Medicine and Genetics at Wayne State University School of Medicine. Our combined efforts include both clinical and basic research.

On the clinical research side, we are using anaerobic threshold testing, carried out in the Pulmonary Laboratory at Harper University Hospital, as a screening tool to identify patients with metabolic abnormalities of muscle, which include Mitochondrial Myopathies. Using this screening tool, for example, we have identified a novel mutation in the PHF8 gene, known to cause an X-linked mental retardation syndrome (Siderius Syndrome), which also leads to a significant muscle metabolic abnormality. Interestingly, molecular analysis of the mutant protein demonstrates that it is mislocated within the cell. Patients with suspected mitochondrial disease are screened by anaerobic threshold testing and worked up further depending on the results of this analysis.

On the basic research side, we have a number of projects centered on the regulation of cytochrome oxidase, the rate-limiting step in mitochondrial dependent oxidative metabolism. In one of these projects, for example, we have shown that different wave lengths of infrared light can either increase or decrease the activity of cytochrome

oxidase. Tissue exposure to the appropriate wave length of infrared light can protect the heart and brain from ischemia reperfusion injury, and may provide a new treatment in the future for heart attack and stroke. Also in the future, these studies might lead to novel ways to regulate mitochondrial function in patients with mitochondrial disease.

6. How many researchers and clinicians are involved at your clinic?

Our clinic consists of five clinicians, one genetic counselor, and one nurse. The research team consists of four investigators.

7. Have you made any discoveries in research?

Our group has shown that infrared light can protect heart and brain from ischemia reperfusion injury, heart attack, and stroke, by regulating the activity of cytochrome oxidase, the rate-limiting step in mitochondrial oxidative metabolism. In addition, we have shown that the pulmonary-specific subunit of cytochrome oxidase, COX4i2, is necessary for the lung to regulate blood flow away from injured or malfunctioning areas, a response called hypoxic pulmonary vasoconstriction. Both of these important findings will provide novel areas for future research and may lead to new treatments for patients with mitochondrial disease.

8. How many mitochondrial disease patients do you see?

We usually see four mitochondrial patients during each half-day clinic that meets on the second and fourth Friday of each month.

9. Are their openings for new patients?

We definitely have openings for new patients.

10. What are your plans and goals for the future at your clinic?

In the future we hope to identify better clinical methods for patient diagnosis and novel treatments for patient therapy. In addition, using the new, next generation of DNA sequencing methods, we also hope to identify novel genes involved in causing mitochondrial disease.

11. Tell us who works on your team?

The clinic consists of the following individuals:

John Kamholz M.D., Ph.D., Adult Neurologist
Lobelia Samavati M.D., Pulmonary Medicine Specialist
Vinod Misra M.D., Ph.D., Pediatric Neurologist
Tamam Mohamd M.D., Cardiologist
Gerald Feldman M.D., Ph.D., Pediatrician and Director of Molecular Diagnostics Laboratory
Kelly Kennelly M.S., Genetic Counselor
Theodora Nwamba, R.N., Nurse

The research team consists of the following individuals:

Lawrence Grossman, Ph.D., Director, Center for Molecular Medicine
Maik Hüttemann, Ph.D., Center for Molecular Medicine and Genetics
John Kamholz M.D., Ph.D., Department of Neurology and Center for Molecular Medicine and Genetics
Lobelia Samavati M.D., Department of Medicine and Center for Molecular Medicine and Genetics

If you would like to have your clinic featured in an upcoming newsletter, contact the Communications Department at the UMDF National Office, toll-free at 1-888-317-8633.

Fundraisers Benefiting the UMDF

August 4, 2012. The fifth annual Run 4 Raley event was held at the Philo Ball Park in Philo, IL. The annual event is held in honor of Raley Kirby. The event raised more than \$20,000. Thank you Leslie and Luke Kirby!



*Pam, Logan, and Bob Craft
outside of Rick's 50's Café.*

August 18, 2012. Rick's 50's Café in Hopwood, PA hosted a sing-off with all proceeds benefiting the UMDF. The event was held in honor of Logan Craft and raised more than \$2,600. Thank you Rick and Renee Rohm!

August 25, 2012. Shoppers supported the UMDF by purchasing a \$5.00 coupon to Macy's Shop for a Cause and enjoyed a day of spectacular discounts. The event raised \$2,500.

September 15, 2012. The fifth annual Savannah's Hope Mito Walk was held at the Adventure Life Reformed Church in Altoona, IA. The event included family-friendly activities, and it raised more than \$2,200 for the UMDF!

September 16, 2012. The Meg O'Malley's Irish Open was held in Melbourne, FL in honor of Connor Marathas. The event was hosted by Meg O'Malley's Restaurant and was organized by Scott and Tracy Marathas. Thank you to the Marathas Family for choosing the UMDF and continuing our mission through your outing!

September 20, 2012. A mitochondrial disease awareness fundraiser was held at Urban Flats in Ponte Vedra Beach, FL in honor of Lauren Quinn and Stacy Young. The event raised nearly \$12,000 for the UMDF and raised a priceless amount of awareness! Thank you to Lisha Wise and Phyllis Bove for organizing such an amazing event!

September 20, 2012. The UMDF was chosen as one of four charities to receive proceeds from the United Health Group Charities Golf Outing this year! Anne Simonsen, UMDF Great Lakes Regional Coordinator, and Bonnie Luskey attended the event to accept the UMDF's portion of the proceeds. The UMDF will receive over \$140,000 as our portion of the event in honor of Patrick Luskey! A special thank you to Sue Hartman for your persistence in submitting the UMDF as a charity of choice!



