



Feel, Function, Survive...

by Philip Yeske, PhD - UMDF Science & Alliance Officer

Read the title of this article again and commit it to memory, because the mitochondrial disease community will be hearing this phrase a lot in the coming years as an increasing number of therapeutics are developed. In the United States, the Food and Drug Administration (FDA) is the regulatory body responsible for approving and monitoring therapeutics. Within the FDA the Center for Drug Evaluation and Research (CDER) makes sure that safe and effective drugs are available to improve the health of people in the US. While safety may be relatively easily understood, what makes a drug effective? CDER defines effectiveness as "an essential component of the basis for marketing approval of a drug; drugs must be safe and effective to justify approval. Effectiveness is defined as a benefit to patients in how they feel, function, or survive due to treatment with the drug."

On October 19, 2015, our disease community had a landmark meeting with the FDA that began the process of defining a mitochondrial disease therapeutic regulatory strategy. Participants in the Critical Path Innovation Meeting



(CPIM) included patients, caregivers, researchers, clinicians and industry - all active and engaged in the mitochondrial disease community. Including others that participated remotely, the total involvement of nearly 90 individuals represented the largest group the FDA had ever hosted for such a meeting - great job, community! I was honored to be able to briefly present in person on the challenges of therapeutic research in mitochondrial disease to the dozen or so FDA personnel that also participated. More importantly, I was able to convey the importance of hearing the "patient voice" in the therapeutic development process. Fortunately, this is a message the FDA is quite attuned to, as in recent years several well-organized patient communities have played an increasingly significant role in guiding FDA decisions.

During the CPIM, information was exchanged between these stakeholders and the FDA personnel, mainly focused on the topics of clinical trial design, selecting outcome measures for those trials, and biomarker selection. The single clearest message from the FDA to the audience of this newsletter was "help us understand what feel, function and survive means for your disease community." One of the best ways you can assist in this process is to register for the Mitochondrial Disease Community Registry (MDCR). MDCR is a tool to identify and characterize every patient, caregiver and family member that is a part of this disease community. Through MDCR-driven surveys, data will be collected over time that captures exactly how you feel, function and survive.

In future articles, we will explore other aspects of the FDA regulatory strategy still in development, including the importance of randomized, placebo-controlled clinical trials and the role of dietary supplements as treatments for mitochondrial disease. Be assured that UMDF, advocating on your behalf, will do all it can to facilitate patient-centered therapeutic development.

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From the Chairman

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Each year, we gather as a community to raise awareness for mitochondrial disease. Some have the ability and energy to tell their story before a television camera, radio microphone or to a print reporter. Others use their energy to hand out information at health fairs, churches, schools, and to physicians and clinicians. Some activated their mitochondria by participating in an Energy for Life Walk, a 5K or a 10K run or walk. Thousands took to social media to share their personal stories or information about mitochondrial disease. No matter how you participated during the third week of September, the word is getting out. You were successful in answering the question “What is Mitochondrial Disease?” We know this because that was the number one hit on www.umdf.org the week of September 20, 2015.

In this issue of UMDF Connect, you can read about all of the events and activities that happened --- and just so you know, your efforts helped us reach more than 30,000 people on social media this year! Great job!

I also want to call your attention to the article written by UMDF’s Science and Alliance Officer, Philip Yeske, PhD. A few weeks ago, Dr. Yeske was part of a meeting in Washington, DC. The meeting was entitled “Mitochondrial Disease Critical Path to Innovation” and was organized by the Food and Drug Administration (FDA). This meeting

is the first step towards starting the discussion between the mitochondrial disease community and the FDA for the possible design and implementation of effective therapies for mitochondrial disease. I’m very proud that UMDF and several of our top medical experts were invited to participate in this very important initial step for the benefit of the entire community.

And finally, I would like to thank all of the people who submitted fantastic artwork for the 2015 UMDF Holiday Appeal. I know it was an incredibly difficult decision. According to the poll taken on Facebook, the artwork designed by Sarah Bataлка, of Quakertown, PA, was chosen. We will have limited copies of this card on sale for the holidays and the artwork will be used in the UMDF Annual Holiday Appeal. It is my hope that you will consider a donation to help us continue our mission.

I wish you the best as we move towards the holiday season. 2016 will be a big year for the UMDF as we approach our 20th Anniversary in April. Look forward to many exciting developments in the year ahead.

Patrick Kelley, UMDF Chairman

REATA LAUNCHES A MITOCHONDRIAL MYOPATHY CLINICAL STUDY

Reata is the leader in developing antioxidant inflammation modulators (AIMs), which are potent activators of the biological transcription factor Nrf2.



Nrf2 controls the body's production of hundreds of antioxidative and cytoprotective molecules. Activation of Nrf2 has been shown in non-clinical studies to improve mitochondrial function and energy production, which are impaired in Mitochondrial Myopathy. To learn more about Reata Pharmaceuticals, visit reatapharma.com.

Clinical Study on RTA 408 Capsules

Reata Pharmaceuticals is actively enrolling the MOTOR study, a placebo- controlled, multicenter clinical study of RTA 408 capsules in Mitochondrial Myopathy. For more information, go to clinicaltrials.gov and search "RTA 408 MOTOR".



Congressional Caucus Update



Dr. David Schubert discusses Stealth Biotherapeutic's current clinical trial for mitochondrial myopathy before the Congressional Mitochondrial Caucus.

The United Mitochondrial Disease Foundation held its seventh Congressional Caucus briefing for lawmakers on October 20, 2015. The briefing focused on mitochondrial dysfunction and cardiac issues.

Speaking at the session was Edward Lesnfsky, MD, of Virginia Commonwealth University and David H. Schubert, Vice President, Regulatory & Quality for Stealth Biotherapeutics. Dr. Lesnfsky's current research interests involve the study of the mechanisms of myocardial cell death during heart attacks and their treatment. The focus of his laboratory is the study of the role mitochondria in the progression of cardiac cell death during heart attacks and treatment.

Cardiac mitochondria normally function as the powerhouses of the cardiac cell, metabolizing fuels to provide energy for the heart. However, during a heart attack, cardiac mitochondria shift their role and become agents of cardiac injury and cell death. His research has found in experimental models that a blockade of mitochondrial function during a heart attack, when mitochondrial metabolism leads to cell death, can actually improve functional recovery and decrease cardiac injury. This could hold the potential to reduce the extent of cardiac damage and improve the outcome of heart attacks in the high risk elderly patient.

Dr. Shubert discussed the mitochondrial myopathy clinical trial for Bendavia that Stealth Biotherapeutics has underway, not only its implications for

mitochondrial disease patients, but for cardiac patients in general. Bendavia may benefit dysfunctional mitochondria with the therapeutic potential to modify disease and improve patient outcomes in diseases, including heart failure, kidney disease, cardiovascular disease, neurodegeneration, and certain skeletal muscle. The briefing was another in a series to help Congress understand the implication of mitochondrial dysfunction in other well known diseases.

UMDF's role in educating elected officials about these scientific links has become more urgent. If we can breakthrough and unlock the secrets to prevention and cures for mitochondrial disease, it would truly be a game-changer for millions.