*Kristen Schroeder (above with glasses) and her family
at the Schroeder's Stroll walkathon.*

September 22, 2012. The Brittany Wilkinson Research Fund with the UMDF held their annual Brittany's Walk Toward Energy for Life in Fresno, CA. The annual event raised over \$1,000 for the UMDF in Brittany's memory. Brittany was the UMDF's first Youth Ambassador and holds a special place in all of our hearts. Thank you Linda and family for your continued support!

September 24, 2012. The second annual "Life for Lila" Golf Classic, supporting the UMDF and presented by Unum, was held on Monday, September 24, 2012, at The Golf Club at Ballantyne, in Charlotte, NC. More than \$71,000 was raised for the UMDF. Thank you Dan and Eddy Richardson!

September 29, 2012: Jennifer Pfefferle of Boise, ID held the sixth annual Energy Bowl at Meridian Bowling Lanes in Meridian, ID. More than \$600 was raised for the UMDF. Thank you, Jennifer for your continued support of the UMDF! You "bowled" us over with your energy!



*Lila and Dan Richardson at the
Life for Lila Golf Classic.*

September 29, 2012. The Breyton Senn Research Fund with the UMDF held a 5K Run/Walk/Stroll event in Howard City, MI. Thank you to Ashlee Senn for organizing such a great event this year and for raising over \$6,000 to go directly toward research!

October 7, 2012. The annual Olivia Steele Memorial Golf Outing was held in Johnston, OH. Thank you JR Steele for organizing the outing and raising \$745 in support of the UMDF.

October 7, 2012: Gary Moberly participated in the Bank of America Chicago Marathon with Team, Hope Energy Life. He raised over \$4,000! This year, UMDF was an official charity with the marathon. If you are a runner and plan on running in the Chicago Marathon in 2013, let us know! Thank you Gary! We want you on our team!

October 13, 2012. Kristen Schroeder's family took a "stroll" through Walnut Hill Park in New Britain, CT to honor Kristen at the inaugural Schroeder's Stroll walkathon. More than \$2,900 was raised and donated to the UMDF. Thank you Kristen for pioneering this awesome event!

October 20, 2012. Jennifer Cox of the Western PA Mito Group organized a Vendor Show in Braddock Hills, PA. The event raised more than \$500. Thank you Jennifer for organizing this event!

Additional Fundraisers for the UMDF

October 27, 2012. The first annual UMDF Friendraiser was held at Dove Creek Farm in Bartonville, TX. The outdoor party raised over \$22,000 for the UMDF and helped to introduce mitochondrial disease and the UMDF to some new faces! Thank you B and Norm Bender, Jay and Risa Bender, and Dan and Pat Wright for your help organizing such a fun event!

November 3, 2012. The fourth annual Fall into a Cure event was held in Alexandria, VA. The annual event raised more than \$35,000 with more donations still coming in! A special thank you to Sharon Goldin and Anne Tuccillo for organizing such a beautiful event every year!

November 3, 2012. The Brittany Wilkinson Research Fund with the UMDF held their annual Poker Run in memory of Brittany Wilkinson. A special thank you to Brittany Bearden for your support of the UMDF and the Wilkinson Family!

November 2012: UMDF participated in the Bon-Ton Community Days event this fall. For a donation of \$5, donors received a coupon booklet for Bon-Ton and Bon-Ton owned department stores. Over 20 booklets were sold!

Gifts from the Heart



Ongoing: Katie Parsons from Marietta, GA continues to make duct tape purses and donate a percentage of her sales to the UMDF. Thank you for your continued support, Katie!

Ongoing: Lauren and Jacob Peters from Buford, GA have been making and selling bookmarks to raise money in honor of their cousin, Ava Oglesby, who has mitochondrial disease. Through their crafting for a cure fundraiser, they've been able to raise about \$100 for the UMDF. Thank you Lauren and Jacob!

Lauren Peters holds up one of the bookmarks she made.

June 15, 2012: Ashley Wruble and Makenzie Park of Dubois, PA held

a lemonade and bake sale to raise money for the UMDF in honor of Ashley's brother, Jayden, who has a mitochondrial disease. The girls raised over \$120 for the UMDF! Thank you ladies for an amazing job!

June 2012: Cassie Rayer of Glenshaw, PA held a fundraiser in honor of her cousin, Aubrey Neely. She planned and organized "Bowling for Berry" as part of her senior class requirements at Shaler Area High School. Thank you so much Cassie for honoring your cousin by raising awareness for the UMDF and collecting donations! You rock!

July 16, 2012: Greg and Carolyn Martin organized the eighth annual Carter Classic golf outing at the Prairie Creek Golf Course in Maquoketa, IA. Each July, family and friends are invited to the event in honor and memory of Carter Martin. About \$500 was donated to the UMDF. Thank you Greg and Carolyn!

July 2012: Brayden Lane of Barboursville, WV celebrated his 5th birthday with family and friends. In lieu of gifts, he asked for donations to be made in his honor to the UMDF. His family and friends gathered together for his 5th birthday and donated over \$1,000! Thank you Brayden for generously giving up your gifts for the UMDF! Happy belated birthday, buddy!

July 2012: The Presbyterian Church of Okemos in Okemos, MI held a pancake brunch in honor of Simon Taylor. Simon's sister, Isabel Taylor, who was recently confirmed within the church and her mentor, Sandra Corder, hosted the event. The breakfast with Simon raised over \$1,700 for the UMDF. Thank you Isabel, Sandra, and the congregation at The Presbyterian Church of Okemos!

August 8, 2012: UMDF Spirit Day at the Durham Bulls game in Durham, NC raised over \$550 dollars in honor of Solana Smith, daughter of Adriana and Travis Smith. As the event organizers, they went on the field and received the big check. Local families affected by mitochondrial disease and their friends attended. Dr. Dwight Koeberl, Metabolic Geneticist at Duke attended, as did Dr. Tim Koves, recipient of UMDF research cash award at this year's symposium. Thank you Smiths and Durham Bulls!



Travis Smith and his daughter Solana hold the check to UMDF with Durham employees at a game.

August 11, 2012: The Cincinnati, OH "Mudathlon" took place with over 4,200 participants. David Murphy, Megan Sheehy, Jeff Williams, and their friends raised funds for the UMDF in honor of Leslie Whitt-Williams. Thanks David, Megan, Jeff, and friends for getting down and dirty for a great cause!



David Murphy (with glasses) at the Mudathlon with friends, including Megan Sheehy (on right) and Jeff Williams (between David and Megan). Megan is the sister and Jeff is the husband of the late Leslie Whitt-Williams.

Additional Gifts from the Heart

August 18, 2012. Stella Lorence, Kelsey Nichols, and Kailey Nichols held a book and bake sale in memory of Stella's brother, Trevor Lorence in Burlingame, CA. The young ladies were able to raise over \$580 for the UMDF in Trevor's memory! Thank you to our young fundraisers!

August 2012: The friends of Laura Perrault of Chicago, IL held an event in her honor. They raised over \$5,000! Thank you Bud and Patty Eidam; you are amazing!

August 2012: Lauren Senn and Alayna Kooistra of Howard City, MI had a lemonade stand in honor of Breyton Senn. The girls, ages 5 and 8, respectfully, did an amazing job! Way to go ladies! Thanks for your support!

September 15, 2012. Faith McColl, one of our Lemonade Princesses, hosted her lemonade stand again this year! Faith raised over \$2,600 at her lemonade stand held in Marietta, GA. Thank you Faith for continuing your amazing lemonade stand!

September 22, 2012: Porsha Williams from Mexico, MO organized a Mustaches for Mito coin box fundraiser at her work place. Each employee set out a coin box with their chosen mustache and patrons donated coins to their favorite mustache. In total, \$40 was raised. Thank you Porsha for thinking up such a creative fundraiser!

September 2012: Girl Scout Troop #2901 of Marietta, GA sold Girl Scout friendship bracelets in honor of their friend, Wesley Slimp. They raised over \$120. Thank you girls!

September 2012: David Porter, of Flowery Branch, GA organized a Spirit Night at Chick-fil-A. The event, which was in honor of David, was held as his place of employment! The event raised \$150. Thank you, David, for pulling together a great event! You rock!

September 2012: Denise Jung of Tupelo, MS donated 100% percent of her commission from her Scentsy party to the UMDF during awareness week. Thank you for this kind gesture and for raising about \$100 for the UMDF. You are scent-sational!



Stella Lorence, Kelsey Nichols, and Kailey Nichols at their fundraiser in memory of Trevor Lorence.



Faith McColl and friends at her lemonade stand.

September 2012. A Jeans for Genes day was held in honor of Ben Stewart at schools in Benton, LA area. Thank you Anna Stewart for continuing to hold jeans day fundraisers in honor of sweet Ben!

September 2012. A special thank you to the Thompson Family in Crooksville, OH for the awareness week events held this past September. The events were held in honor of Baylee Thompson and raised over \$250 for the UMDF! Thank you Jody for your continued support!

September 2012. Elena's Hope Research Fund with the UMDF held two awareness week events for the UMDF through sales of Thirty-One Gifts and Matilda Jane Clothing. A percentage of sales were donated to the UMDF in Elena's name. Thank you to the Welhouse Family for your continued support!

October 13, 2012: Ann Schoeller of Atlantic Highlands, NJ and her brothers, Mike and Colby Bayne, participated in the Baltimore Marathon in memory of Ann's children, Sadie and Graham. They raised over \$4,000 for the UMDF! Thank you Team FM!

October 13, 2012: A fall festival was held at Grace Baptist Church in honor of Gavin Self with \$175 being donated to the UMDF. Thank you Erin Tonge for organizing this event and getting a head start on fundraising for the 2013 EFL Atlanta walkathon!

October 20, 2012: Bruster's Ice Cream of Ingomar in McCandless Township, PA held a fun party and costume contest to benefit the UMDF. The event raised more than \$70 for the UMDF. Thank you Marta Greco and Marco Sauret!

October 21, 2012: A special thank you to the Angeloff family of Kingsford, MI for your ongoing fundraising efforts in honor of Austin. On October 21, 2012, the Angeloff's church held a special performance and donated a portion of the funds to the UMDF in Austin's name! Thank you for your support!

October 2012: Debby Ricketts, of Stamford, CT held a Silpada Jewelry Party in honor of Michelle Mohan. Debby donated her commission of over \$300 from that party to the UMDF. Thank you Debby!

Upcoming Events to Benefit the UMDF

January 2013. During the month of January, Polished Salon in Roanoke, VA will offer a special pedicure with a percentage of sales donated to the UMDF in honor of Olivia Goldberg.

February 2, 2013. The Energy for Life Walkathon: Houston will be held at Sam Houston Park in downtown Houston, TX. Join us for our annual EFL Walk by forming a team, collecting pledges, and walking with us on the beautiful route through the city. Register today at www.energyforlifewalk.org/houston/

March 23, 2013. The fourth Annual Mito – What 5k in honor of Jackson Culley will be held in Millington, TN. Register today at: www.mitowhat5k.blogspot.com

Ongoing: Julie Dailey will be selling a 2013 calendar featuring her artwork. Her artwork can be viewed at juliedailey.com. The calendars are being sold for \$21.50 (plus shipping and handling) and \$5 from each sale will come to the UMDF. If you are interested, e-mail Julie at julie@jul1313.com or call 214-532-0452. Julie will be donating to the UMDF in honor of Grace Brewer.