Spotlight: Unstoppable Nina Hall

Nina Hall is a precocious and tenacious three year old; like many other kids her age, she loves all things Disney. In 2013, her parents, Michael and Amy, received some devastating news: Nina had Leigh's disease. Michael and Amy started looking into any and all possible options for their daughter. These options included clinical trials, as well as setting up a research fund for Leigh's disease through the UMDF. Now, the Hall family is not only helping Nina, but so many other people around the world.

The Hall family had set a lofty goal to raise \$100,000 for Leigh's research. Today they have not only reached that goal, but completely surpassed it! The journey to reach their goal was one filled with endurance and love. Endurance quite literally, the Hall family wanted to combine their love of the outdoors and endurance sports into a fundraiser for their research fund. This led them to the UMDF program "Activate Your Mitochondria." This platform allowed them to form a team with their friends and family to run marathons all over the world (They have a family friend living in Japan who runs and fundraises for them!).



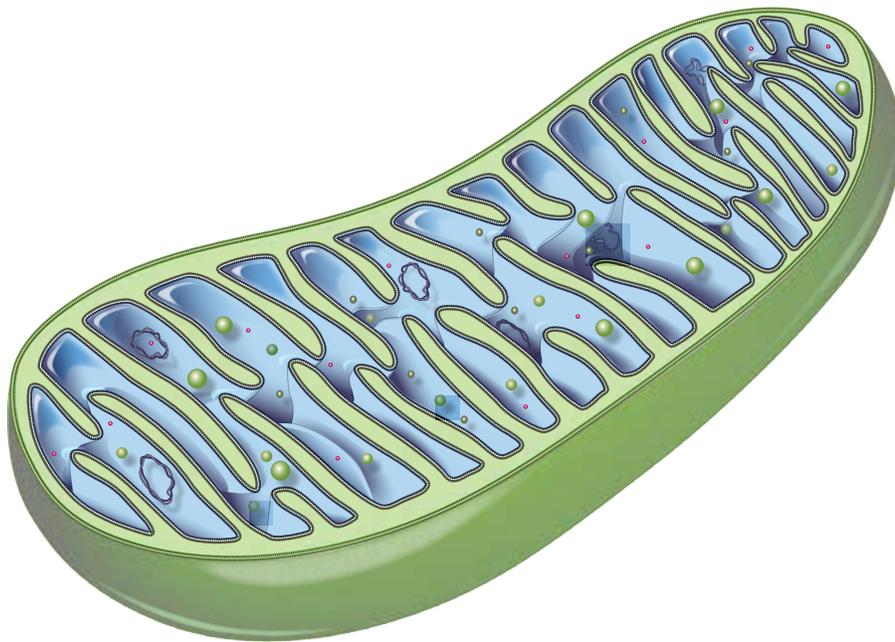
The very first event the Halls ran raised over \$37,000, thanks to special members of their team; Matt Bain, Eric Boyle, Bobby Moelter, Michelle Conlon, and Kim Siragusa! The Halls were well on their way to achieving their goal.

This past October the Hall's were able to see the fruition of their efforts, On Sunday October 4, 2015, Team Unstoppable Nina participated in the Boulder Rez Marathon. From that race the family exceeded their \$100,000 goal! UMDF Director of Development Beth Whitehouse was in attendance to cheer them on at the finish line. "It was a wonderful and humbling experience to be part of Unstoppable Nina Hall's event this year," said Beth. "The outpouring of support from family, friends and the entire community was truly remarkable. Huge thanks to Amy, Michael and Nina for their efforts in making this event a reality."

The Hall family is not going to stop here. They will continue to run for those who can't, and raise funds to help all those affected by mitochondrial disease. "We desperately want to see further progress made toward additional treatments, and maybe even a cure, for Nina and the thousands of children and families affected by Leigh's and other mitochondrial diseases, now and in the future. While we are ultimately looking to raise funds, we are also hoping to generate energy and momentum for many races and events to come. We welcome anyone willing to join our team!"

Stealth BioTherapeutics

is committed to the development of therapies for mitochondrial disease and proudly supports the advocacy efforts of the UMDF



To learn more about our work, please visit StealthBT.com or follow us on social media:



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Hiking to Raise Awareness

by Tara Maziarz - UMDF Development Associate

This summer, a feat of amazing human endurance took place right in the UMDF's backyard.

Adam Kohr, a Harrisburg native transplanted to Chicago, hiked from his *new* hometown to his *old* hometown. He walked a whopping 645 miles. The hike wasn't just a feat of strength; it was an act of brotherly love.

Adam's brother, Andy, was diagnosed with mitochondrial myopathy at age 14. As the Kohr brothers grew up, they did many things together. It wasn't until a few years ago that Adam realized how badly the mitochondrial deterioration was affecting his brother's life. Last year, their mother ran the Chicago Marathon, prompting Adam to think of ways that he could help his brother and others affected by mitochondrial disease.

That was when a crazy idea popped into Adam's head: he was going to walk from Chicago to Harrisburg - 645 miles - a total length of 27 marathons. He trained for the next six months for the walk.

On June 15, 2015, Adam set out on the adventure of a lifetime. Fortunately, his employer, Cutter Studios, gave him a month off of work. Along with one of his friends, Adam started his epic trek. Although the friend only made it three days into the trip before he had to pack up and go home, Adam continued on. As Adam will tell you, he is not the most

outdoors-y guy and about two weeks into the trek he suffered terrible shin splints. His goal was to walk 25 miles a day, and as the journey progressed he travelled between 28 to 36 miles a day!

The other very challenging aspect was the lack of human interaction. He missed his girlfriend of 10 years terribly. At the end of every day, it was a relief, knowing he could rest and take a break, but he realized this is how his brother feels every single day, and doesn't get to choose when he can take breaks.

As the days went on, he learned some tricks. For example, he figured out pushing a cart with all of his gear was much easier than carrying it in his backpack. Many people he met thought he was homeless; some even called law enforcement on him! Folks in Pennsylvania thought he was one of the escaped convicts from the prison in Upstate New York. There were a few people that opened their homes to him once they learned about his story. Those people even stayed in touch with him after his journey! On his trip, he only met one person who actually knew what mitochondrial disease was - a doctor that was biking in Pennsylvania.



Adam Kohr and Tara Maziarz at the UMDF office in Pittsburgh

Adam's family and friends all joined him to walk his last mile. The most amazing feeling was seeing his brother, girlfriend, and family members there for him at the end.

A year ago, Adam never thought he could accomplish something like this, now he has the amazing memory of a journey he will never forget. Adam wants to encourage everyone to research something they don't know anything about, and then help someone with your new knowledge.

For more of Adam's story, visit www.thefutureof645.com.

Through Mito Eyes: Birthday Wish

by Liz Kennerly



Every year, in early December, I close my eyes, make the same silent wish and blow out the candles on my cake. The number of candles increases every year, but my optimism has never faded. My optimism has actually increased. On May 21st, a bill known as the 21st Century Cures Act was passed unanimously in the House Energy and Commerce Committee. It went on to pass in the House 344-77. That light at the end of the tunnel is now brighter than it has ever been.