Coins for a CureSM

To benefit the United Mitochondrial Disease Foundation



Students at Midland Middle School in Midland, GA putting coins in the box.

Are you looking for an easy way to raise money for mitochondrial disease research? The answer is Coins for a Cure. It's as easy as one, two, three... and it shows children that they can make a difference in the world through their actions, one coin at a time.

All you need is a few coin collection containers and some willing participants. Simply approach your school or a local business owner you may know and ask for

their approval to hold a Coins for a Cure campaign for the UMDF. Then, set out the containers and let the fun begin!

When the campaign is completed, collect the containers, count the coins, send in the proceeds, and rest assured that you have made a difference in the lives of thousands of affected children and adults!

The UMDF will supply you with coin boxes, stickers for them, informational literature on mitochondrial disease, and a certificate for the winning classes or stores! We will need your help to organize the event and obtain permission from your Coins for a Cure location. Encourage students or store patrons to participate, collect and count the coins, and return the final amount to the UMDF to continue our mission.

Here are some helpful hints when planning your Coins for a Cure campaign:

1. Make Coins for a Cure a friendly competition between classes or stores!
2. Hold a Coins for a Cure campaign in honor of a child or adult with mitochondrial disease!
3. Use incentives for the top fundraising class or store (i.e. , pizza party or sundae bar)!

If you are interested in holding a Coins for a Cure campaign in your community, please go to www.umdf.org/coinsforacure, to register online. For questions, contact events@umdf.org!

Teacher Educates Faculty and Students

Jill Wilson, a Sixth Grade Earth Science Teacher at Midland Middle School in Midland, Georgia, held a five-day Coins for a Cure fundraiser in honor of her daughter, Ava Wilson, who has mitochondrial disease. Wilson was able to impact almost 900 faculty members and students of Midland who learned about her daughter's illness through a news segment that they watched. During those five days, Wilson distributed about 850 UMDF bookmarks outlining what the disease is. This is the third year that she has done this fundraiser, and this year, the 6th, 7th, and 8th graders raised over \$1,300.



Students learn about mitochondrial disease.

Patchwork Peddler Names UMDF as its Charity

John and Katie Lozoya, who own and operate Patchwork Peddler, a home-based business in Central Tennessee, have chosen the United Mitochondrial Disease Foundation (UMDF) as their primary benefactor. Each year, they will donate 2% of their net sales to the UMDF and 5% of every UMDF product sold.

The Lozoyas make a variety of products, including G-Tube pads, which help reduce site irritation and granulation tissue with their special design and fabric. The pads are made out of Bamboo, which is hypoallergenic. They have also found that it is soft, stretchy, and highly absorbent. They have about 250 designs to choose from and have even created some with the UMDF logo on them.

The couple chose UMDF because of several reasons. They were touched by a little girl named Emily, who had mitochondrial disease and was their first G-Tube pad customer. They were also inspired by John's daughter, Corrina Lozoya. The Lozoyas said, "We did research on the UMDF and fell in love with everything that the UMDF is striving to do and doing; then thought and prayed over it, and knew in our hearts it was the thing for us to do. So we say that Emily started us on this path and that Corrina's inspiring life and experiences inspired us and continue to drive us and give back to the special needs community." To learn more about Patchwork Peddler and purchase your G-Tube pads, go to www.patchworkpeddler.com/ or contact the UMDF Events Department at events@umdf.org.



The Patchwork Peddler's UMDF G-Tube pads

Energy for Life Walkathons



Suzanne Cogswell, a member of the Kisses for Kelly Team, gets a smooch from a pooch at the Energy for Life Walkathon in Camden, NJ.



Cooper Groves of Coops Crew at the Energy for Life Walkathon in Sugar Grove, PA.

August 25, 2012: The Minneapolis/St. Paul Chapter held their third annual Energy for Life Walkathon at the Normandale Lake Bandshell in Bloomington, MN. The event raised more than \$62,000 for the UMDF, passing their goal of \$60,000! Thank you Co-Chairs Anne Simonsen, Kalynn Wendt, and Stacey Pieper and thanks to your committee and participants for an outstanding year!

September 8, 2012. The Energy for Life Walkathon: Delaware Valley was held at Campbell's Field (Riversharks Stadium) in Camden, NJ. Thank you Chair Gina Gorski and to all of the walkers, donors, and committee members who helped them surpass their goal by raising over \$37,000.

September 9, 2012: The third annual Energy for Life Walk was held at Sugar Grove Amvets Post 50 in Sugar Grove, PA. A barbeque was held following the walk. The walk raised more than \$10,000! Thank you Chair Jobie Groves and committee for your amazing work!

September 15, 2012. The Kansas City Group held an Energy for Life Walkathon at the CommunityAmerica Ballpark (Kansas City T-Bones Stadium) in Kansas City, KS. The walk raised more than \$37,500 for the UMDF. Thank you Robin and Chris Jones for being the Event Co-Chairs and thanks to everyone who contributed to the walk.

September 15, 2012. The New York Chapter held an Energy for Life Walkathon at Island Park in Williamsville, NY. A picnic was held after the walk. The event raised more than \$28,000. Thank you Co-Chairs Jennifer Schwartzott and Linda Roesch and to the Energy for Life Western New York Walk committee for planning such a wonderful event!

September 15, 2012: Co-Chairs Manuel Castro and Jennifer Coyle and their committee celebrated their first annual Energy for Life Walkathon at Old Settlers Park in Round Rock, TX. Thank you to all who participated in the walk, which helped to raise over \$33,000, passing their goal of \$30,000! Way to go Central Texas!