I cannot tell you my wish, but it's probably very similar to others in my shoes. It doesn't have a price and it will change many, many lives for the better. This is almost like the old MasterCard commercials. Doctors appointments: X dollars. Medications: Y dollars. Traveling to and from appointments: Z dollars. But, for everything else: there's science and hope. Everything has monetary value, but the end result can't be bought like other things.

Up until recently, there wasn't a single pharmaceutical company that expressed interest in Mitochondrial Disease. This changed with Edison Pharmaceutical Industries and their one drug currently in FDA trial, the EPI-743. This drug has produced significant improvements. It is a true miracle drug! There are three other companies in the U.S. - Raptor, Stealth BioTherapeutics and Reata - now in the Mitochondrial Disease space. These clinical trials have broader inclusion criteria and include those with Mitochondrial Myopathy, instead of a single specific mutation or disease underneath the Mitochondrial Disease umbrella like Leigh's and Alper's Disease.

I've been posting a lot about the 21st Century Cures Action social media. This will be huge for everyone if it becomes law! I'm hearing a bit of Schoolhouse Rock. This is not "just a bill on Capitol Hill," it will increase both NIH and FDA funding. It will also incorporate our voice in the drug development process.

Yes, the patient voice! The FDA now hosts public webcasts asking patients for their input. Their ideas of what the patients need and want could be different from those living with or caring for those with the condition. A cure is always the clear end goal with any rare disease, but sometimes we need the most help with one specific symptom of the disease.

I want a cure for Mitochondrial Disease, but the metabolic crashes are my primary concern. As a parent from one of the webcasts said, "We aren't waiting for the Queen Mary. We are just looking for a life raft." This will also speed up the clinical trials process! It currently takes 13-15 years for new drugs to get from the lab at the pharmaceutical company to our pillboxes. The EPI-743 and others in trials for mitochondrial disease are only moving as fast as they are because they meet certain criteria set by the FDA. They serve an unmet medical need: treatment for a disease where no current therapy exists.

This bill would also help with the design of mobile apps! I don't know about my other dysautonomia friends, but I would love to ditch my "dinosaur" blood pressure cuff! Maybe a smaller cuff to fit around my index and attach to my phone.

This bill, HR6, hits a personal note. I've known the man who wrote it for a very, very long time. He is my former Congressman, and it is really special that I'm in a position to advocate for it this measure.

Liz Kennerley earned her BA in Society & Health from Simmons College in Boston MA. She also majored in Sociology and minored in Psychology as well as Music. She shared her patient perspective at UMDF's first congressional caucus briefing in 2013. She currently lives in Solebury, PA.

Meet your UMDF Ambassadors

The UMDF is about *coordination, communication and collaboration*; coordinating our efforts and resources, communicating our needs and abilities and forming collaborations to bring information, patients, medical professionals and resources together to enhance progress for treatments and cures.

UMDF Ambassadors are an essential part to those efforts. They are a resource for members seeking to gather information. They coordinate efforts with other members to make a difference in their local areas, and they are key collaborators with the UMDF regional and national staff. We'd like to introduce one of our UMDF Ambassadors: **Barb Yarina** of Ferndale, MI.

If you would like more information about the UMDF Ambassador program, please contact us at connect@umdf.org.



Barb (center), with her husband Steven (left) and son John (right)

How long have you been an Ambassador with the UMDF?

Barb: I joined the Ambassador program in July of this year.

How are you connected to mitochondrial disease and the UMDF?

Barb: Our son, John, is suspected to have mitochondrial disease. They believe he has partial CPT2 and something else. We call it "John Syndrome" because that's what all the doctors say when they review his records. Lows should be high. Highs should be low. Nothing makes sense but in a quirky way over time they do.

How are you active as a UMDF Ambassador?

Barb: I've handled requests for more information and support from new members. I manned the Mito information booth at the Detroit Energy for Life Walk in September. I check the UMDF Facebook page daily to see if there is anything positive I can contribute to help those asking questions. John's been ill all his life and mitochondrial disease affects all of his body systems. I feel I'm pretty fluent in the testing people are asking about or the symptoms they are seeing.

During your time as an ambassador, what has been the most rewarding?

Barb: Seeing all the families at the Energy for Life Walk. It was a reminder that our family is not on this journey alone.

As you know, mitochondrial diseases are very challenging. What advice would you give to a newly diagnosed family?

Barb: First, take a big deep breath, fasten your seatbelt securely because the roller coaster ride you are on will have more hills and valleys than you think you can handle. I always recommend they get and read the book "Living Well with Mitochondrial Disease". I also tell folks to read the UMDF web site because there is a lot of information there. I tell patients, especially Moms, to trust your gut. You have your God-given Mother's intuition that something isn't right. Trust it to guide you in seeking care for your child. Finally, I tell them to ask questions, don't be afraid to ask any question. Especially on Facebook, if the people on Facebook don't know the exact answer, they know someone who does and they will connect you to the resources you need.

The UMDF will be recognizing its 20 year anniversary next year. If you could give one piece of advice to yourself 20 years ago, what would it be?

Barb: Be confident to speak up and ask questions. Now, I don't care if I get labeled as that annoying Mom. Advocate for your child because they are counting on you. You know your child best.



At UMDF's home base in Pittsburgh, the Gulf Tower, an iconic downtown skyscraper, was lighted green.

Awareness Week 2015

With hundreds of activities around the country, the UMDF, along with affected individuals, families, friends and coworkers, celebrated Mitochondrial Disease Awareness Week September 20-27, 2015.

More than 17,000 informational pieces were sent from the UMDF office to those who participated in week-long events. Events to raise awareness of mitochondrial disease ranged from classroom education for students to physician education by patients. Additional Awareness Week events included educational presentations at malls, hospitals and churches.

Awareness was spread throughout the media. Many patients and families managed to have local television stations and newspapers interview them about mitochondrial disease and their personal stories. Social media was abuzz with news about Mitochondrial Disease Awareness Week, with posts circulated by UMDF and shared across Facebook and Twitter. We reached more than 32,000 people!



RoseMary Wasielewski spread awareness at a health and wellness fair at Prairie State College near Chicago.

education



Thank you to the brave men and women of Ceres, CA., Firefighters Local 3636 for your support of Kenley and the UMDF and for raising awareness for those who are battling mitochondrial disease.



Linda Roesch, a UMDF Ambassador in Western New York, spread awareness at a health expo in Buffalo.



Samantha Lee helped her mother, Elizabeth, set up a "Mito Awareness" table at her father's work. Samantha lost her older brother a year ago. He had POLG1, and the family walked in his memory at the Energy for Life Walk in Charlotte on October 17.



Mary Schafhauser, sister of EFL Minnesota co-chair Sara Schafhauser-Wright, is in the Peace Corps in Mongolia. On August 8, she wore her "Leo's Lions" team shirt and participated in EFL: Minnesota "virtually" from Mongolia.