Mohamad Sallaj gives a thumbs up at the Energy for Life Walkathon in Williamsville, NY.



Volunteers at the Energy for Life Walkathon in Kansas City, KS, who are with Higher MPact, a non-profit organization offering mentoring and assistance to high-risk urban youth in Kansas City.



Some of the many wonderful volunteers at the Energy for Life Walkathon in Round Rock, TX.



Team Family of Hope smiling at the Energy for Life Walkathon in Akron, OH.



Our amazing volunteers pose for a picture at the Energy for Life Walkathon in Milwaukee, WI.

Do you want to "walk" beside these fantastic fundraisers and assist them with their efforts? To donate, go to www.energyforlifewalk.org and choose a walk to support.



September 15, 2012. The Energy for Life Walkathon: Salt Lake City was held at Liberty Park in Salt Lake City, UT. The teams came together on a beautiful day and raised over \$9,000 for the UMDF. Thank you Co-Chairs Michelle Agnew, Laura McCluskey, and Diana Reed, and to the committee for all of your hard work this year!

September 16, 2012: The Chicago Chapter held an Energy for Life Walkathon at the Katherine Legge Memorial Park in Hinsdale, IL. A picnic was held after the walk for the families to celebrate their successes. Through the efforts of all the teams, almost \$65,000 was raised for the UMDF, surpassing their goal of \$60,000! Thank you Co-Chairs Cheryl Lawson and Char Bahus and to the rest of the committee and volunteers who helped to make the day go so smoothly!

September 29, 2012. The Energy for Life Walkathon: Milwaukee was held at Greenfield Park in Milwaukee, WI. The inaugural walk raised nearly \$20,000 this year and the group is excited to continue the success! Thank you Co-Chairs Karen and Ken Loftus, the entire committee, volunteers and walkers who made the event such a success!

October 13, 2012. The Carolina Foothills Chapter held an Energy for Life Walkathon in Freedom Park in Charlotte, NC. The event raised more than \$106,000 for the UMDF. Thank you Co-Chairs Christy Koury and Jennifer Schulz and to every committee member, walker, and donor who made this walk a success!

October 20, 2012. The Energy for Life Walkathon: Akron/Cleveland was held at Lock 3 in Akron, OH. Even on a cold, rainy day, over 400 participants came out for the first Energy for Life Walkathon! The event featured a 'Trick or Treat' trail for all of the tiny walkers and raised over \$45,000 for the UMDF. Thank you Co-Chairs Mary Beth Towell and Karen Ricci and to the amazing committee for such a great year!



Roy and Elizabeth McCluskey holding hands at the Energy for Life Walkathon in Salt Lake City, UT.



Mario Byers and Shequila Byers-Powell of Aniyah's Smiling Angels at the Energy for Life Walkathon in Charlotte, NC. Photo by Joseph P. Martin.

Member Shares Experiences with Walk and Her Service Dog

by Diana Stocksdale of Blue Springs, MO

There are two reasons that made the Energy for Life Walkathon on September 15, 2012, in Kansas City, Kansas, a very special day. First, I got to see Naomi Wolfson, my dear friend from Omaha, Nebraska, whom I met at the Kansas City walk last year. After meeting last year, we have become very good friends. We even shared the title as co-captains on our team which we called, "Mito Sisters." Little did I know after making her acquaintance last year, that we had so much in common. It has been a real help to know someone who deals with mitochondrial disease and is also in the same family situation. This next fact is personal but important for you to understand why we connected so well and became such dear friends. We are both grown adult women, and we both live with our parents and another sibling. It might not seem like much, but we share the trials of being a young adult, trying so hard to balance gaining independence while living under our parents' roof. I say this because I have met two categories of people that are affected with mitochondrial disease, young children with young parents, or married women with children. With these folks I can communicate on a certain superficial level, but I can never understand the depths of their circumstances because I am not living it, despite sharing the same disease. This statement is not a complaint but a fact that makes it difficult to compare living with this disease with another in a very similar setting.

The second thing that made my day at the walk so memorable was that Naomi brought her service dog, Fargo. We shared the same graduating class at Paws For Freedom and both received service dogs this year. It's another journey we have shared together that has helped us both gain a measure of independence and given us a huge self-esteem boost. My service dog is a black Labrador Retriever named Gibson, and she was matched to Fargo, a yellow Labrador Retriever. These dogs have literally changed our lives. But, getting to see each other again, at the walk, and both of us with service dogs in tow, was an experience I will never forget.

The Director of Paws For Freedom, Lea Ann Shearer, was in attendance at the walk. She wanted to support both this

year's graduates and check up on how our being new service dog handlers and working as brand new teams were fairing. She was very impressed. Both Naomi and I have worked very hard to keep up the work it takes to have a service dog.

Getting a service dog is not like receiving and caring for any dog. A service dog requires everything a pet dog does: food, shelter, vet care, and tender loving care. In addition, a service dog handler has to get an already fully trained dog to obey commands when WE have to command the dog. This requires an inordinate amount of patience as this period is very critical in establishing who is the "pack leader" or mommy - the one giving the orders. This simply takes time and of course ENERGY. People with mito are very short of both patience and energy.

I can only speak for myself, but I can attest to the fact that Gibson has already changed my life. He worries about me. He comes looking for me even if he is in the middle of playing in the living room with my family members. He usually finds me still asleep after rounds and rounds of seizures. He jumps up on my bed to take care of me, forgetting the excitement left in the living room. After coming around after the seizures, Gibson showers me with affection and concern. I don't know how to describe in words the calm and sense of security this brings.

Thanks for listening. I wanted to share a report from the walk and its far reaching benefits.