Energy for Life sponsor, The Texas Chili Company, donated tickets to our Southern California UMDF families to attend the Anaheim Angels game on September 26.

Three C's to a Cure

by Chuck Mohan - UMDF CEO/ED

The UMDF mission is to “promote research and education for the diagnosis, treatment and cure of mitochondrial disorders and to provide support to affected individuals and families.” In order to meet the goals of our mission, we are committed to coordinating our efforts, communicating our needs and collaborating to build relationships and capitalize on our combined talents and resources.

Coordination - *the organization of the different elements of a complex body or activity so as to enable them to work together effectively.*

UMDF continues to reach out to other patient advocacy groups, academic institutions, health care facilities and industry partners identifying similar goals and interests. We firmly believe that our similarities are greater than our differences. We need to know who is working on what, and who is interested in any of the many components of mitochondrial function and disease. In my roles as Co-Chair of the Coalition of Patient Advocacy Groups (CPAG) and Board member of the National Organization of Rare Disorders (NORD), I have the opportunity to connect with and build professional relationships with many other patient groups involved with similar missions. UMDF is also a founding member of the International Mitochondrial Patients group (IMP) which is a global organization consisting of mitochondrial organizations from 12 countries.

Over the years, UMDF has had the opportunity to work

with many patient groups, clinicians and researchers from academic institutions and health care facilities across the US. We have sponsored 17 international symposia at strategic locations across the country. UMDF symposia has been a primary gathering place for mitochondrial experts and those interested in learning more about mitochondria from around the world. This coordinated exchange of information has been and continues to be invaluable.

Communication - *Sydney Harris said, “Communication and information are often used interchangeably, but they signify two different meanings. Information is giving it out and communication is getting it through.”*

The UMDF Trustees and staff are very interested in getting accurate and important information to you, and we know it is also important for you to be able to convey accurate information about UMDF and mitochondrial disease to your family and friends. Our website contains the most up to date and accurate information on mitochondrial disease and current “happenings” in the world of mitochondrial medicine, such as clinical trials. Our website currently get 23,000 visitors each week, and our membership in the International Mitochondrial Patients group enables us to communicate with other patient groups and researchers from around the world.

UMDF has created the first-ever Congressional Caucus on Mitochondrial Disease. The caucus is focused on educating members of Congress about the importance of

funding research on mitochondrial disease. To date, we have presented to over 400 Congressional representatives. UMDF continues its Congressional communication by sponsoring UMDF Day on The Hill. In three sessions, 670 UMDF members met with 319 members of Congress and 162 members of the Senate.

UMDF has the only Grand Rounds program focused solely on mitochondrial disease. To date, we have sponsored mitochondrial experts to present to over 4000 medical professionals at hospitals across the country.

Collaboration - *a working practice whereby individuals work together to a common purpose to achieve business benefit.*

UMDF continues to foster relationships with our patient, academic and industry partners. We continue to partner and support the North American Mitochondrial Disease Consortium (NAMDC). This consortium consists of 16 institutions across the US committed to finding treatments and cures for mitochondrial disease.

We support and administrate the efforts of the Mitochondrial Sequence Data Resource (MSeqDR). This is an open source database that contains sequenced genomic data enabling researchers to look for variants which could improve their ability to diagnose.

We work closely with the National Institutes of Health (NIH), Office of Rare Disease Research (ORDR) and the National Center for Advancing Translational Science

(NCATS). This relationship has enabled UMDF to have a “seat the table” to various NIH and FDA meetings and events when they are seeking input from the rare disease community.

UMDF has developed and implemented a patient populated database and is making it available to the entire mitochondrial community. The Mitochondrial Disease Community Registry (MDCR) currently has over 1100 registrants and is being offered to other mitochondrial groups across the country and around the world. We are excited that the Leigh’s Disease Clinic at Hermann Memorial Hospital, under the direction of Dr. Mary Kay Koenig, is the first to take advantage of this benefit. There is now a separate Leigh’s Disease portal to MDCR. This collaborative effort is being promoted by the patient group “People Against Leigh’s Syndrome” (PALS).

Collaboration and communication with our industry partners is identifying numerous companies interested in mitochondrial disease. We are currently collaborating and coordinating with five companies in the pre-clinical stage and four in actual clinical trials and have identified an additional 30 companies involved in early drug discovery.

The three C’s; Coordination of efforts, Communication of needs and Collaboration to build relationships and capitalize on our combined talents and resources will pave the road to the fourth and most important “C” – Cures!



UMDF Holiday Card Contest

The United Mitochondrial Disease Foundation is pleased to announce the winner of our 2015 Holiday Card Art Contest. The artist is Sarah Bataika of Quakertown, PA. Sarah is self-taught and has been drawing for as long as she can remember. Her love of realism can be seen in the details she meticulously renders in her work, which covers a variety of subjects including animals, still life, landscapes, florals, and portraits of pets and people.

Sarah has early childhood onset Mitochondrial Disease. She is power wheelchair dependent/bedbound, requires daily life-sustaining IV's, noninvasive ventilation, supplemental oxygen,

and many medications, as Mito affects most of her organs. Through art, Sarah has found a way to transcend the pain and restriction of her life. She has used her artistic talent to raise awareness for Mitochondrial Disease via social media, and she's been a long-time member and supporter of the UMDF, which promotes research and education for the diagnosis, treatment, and cure of mitochondrial disorders.

We will have a limited supply of Sarah's Holiday Cards on sale in the UMDF Store. You can visit at www.umdffundraiserstore.com

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.umdf.org. Please note that information contained in Ask the Mito DocSM is for informational and educational purposes only. Such information is not intended to replace and should not be interpreted or relied upon as professional advice, whether medical or otherwise.

Q: I have a paternal aunt, my father's sister, who had two children with very, very severe mitochondrial disease (feeding tubes, seizures, mental retardation, no ability to walk, etc.). My aunt said the closest diagnosis was mitochondrial cytopathy. At the time (1985), after the birth of her first child, a son, the doctors deemed it a fluke that wouldn't happen again. My aunt had her second child two years later, a girl, who had the same disorders as the first child. The doctors told them it must be the combination of my aunt and her husband's genes but was unlikely to happen a third time. I don't know what type of mutation she/my uncle have. My dad had three daughters (including me) who have no mitochondrial issues. My dad has two other sisters (same parents as the sister with the children with mitochondrial disease) who each had children (sons) without any signs of mitochondrial issues. I am trying to assess if I am at risk for bearing children with this disease. Is there any genetic testing I should undergo to assess my risk prior to becoming pregnant?"

A: I'm sorry to hear about the severe mitochondrial disease diagnosed in your aunt's children. Most mitochondrial disorders in children are inherited in an autosomal recessive form, meaning that both parents (who are normal) carry an abnormal dysfunctional gene related to mitochondrial function. In order for disease to manifest, a child needs to inherit two abnormal copies of the gene, one from the father and one from the mother. The recurrence risk in such families is 25% or a 1 out of 4 chance for each subsequent pregnancy. In other words, the risk to have an affected child if the parents carry an abnormal gene is high. Please note that this type of inheritance is different than the maternal inheritance that occurs in families who harbor a mutation in mitochondrial DNA.

It is possible that your father is also a carrier for an abnormal gene that affects mitochondrial function, but it would be unlikely (but not impossible) for your mother also to be a carrier for a deleterious mutation in the exact same gene. In other words, your risk to have a child with mitochondrial disease is low given your family history. In order to provide more precise counseling, however, it would be necessary to know the exact gene that is involved in causing disease in your family. This would typically be done by performing DNA analysis on a large number of genes known to be related to mitochondrial function in the affected children, but there is no specific test for you or your husband at this point.

I think it would be a good idea for you to discuss this further with a prenatal genetic counselor, who would be able to explain the genetic implications of your family history in further detail. - *Greg Enns, MD, ChB*

Q: I have heard gabapentin was recently found to be mitochondrial toxic. Any validity to that? Also, are there any laxatives or stool softeners that are as well? I'd heard there was one laxative named recently but can't recall what it was and want to be safe should these last two things be recommended.

A: While many medications may theoretically have some mitochondrial toxicity, it does not automatically mean that they are not safe to use in a patient with primary mitochondrial disease or secondary mitochondrial dysfunction. The current list of medications that might need to be avoided is relatively short and even these are not absolute contraindications (meaning, we may use them cautiously in mitochondrial patients when needed and no other or better options are available).

Gabapentin is generally well tolerated in mitochondrial patients, though it does have a side effect of creating sedation or fatigue in any patient who takes it. Glycolax/Miralax is a stool softener that is generally safe to use in mitochondrial patients. You should speak with your physician prior to taking any of these to ensure they are safe for you. - *Sumit Parikh, MD*

Q: Our son (age 15) has Complex III. It has been discovered that he also has a tumor on his pituitary gland. He has been experiencing bouts of incontinence and bowel control issues. We are at a loss. Any suggestions?

A: Thus far, the only link between pituitary tumors and mitochondrial disease has been the finding of mutations in SDHD in a family that presented with a pituitary adenoma secreting growth hormone and familial paragangliomas. Mutations in SDHD are associated with complex II deficiency and not complex III deficiency. Perhaps the pituitary tumor is not connected with mitochondrial dysfunction or disease in this case. Has he been seen by an endocrinologist? If he has issues with bladder and bowel control, he may need to be seen by a neurologist to assess for dysautonomia. I hope this helps. - *Fernando Scaglia, MD, FACMG*

You can quickly and easily find "Ask the Mito Doc" Q/As on topics of your choice by going to the UMDF home page at www.umdf.org. Go to "Find Support" and click on "Ask the Mito Doc." Click on the search "Ask the Mito Doc" link; this will pull up a search box. Type in a keyword or phrase you are interested in and click "Go." The search engine will pull up every Q/A that mentions your word or phrase. If you are not satisfied with the results, try variations or synonyms of your word/phrase.

AACT Update

For this newsletter, we asked all members of AACT to share a tip that they find helpful. Below are the tips we received from AACT board members:
Please check with your physician or medical prescriber before changing or adding any medications or supplements.

✓ **Tip Topic: Headache Relief**
 Peppermint oil is great to rub on your temples or the back of your neck for some relief. You can also buy peppermint balm it looks like a tube of lip balm, not as messy as oil. I also keep a gel eye mask in the freezer-very soothing!
Kailey Danks – Toronto, Canada

✓ **Tip Topic: Travel Advice**
 I have to travel for my job internationally & domestically, and one tip I have involves travel: I have a definite regimen and routine when at home because of all the meds/supplements/exercise I have to do to stay fit enough to work. When I travel, I do what I can to KEEP the routines, even when it is inconvenient and difficult to do. This is especially true for the meds/supplements/exercise part. It is easy to get out of the routine and let it go (although sometimes you have to) but, to the degree I can, I try and keep it up. It really makes a difference when I don't. In addition, I have to pre-medicate while traveling (e.g. Imodium) to keep the anxiety and symptoms in check. Hope that helps!
Whit Davis – Pennsylvania

✓ **Tip Topic: Muscle Pain Relief**
 Many of us have deep muscle pain, especially at night. For me, it's mostly in my quadriceps and in my tibialis anterior muscles. In my case, I have never found that NSAIDs help with this. Usually, a hot bath with Epsom salts or Dead Sea Salt helps - and it's not unusual for me to get into a hot soak at 2:00 am, after I've given up on trying to go to sleep without it. I mix Epsom salts with eucalyptus oil and peppermint oil sometimes. Or sometimes I take a shortcut and buy this: <http://www.cvs.com/shop/beauty/bath-body/bath-salts-soaks/cvs-muscle-relief-mineral-bath-salts-skuid-699289>. On rare occasions, even hot baths don't help, and the ache seems to go deep into my bones. When that happens, I sometimes find relief with arnica - either a homeopathic mixture or the commercially available Arnicare cream: <http://www.cvs.com/shop/health-medicine/pain-fever/joint-muscle-pain-relief/arnicare-pain-relief-gel-skuid-833266>. I am sure there are other brands and sources for both of the over-the-counter products that I mentioned. By no means am I endorsing these brands over others.
Christy Koury – North Carolina

✓ **Tip Topic: Stress Relief**
 We must remember that stress of any kind can be hard on those of us with mitochondrial disease. Practice the art of taking "minute vacations" from the current stressful situation. Even sitting too long in one spot is stressful. Get up and move around. Need a break from mental stress? Have a quiet corner where you can meditate. Relax with calming music. These small changes can be very worth putting into practice.
Joy Krumdiak – Washington

✓ **Tip Topic: Relaxation Technique**
 I start my day before getting out of bed with 10 deep slow breaths (in through the nose and out the mouth) and end my day with the same breathing routine.
Terry Livingston - Florida

✓ **Tip Topic: Energy Boost**
 My mito specialist prescribes mega lipodoses of "energy" supplements. I take 1200 mg CoQ10; 2 mg Folic Acid; 300 mg Alpha Lipoic Acid; 300 mg Levocarnatine; 4000 mg Ribose; 2500 mg Creatine Monohydrate twice a day. This helps me a lot to make it though the day energy-wise!
Deb Makowski – Arizona

Adult Advisory Council Team (AACT)

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 Gail Wehling, AACT Co-chair, Illinois
 Devin Shuman, YA Coordinator, Washington
 Kailey Danks, Canada
 Whit Davis, Pennsylvania
 Rev. David Hamm, Maryland
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Christy Koury, North Carolina
 Joy Krumdiack, Washington
 Terry Livingston, Florida
 Deb Makowski, Arizona
 David McNees, Ohio
 Sharon Shaw Reeder, California
 Gregory Yellen, Maryland