Energy for Life Walkathons are not just about raising awareness for mitochondrial disease and raising money for support and research for a cure. These walks are also about making new friends and creating memories with others who share your joys and struggles in life.

Thanks to all those volunteers who help with fundraising efforts for the United Mitochondrial Disease Foundation.

If you are interested in starting or participating in an Energy for Life Walkathon in your area, go to www.energyforlifewalk.org.



Diana Stocksdale with Gibson, Lea Ann Shearer, and Naomi Wolfson with Fargo

A Heroine Among Us

by Alison Cooley, UMDF National Office

As you all know, Superstorm Sandy came ripping through the United States East Coast on Monday, October 29, 2012. Sandy's wrath caused devastation to many people from Massachusetts to North Carolina. However, what many people may not think of during a natural disaster are disabled people.

Crystal Evans-Pradhan, a member of the United Mitochondrial Disease Foundation who has Mitochondrial Myopathy and uses a wheelchair, remembered. As she sat in her home in Boston, Massachusetts, and listened to the news that Manhattan, New York, was experiencing a power outage due to flooding caused by Sandy, she remembered two people that needed help. She had only talked to Nick Dupree online and had never met him and his partner Alejandra Ospina in person, but she knew that they lived in Manhattan and that Dupree was ventilator dependent. Evans-Pradhan immediately went to Facebook and saw on Dupree's page that he had lost power. Thankfully, Dupree had two back-up batteries for his ventilator and volunteers were taking the batteries to the local fire department to be charged and then bringing them back to him.

Sitting in her wheelchair in another state and unable to reach Dupree and Ospina, Evans-Pradhan knew there was little she could physically do to help her friends. Therefore, she began to seek help through social media; she asked for help for the couple on her own Facebook page. Friends started tweeting about the situation. Shortly thereafter, she remembered an article that she read on the Centers for Disease Control and Prevention website, which talked about powering motorized medical equipment by using a charged car battery, which would last up to 12 hours.

Evans-Pradhan said, "Nick was one of the first people to be diagnosed with mitochondrial disease in 1984 and has been ventilator-dependant since age 9. Many individuals who have died from mitochondrial disease couldn't have had their death prevented since scientific advances weren't there yet, but Nick has fought this disease for 30 years, so there was no way I was going to let him die as a result of a power outage from a storm."

Evans-Pradhan sought help from the Federal Emergency Management Agency's Office of Disability Integration and Coordination and the Muscular Dystrophy Association in New York, but they were not able to help. Still unable to reach Dupree and Ospina, and knowing that time was of the essence, Evans-Pradhan and her friend, Sandi Yu decided to take a road trip to Manhattan.

As she was preparing to leave, she gave her Facebook friends her PayPal address and asked for their help with the cost of purchasing a car battery and power inverter for Dupree. Much to her surprise, Evans-Pradhan received \$1,410. In the meantime, the HopeMob, strangers who join together to bring hope to people in devastating situations, delivered a car battery and

power inverter to Dupree. Evans-Pradhan and Yu were elated at this news and used the donated money to purchase two more car batteries, a battery charger, and supplies, such as distilled water for Dupree's ventilator. According to Ospina, Paul Timmons and Portlight Strategies, a nonprofit organization that assists people with disabilities during natural disasters, was another group that assisted Dupree and Ospina during this tragedy.

It was not long before the women arrived at Dupree's New York home and hooked Dupree's ventilator up to a car battery. It worked! Evans-Pradhan took the initiative to help save Dupree's life and was successful with the assistance from many compassionate people. It's incredible what one can do for others with a few acts of courage and selflessness.

Dupree stated, "People were so amazing during the blackout crisis. They went to incredible lengths, biking across the Brooklyn Bridge with batteries, huffing up 12 flights of stairs with recharged ventilator batteries every three hours, cannibalizing cars for their batteries, even helping out directly with my hands-on care. That is the story here, human kindness on a previously unimaginable scale, organized online divvying up battery shifts and other tasks—such an amazing example of how the Internet, Google docs, and Facebook, can enable spontaneous order to do good works—to keep me alive and at home, not a footnote in a tragic hospital story. The best people ever coming here, keeping me going despite Tribeca (Nick's neighborhood in Lower Manhattan, New York City) being dark and abandoned like a scene from "I Am Legend" or "The Stand," keeping me going despite very steep and difficult stairs, keeping me

going so my life and all I want to do can continue. I'm so full of gratitude, overwhelmed by this. I want to thank everyone, profusely."

If you would like to tell a story to UMDF members, call the UMDF Communications Department, toll-free, 1-888-317-8633 or send us an e-mail to news@umdf.org.



Crystal Evans-Pradhan with her daughter Sophie.



Nick Dupree

Mito Cocktail Helps David Achter

by April Achter, MPH, CHES of Warrenton, VA

Marked with the stain of new motherhood and reeking with inexperience, everything was chalked up to “he was a little pre-term, he’ll outgrow it.” I had to fight my way through the medical system’s inefficiency, arrogance, and indifference, because I was certain that something was wrong.

David was born at 36 weeks and although required a little early assistance appeared to be a healthy, happy newborn. He was gaining weight, although squeaking by mere ounces at his weight checks. He had severe reflux, but the stories about my older brother were legendary and I didn’t give it much thought. Yet during playtime with others, he would often move over to the side of the room, go into child’s pose, and observe. Even as an infant he would play for a few minutes, rest, play, rest. Friends and family commented on this, but I was reassured that all children are different. Then there was the speech delay, the sleep apnea, low blood sugars, blood in his urine, drenching night sweats, ptosis, and finally, episodes that appeared to be seizures.