Medical Advisors:
 Bruce H. Cohen, MD

Amy Goldstein, MD

Purpose of AACT

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

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

✓ **Tip Topic: Muscle Pain Relief**

As my diagnosis was becoming clear in 2011, I just happened to be working with Zen Buddhist teacher Thich Nhat Hanh on the Mindfulness in Education movement. My study of meditation and mindful thinking deepened tremendously. We all know the personally devastating factor of intense muscular or nerve pain: it can consume you. When the pain takes over, the amygdala is hijacked into a state of sympathetic response. The resultant fear response makes us worry and fret about the future. Living with pain on the horizon puts us into a space where we must look ahead constantly to avoid the feeling that we recall, the echo of past pain. This takes us out of that mindful present moment which, I believe, is the only moment that we can actually have affect. We desperately try to find homeostasis with a myriad of additives: enzymes, vitamins, painkillers, etc; but it is vital that we utilize our own natural ability to support our parasympathetic system as well. With much practice, I have been able to bring myself to a state of mindfulness amidst the pain. With a focus on my breath, and a practiced meditative state that expels thoughts about the past or future (really, no thoughts at all), I am able to help my body control the pain. Whether it's as serious as rhabdomyolysis, or the electrical storm of somebody cutting me off on the road, or just the muscular burning and exhaustion from a flight of stairs, I try to give myself four or five (or a hundred) breaths to bring my body, mind and spirit back to each other. And it has made all the difference. My tip for dealing with pain? Just breathe. I know that sounds a little preachy and simple. But simple is good in the complexity of what we're dealing with. Have faith in yourself, and that there is still something inside of you that can control this thing, if even for a moment of peace. Practice mindfulness. Breathe.

David McNees – Ohio

✓ **Tip Topic: Attitude, Behavior, Perception, Response**

Our list of symptoms and navigating all we do is not always in our control as the very nature of this disease is progressive. We take action to control, stabilize, monitor and improve all we can physically. But for me, without the practice of mindfulness, physical management alone is not enough. I live by Wayne Dyers quote "Change the way you look at things and things you look at will change". I call it a "reality check" and ask myself these questions as I too navigate the changes in my body that are out of my control:

- "I sure know my opinion and how I feel but can I imagine what is it like for the other person?"
- "What is the underlying lesson for me in this tough situation, other than the outer obvious?"
- "How can I bring my best anyway when I am feeling my worst?"
- "How can I make things better even when they aren't?"
- "Am I on my side no matter what?"
- "Feelings are important and expressing them in a healthy way is crucial but feelings aren't facts, they are feelings"
- "Am I listening to where my energy is at not what I want to get done?"
- "Why am I pushing myself beyond my physical ability, what am I trying to prove that's more important than honoring where I am at?"
- "How can I love and support myself the most? What does this look like? What changes can I make to get here?"
- "Have I been kind and loving today, no matter what?"

When faced with life altering information we can let it control us or we can take charge and make a difference not just for ourselves but for others. I believe we are given the hand that is dealt but how we play the cards is up to us, and when played well, our actual response can be more powerful and empowering than the cards dealt!

Sharon Reeder – California

AACT Council Members Appeal

Currently, there are over 300 mitochondrial-related clinical trials and studies ongoing worldwide. What an exciting and pivotal time.

It begins with us and it is now up to us, the mitochondrial community, who have battled this disease for so long to take the first step. Otherwise, we will not reach our goal - finding treatments and cures for mitochondrial diseases.

So, please take the first step and go to the UMDF website to read about current clinical trials and studies seeking participants.

We are in this fight together. Now, please become a part of the path toward its cure. Thank you.

Many of us have participated or are currently participating in a clinical trial or study. If you have questions about participating in a clinical trial or study, we would be happy to share our experiences with you. Please contact us at AACT@umdf.org.

AACT WEBINAR RECORDED

On Wednesday, October 28, AACT Medical Advisor, Dr. Bruce Cohen, conducted a webinar for Adults & Young Adults entitled: "**Current Therapies and Treatments in the Mitochondrial Disease in the Adult Patient**"

This webinar was recorded and is available on the UMDF website. You may watch or listen to this webinar and other webinars we have recorded by visiting www.umdf.org/AACT.

✓ **Tip Topic: Create a Journal**

Creating a medical journal can be great for tracking symptoms but also for tracking energy levels. Monitoring energy levels after big events can help you understand your limits. Though even with the best tracking, energy levels can be a rollercoaster, so make sure you stay in tune with how you are feeling.

Devin Shuman – Washington
(AACT Young Adult Coordinator)

✓ **Tip Topic: Heart Warning**

My tip was learned the hard way. As many of you know, cardiac problems are common with mito. I see a cardiologist every six months and have regular EKGs, echos and even a stress test. I started having heartburn and they treated me for GERD. Then I started having chest pain and they treated me for costochondritis/muscle pain after the tests were normal. My poor lung function was mito or asthma. I told all my docs about the pain shooting down my arms and in my jaw. They thought muscle and nerve. When the pain got severe, I went to the hospital and was sent home when the EKG and other tests were normal. After another ER visit, a doctor ran my troponin levels which were very high. I was admitted to the ICU and scheduled for the Cath Lab. I was having a heart attack, probably not my first, and the EKG was normal. My main artery was 99% blocked (my cholesterol is only borderline). I now have a stent and am lucky to be alive. The heartburn, pain and poor lung function are gone and I have more energy. I knew something was wrong and was vocal about it to at least 20 doctors. I didn't know to ask for troponin tests. If you feel the docs are missing something, force them to listen. Even good docs make mistakes. It could save your life.

Jennifer Schwartzott – New York

✓ **Tip Topic: Eye Care**

Many of us have cornea exposure (keratopathy) due to our associated mitochondrial disease that can cause pain, affect vision, and become chronic that can lead to serious complications. Following are some tips that can help alleviate, stabilize, and keep your eyes as healthy as possible.

- **Eye Drops:** Best to use artificial tears and/or lubricating drops. Use them often! They are harmless and can provide great relief. Plus, helps remove pollens, etc, from irritating eyes. Once applied, close your eyes and using your lower eyelids, gently push upward and massage in. There are many very good name brands, including preservative free (don't sting or burn) and thicknesses. Buy smaller bottles or ask your ophthalmologist for free samples to see which works and feels best.
- **Humidifier:** Best to use a warm mist humidifier that can provide moisture, especially helpful if live in a dry climate and/or during dry winter months.
- **Warm Steam:** While in the warm shower and/or steam sauna, close your eyes and using your lower eyelid, gently push upward with a towel and massage eyes (like with eye drops); do several times. Amazing how quickly your eyes will feel better.
- **Eye Hygiene:** Daily, clean eyes/eyelids area thoroughly - A.M. & P.M.
- **Sunglasses:** To help protect and prevent sun eye damage, wear sunglasses throughout all daylight hours and on partly cloudy days. Also, many of us have photophobia (painful light intolerance) with related retina issues that cause glare and contrast problems that adversely affect our vision as well. Sunglasses can provide much help. However, most sunglass lenses are black, brown, gray or dark green which can make it very difficult to see well, especially with retina issues. Try sunglasses that have dark

rose/pink, orange or yellow lenses (no 'blues' in them.) What an immediate and remarkable difference these lenses can make with the same UV protection. Visual field "pops" and brightens which provides much better clarity, even on cloudy days! Hope you give them a try. Literally, you will see a dramatic difference!