Our local pediatrician referred us to specialty after specialty. The various doctors reviewed individual systems, gave cursory examinations, patted us on the head and told us to go home and enjoy our healthy child. The episodes continued. David would lie on the floor and cry because he was exhausted. He screamed with abdominal pain and projectile vomited certain

foods. In addition, the episodes – his entire body drenched in sweat and racked with muscle spasms, he would beg - “Mommy, please, make it stop.” Then, we were both in tears.

After a specialist called our local pediatrician to ask if he trusted us, I was at the end of my rope. A ten-minute exam didn’t reveal a diagnosis so it must be our fault? In desperation, I called a parent support line, and they gave me the name of one more doctor to try, Dr. Carol Greene with the University of Maryland.



David Achter

Therefore, we packed up and drove to yet another appointment. Only this time we were heard. Dr. Greene was honest, she didn’t initially know what was causing the puzzling symptoms, but she was willing to try to figure it out. She did. In June 2011, David was diagnosed with a mitochondrial disease. He started on the cocktail, and now I have a different child living in my home. The same little boy that used to lie on the floor and cry rides his bike around the neighborhood.

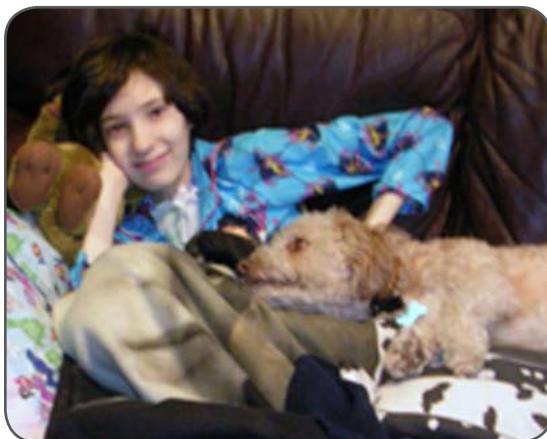
We don’t know what the future holds but hope that early detection and treatment improve his chances for a positive outcome. David is an inquisitive one, and asked many questions. “What is medicine? Why do I have to take it? How does it work? Why does it taste bad?” However, the one that brought me to tears – “Why do I feel good?” Only this time they were happy tears.

Dreams Really Do Come True

by Alison Cooley, UMDF National Office

Using her imagination and positive spirit, Rina Goldberg wrote a story called, “The Magic Bracelet.” The story is a fictional film about a bracelet with a mysterious past and mystical powers that link two teenage best friends, one of whom has mitochondrial disease. According to Goldberg’s mom, Stacy Goldberg, “It was Rina’s dream and vision to raise awareness about mitochondrial disease in a fun, creative, and positive way by writing a film in which the main character had mitochondrial disease.” It not only educates people about mitochondrial disease, but it delivers a message, which Goldberg lived by: “Love life, Dream Big, Be Positive.” She really wanted to see this story become a Hollywood film, but her life was taken by mitochondrial disease at the age of 15 on December 29, 2010.

For the past one and half years, Stacy has been trying to fulfill a promise she made to her daughter regarding getting her film made into a Hollywood movie, and now that dream is becoming a reality. Academy Award-winning writer Diablo Cody, who wrote the screenplay for the movie, “Juno,” adapted Goldberg’s original script for a short film.



Rina Goldberg with her companion dog, Diego.

The Magic Bracelet will be made into a movie through the Make A Film Foundation, which makes movies for children who have life-threatening illnesses. Jon Poll will direct the movie and Actresses Hailee Steinfeld and Bailee Madison will star in it. Filming will be December 7 – 10, 2012, in Los Angeles, CA. Stacy said that the film will be entered into the U.S. and international Film Festival Circuit and shown at medical conferences, and then a Red Carpet LA Premiere will be held in the spring of 2013. Be sure to watch for this movie at box offices near you!

To read about the Magic Bracelet project, go to www.rinasmovie.com, and to be kept updated on it, go to www.facebook.com/magicbraceletevent and click on “Like.”

U.S. Senate Approves S. Res. 490

The U.S. Senate approved S. Resolution 490 on November 15, 2012. In June 2012, Senator Barbara Boxer (D-CA) introduced S. Res. 490. The resolution designated the week of September 16, 2012, as Mitochondrial Disease Awareness Week. It also reaffirmed the importance of an enhanced and coordinated research effort aimed at improving the understanding of primary mitochondrial diseases and the development of treatments and cures. The resolution also called attention to the work of the UMDF's first Youth Ambassador, Brittany Wilkinson, who worked tirelessly to educate the Senator and other elected officials about mitochondrial disease and its impact on affected individuals and families. Wilkinson passed away in September 2009.

Sen. Boxer's Resolution commended the National Institutes of Health (NIH) for its efforts to organize a workshop to improve the understanding of mitochondrial diseases and to enhance collaboration and chart a course for future mitochondrial disease research. The Senator has been instrumental in facilitating meetings between the NIH, UMDF, and the scientific and medical community to expand research into mitochondrial medicine. Through Senator Boxer's efforts, numerous meetings between the NIH, UMDF, and the scientific and medical community have been held.

S. Res. 490 also encourages the NIH to place a greater priority on research into primary mitochondrial diseases, to continue to explore the connections between mitochondrial dysfunction and other systemic diseases, to promote collaboration and coordination among the Institutes of NIH and with other organizations, and to consider the recommendations and address research directions identified in the white paper developed from the workshop meeting.



Senator Barbara Boxer (D-CA)

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The UMDF Receives Support from UnitedHealth Group, Chase Bank, the Pittsburgh Foundation, and Wells Fargo

The United Mitochondrial Disease Foundation (UMDF) is pleased to learn that it was chosen to receive financial support from the UnitedHealth Group's Annual Charity Golf Tournament, the Chase Bank's Community Giving fall 2012 program, the Pittsburgh Foundation's Day of Giving program, and the Wells Fargo Days of Giving celebration.