Gail Wehling - Illinois

✓ **Tip Topic: Garlic**

Garlic can provide many health benefits. I was diagnosed with Blepharitis (inflammation of the eyelids or eyelid margins), and after consulting with my local health store, I began taking garlic supplements (2600 mgs) daily. Soon, thereafter, it completely cleared it up.

Gregory Yellen – Maryland

Corporate Partnership Spotlight

UMDF Corporate Partnership provides your organization with the opportunity to reinforce your brand image with a health and wellness-minded audience, to increase image awareness and name visibility for your services and products, and to generate goodwill throughout the community. You can accomplish this while helping a very worthy cause.

Many UMDF Corporate Partners are personally tied to our mission, like Staples Oil Co., Inc. of Jackson, Minnesota. Brent and Nicole Staples are cousins to an affected family and have actively supported the Minnesota Energy for Life Walk since 2010.

The Staples Oil Co. partnership goes far beyond their financial support of the EFL. Their annual Dairy Queen and BP Expressway fundraiser is promoted on the local radio station and in newspapers. They seek donations from other local businesses and “give back” a free cone for every dollar donated from the local community. Staples Oil employees participate on their walk team and educate customers about mitochondrial disease. Brent and Nicole say the partnership has given back to them as well.

“We have been honored to partner with the UMDF over the last five years to help raise money for such an important cause. Teaming up with Andy, Lindsay and Sylvia of Leo’s Lions for our annual fundraising event has been a wonderful way to raise awareness and money in memory of Leo Chapman-Nesseth, both causes that are personally important to us. It has provided us a way to get the community involved in supporting Leo’s Lions each and every year, and we are thankful to our family and friends in the Jackson, MN, community that have helped to make this such a success.”



If you would like more information about Corporate Partnership opportunities, please contact the UMDF Development team at events@umdf.org.

Donor Spotlight

July 1, 2015 - September 30, 2015

\$49,999 - \$10,000

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Mr. Jason Schmid

\$9,999 - \$5,000

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Ms. Angelina Foglia
Miss Marni Gittinger
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Mr. Brent Staples

\$4,999 - \$1,000

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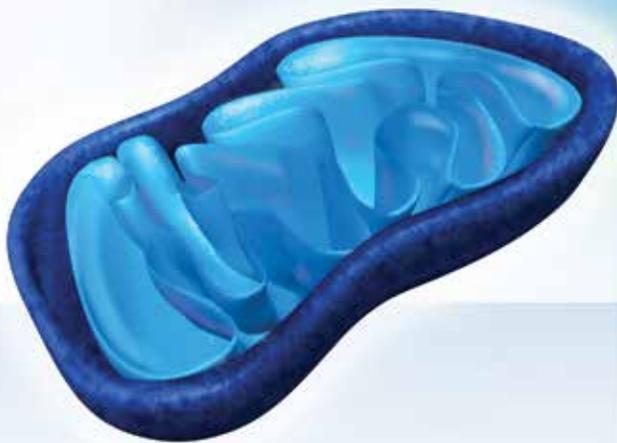
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The Baylor Miraca Genetics Laboratories (BMGL) is committed to providing quality genetic testing services relevant to patient care today. BMGL continues to develop comprehensive molecular testing and mitochondrial disease panels/testing, as well as testing for other disorders. We have specialists available to answer questions about billing and testing for your convenience.

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Russell Saneto, DO, PhD

Seattle Children's Hospital / University of Washington

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Akron Children's Hospital

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We're excited to announce that we've partnered with Insurance Auto Auctions (IAA) to establish a vehicle donation program that will allow us to increase our fundraising capabilities.

IAA is a leading automotive auction with more than 30 years of experience. With 165+ auction facilities throughout North America, IAA sells millions of vehicles to buyers around the world, working to maximize returns for sellers. This partnership will save us the time and money required to establish an in-house vehicle donation program. IAA will process and auction vehicles donated to us, and we'll receive the proceeds!

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1.

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IAA Donation Division



2.

IAA Tows
the Vehicle



3.

IAA Auctions
the Vehicle



4.

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to File for Tax Deduction



5.

Charities Get
the Proceeds

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- Web ads
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UMDF events

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Fundraisers Benefitting the UMDF

July 31, 2015 – Run 4 Raley was once again held in Philo, IL, this year. A huge turn-out led this annual event to raise over \$17,000!

August 1, 2015 – The Annual Softball tournament “Baylee’s Ball Bash” was held in Cannelville, OH!

August 1, 2015 – The first Annual Carter Lackey Memorial Miles run was held in Waverly, NY, at Waverly Glen Park. All proceeds from this event benefitted the Carter Lackey research fund through the UMDF.

August 2, 2015 – Andrea Emery jumped out of a plane to benefit her EFL Walkathon: Minnesota team Quinn’s Quest!

August 3, 2015 – The ExpressWay BP and Dairy Queen donated all proceeds from Dairy Queen and \$.10 off every gallon of gas to benefit EFL: Minnesota team Leo’s Lions!

August 12, 2015 – Blakes Super Powered UMDF Fundraiser was held at Chuck E. Cheese to benefit EFL: Detroit Blake’s Super Powered Team!

August 15, 2015 – Faith McColl is headed to college and has closed out an amazing 10-year run of her lemonade stand! Faith will continue fundraising at college and is also working with the UMDF to help others set up their own lemonade stands. For more information about this endeavor please email Tara at TaraM@umdf.org.

August 15, 2015 – EFL: Charlotte team “Life for Lila” held an amazingly fun bowling event in downtown Charlotte, NC! The event boasted cosmic bowling and an amazing list of prizes that were raffled off!

August 29, 2015 – UMDF members had the chance to purchase passes through the month of August. These special discount passes were used on Macy’s annual Shop for a Cause day!

August 30, 2015 – EFL: Charlotte team Zanebash held their very own “Zane Bash”! The exciting event had live music and a silent auction in NODA at Jack Beagle’s!

September 1-30, 2015 – STAGE Stores in Shreveport, LA, selected the UMDF as their partner charity for the month of September.

September 1-30, 2015 – Aidan’s Mito treats was a candy sale held in Santa Ana, CA, throughout the month of September.

September 10, 2015 – The 7th annual CURE ride for LHON was held in California. Over the years, the CURE Ride guys have raised \$175,000!!!

September 12, 2015 – The annual MitoBowl (formerly the EnergyBowl) was held in Meridian, ID.

September 13, 2015 – EFL: Del Val Team Ja’Nell held “Saving Squirt One Shake at a Time,” a Zumbathon, to benefit their EFL team.

September 18, 2015 – Kim Clifford held a Mary Kay fundraiser online in memory of her Fiancee’s son, Brody Bivens.

September 18, 2015 – The second annual Carlos Alberto Memorial Golf Outing was held at the Pipestone Golf Course in Miamisburg, OH. The event had a golf scramble accompanied by a dinner.

September 18, 2015 – “Hats Off to Doctor Seuss” was held in Wilmington,

NC, at the Gallery of Fine Art. The gallery had a special viewing of many of Dr. Seuss’s original pieces and proceeds from a raffle came to the UMDF.