The UnitedHealth Group (UHG), located in Minnetonka, Minnesota, held their 15th annual Charity Golf Tournament on September 20, 2012, at the Majestic Oaks Golf Course. The UMDF received \$146,338 from the event. Every year, the UHG asks its employees to nominate charities to give the money to that it raises at its annual golf tournament. This year, the UHG gave the money to four charities, and among them was the UMDF. Sue Hartman, a UHG employee, nominated the UMDF to be a recipient of the money in honor of her nephew, Patrick Luskey, age 9, who has mitochondrial disease. Patrick is the son of Bonnie and Jeff Luskey and lives in Belle Plaine, Minnesota, where he attends



Patrick Luskey holding the check for \$146,338 for the UMDF.



Cheryl Porter, UMDF member with Kaye Hutton, Principal Relationship Manager at Wells Fargo in Atlanta, GA.
Photo by Alison Church Photography.

Oak Crest Elementary School. He has an older brother, Tucker, age 21, and two older sisters, Abby, age 19, and Sarah, age 14, none of whom have mitochondrial disease.

The UMDF was named one of the top 196 organizations in the Chase Community Giving Fall 2012 Program. This year, Chase Bank asked its customers and employees to nominate their favorite charities. Many of you voted for the UMDF via Facebook, and we thank you. According to Chase Bank, the UMDF was one of nearly 30,000 charities that were nominated, and the UMDF will receive \$10,000.

Each year, the Pittsburgh Foundation holds a day where people can make donations online to their favorite charity, and a portion of their donation is matched by the Pittsburgh Foundation. This year, that day was on October 3, 2012, and the UMDF received \$7,814 in donations. According to the Pittsburgh Foundation, it will match 10.5 cents for every dollar received. Thank you to all who contributed!

Wells Fargo presented the UMDF with a \$1,000 grant at the company's Days of Giving celebration at the Mansour Center in Marietta, Georgia, in late October. The UMDF was nominated by Amanda Smith, who was the Vice President of Professional Services at the Wells Fargo Atlanta Office earlier this year. After receiving information that the UMDF was nominated, Wells Fargo asked the UMDF to apply. Nicole Shanter of the UMDF Development Department submitted the grant proposal, and the UMDF was then selected by Wells Fargo employees. Cheryl Porter, who lives in Flowery Branch, Georgia, was asked to accept the check and certificate on behalf of the UMDF.



After the Holidays, we all need to recharge...

... but too many of those affected with mitochondrial disease never feel recharged. So this year, after you have dropped the family off at the airport, washed all the dishes and you finally have a chance to sit down again, remember that some of our friends and family feel like this all year long.

At the end of the year, we are putting all of our energy towards support and education for affected individuals and research to find a cure. We are working harder than ever. I know that we have a long fight ahead of us, **but we cannot tire now.**

This past year we have accomplished some amazing things. We have fought to **make your voice heard in Congress.** We have encouraged the NIH to expand its funding for mitochondrial research, **brought together clinicians, scientists, and patients** annually from all over the world to present the most recent advances, supporting symposia both here and abroad, and **funded some of the most promising mitochondrial research.** To date, the UMDF has supported nearly \$11 million in grants focused on primary mitochondrial diseases.

But even with all we have been able to accomplish, you know as well as I, that we have much further to go. I know that this year we will accomplish great things. We will continue to push our elected leaders to prioritize mitochondrial research, we will grow our funding for the most important research in the field, and we will focus on helping those affected with this disease navigate the unknown.

So join me today and help us recharge the fight against mitochondrial disease. Together we will find better treatments and cures.

Sincerely,

Charles A. Mohan, Jr.
Executive Director/CEO

PS: In lieu of a holiday card this year; please accept my heartfelt wishes for a happy and healthy holiday season and a joyous and prosperous new year. Join us this holiday with a gift of \$50 towards hope and cures.



YES, I want to help **RECHARGE** UMDF this year with my gift of:

\$[25] \$[50] \$[100] \$[250] Other: \$_____

Contributions to UMDF are tax-deductible to the fullest extent of the law.

Please make your check payable to the UMDF.

Please update my e-mail address _____

You may also give us permission to charge your credit or debit card by providing the information below.

Visa MasterCard American Express Discover

Cardholder name (please print) _____

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My gift is made:

As a general donation In Honor of (print name): _____ In Memory of (print name): _____

Please inform the following person(s) of my contribution:

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Please do not publish my name. I wish for this gift to be made anonymously.

You may be able to double your contribution with a matching gift from your employer. Contact your Human Resources department for more details specific to your company.

I want to make even more of an impact!

I would like to make a recurring, monthly gift in the amount of \$_____ to begin on the 1st or 15th of the month.

The official registration and financial information of the United Mitochondrial Disease Foundation may be obtained from the Pennsylvania Department of State by calling toll-free, within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement. The UMDF is a 501(c)(3) nonprofit organization, contributions to which are tax-deductible to the fullest extent permitted by law.

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Visit www.umdff.org.

*The entire staff at the United Mitochondrial Disease Foundation
would like to wish you a happy holiday season!*

*Although we did not create a new holiday card this year for you to purchase, you can always find them on our website!
Please visit www.umdffundraiserstore.com.*



UMDF Mission:

***To promote research and education for the diagnosis, treatment, and cure of
mitochondrial disorders and to provide support to affected individuals and families.***

UMDF's intent is to keep you informed. We ask that you always discuss any diagnoses, treatments, or medications with your personal physician. UMDFF assumes no liability for any information in UMDFF Connect.