September 19, 2015 – The Run Bryn Athyn 5k took place in Bryn Athyn, PA, as a part of a Senior Project. All funds raised benefited the UMDF.

September 19, 2015 – The Cutliff Family hosted an Awareness Walk in memory of their beloved Samuel. The walk was held at the AnMed Health Track in Anderson, SC.

September 25, 2015 – A three-day video game tournament held in Greenwood, IN, was hosted by two great friends fighting mitochondrial disease!

September 26, 2015 – The 2nd Annual Jaxon’s Warriors 5k and Little Warrior Fun Run had a new surprise this year... a 10k option! The event raised over \$15,000 for the Jaxon Sharma Research Fund!

September 26, 2015 – The Ribeiro family hosted a pizza party and coins and cans for a cure fundraiser in La Mirada, CA.

October 9, 2015 – The very first Emma Frances Golf Outing was held in Northborough, MA, in memory of Emma Frances Dalton. The event raised over \$8,000, all benefitting the Emma Frances Dalton Research Fund.

October 10, 2015 – Mary Alexis Rohrer held a yard sale in memory of her good friend, Rachel Albertson.

October 11, 2015 – The Chicago Marathon once again had a fantastic team supporting the UMDF! Way to go everyone!

The UMDF will offer a regional symposium at Children's Memorial Hermann Hospital in Houston, Texas, in February 2016.



Upcoming Events

October 29, 2015 - A paint night will be held in Vincennes, IN. All proceeds benefit the Brady Sterchi research fund through the UMDF.

November 7, 2015 - The Radney family is participating in the BELK Charity Sale. Participants can purchase \$5 passes for \$5 off of a purchase. All proceeds benefit the Andrew Radney research fund through the UMDF.

November 7, 2015 - The 7th annual Fall into a Cure Wine Tasting and Auction will be held at Creek's Edge Winery in Lovettsville, VA. Tickets are \$30 a person which includes three wine tastings and appetizers. For more information regarding lodging and purchasing tickets, please visit the website at www.umdff.org/fallintoacure.

November 11-14, 2015 - BonTon and Carson's Community Days will be taking place nationwide. You can purchase a pass for special sales and discounts. Proceeds benefit the UMDF. You can order your booklets here http://www.bonton.com/product/311676.html?utm_source=premiere&utm_medium=htmlversion&utm_content=261561&utm_campaign=15FCMDAYBK&ICID=15FCMDAYBK261561.

November 14, 2015 - PLEASE NOTE THE DATE CHANGE! The Mito Disc Golf Fundraiser will be held in Knoxville, TN, as a part of the Knoxville Disc Golf Association. Contact Justin Forbes for more information at justinforbez@yahoo.com.

December 5, 2015 - The second Annual Carter's Christmas craft fair, raffle, and photos with Santa will be held at the Sayre Elks Club in Sayre, PA. Proceeds will benefit the Carter Lackey research fund through the UMDF.

April 9, 2016 - The first Brady's Bunch Miles for Mito 5k will be held in Vincennes, IN. Please keep an eye out for more information closer to the event.

June 4, 2016 - The Annual Greater Mito Open (Birdies for Brianna) will be held at the Broadlands golf club in North Prairie, WI. Please keep an eye out for more information closer to the event.

Upcoming Symposia

Central Regional Symposium UT Health/Children's Memorial Hermann Hospital, Houston, TX

February 12-13, 2016

Full CME day on Friday for medical professionals and morning meetings on Saturday for patients/families.

Course Chair: Mary Kay Koenig, MD

CME Chair: Bruce H. Cohen, MD

www.umdff.org/symposium/central

Southeast Regional Symposium

Duke University School of Medicine,
Durham, NC

February 19-20, 2016

Full CME day on Friday for medical professionals and morning meetings on Saturday for patients/families.

Course Chairs: Dwight Koeberl, MD and Edward Smith, MD

CME Chair: Bruce H. Cohen, MD

www.umdff.org/symposium/southeast

Great Lakes Regional Symposium

Mayo Clinic, Rochester, MN

May 20-21, 2016

Full CME day on Friday for medical professionals and morning meetings on Saturday for patients/families.

Course Co-Chairs: Ralitz Gavrilo, MD and Marc Patterson, MD

CME Chair: Linda Hasadsri, MD, PhD

www.umdff.org/symposium/greatlakes

Mitochondrial Medicine 2016: Seattle - National Symposium

DoubleTree by Hilton, Seattle, WA

Scientific Program - June 15-18

Family & LHON Program - June 17-18

Course Chair: Russell Saneto, DO, PhD

CME Chair: Bruce H. Cohen, MD

Reserve your hotel room now!

www.umdff.org/symposium

For details on all UMDF Symposia visit www.umdff.org/symposium.



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 walkathon

Upcoming EFL Walkathons

Our Fall 2015 EFL Walk season is coming to a close! We had our largest season yet with 17 walk locations across the country! Over 350 teams came out and fundraised over \$710,000, with more donations coming in each day!! A special thank you to each and every one of our teams, walkers, volunteers, donors, committee members and sponsors who supported an EFL Walk this year!!!

THANK YOU TO:

- Energy for Life Minnesota
www.energyforlifewalk.org/minnesota
- Energy for Life Indianapolis
www.energyforlifewalk.org/indianapolis
- Energy for Life Western New York
www.energyforlifewalk.org/westernnewyork
- Energy for Life Kansas City
www.energyforlifewalk.org/kansascity
- Energy for Life Central Texas
www.energyforlifewalk.org/centraltexas
- Energy for Life New Orleans
www.energyforlifewalk.org/neworleans
- Energy for Life Detroit
www.energyforlifewalk.org/detroit
- Energy for Life Delaware Valley
www.energyforlifewalk.org/delval
- Energy for Life Chicago
www.energyforlifewalk.org/chicago
- Energy for Life Omaha
www.energyforlifewalk.org/omaha
- Energy for Life Southern Wisconsin
www.energyforlifewalk.org/southerwisconsin
- Energy for Life Akron
www.energyforlifewalk.org/akron
- Energy for Life Seattle
www.energyforlifewalk.org/seattle
- Energy for Life Birmingham
www.energyforlifewalk.org/brimingham

- Energy for Life Charlotte
www.energyforlifewalk.org/charlotte
- Energy for Life Columbus, GA
www.energyforlifewalk.org/columbusga
- Energy for Life Southwest Florida
www.energyforlifewalk.org/southwestflorida

P.S. It's not too late to make a donation or to double your donation with a matching gift! Ask your employer if they match gifts!

We are looking forward to our Spring Walks! Please help us reach those goals by supporting one of these amazing cities!

- Saturday, April 9 – San Francisco Bay Area
www.energyforlifewalk.org/sanfrancisco
- Saturday, April 16 – Atlanta
www.energyforlifewalk.org/atlanta
- Saturday, April 23 - Tampa Bay
www.energyforlifewalk.org/tampabay
- Saturday, April 30 - Dallas/Fort Worth
www.energyforlifewalk.org/dallasfortworth
- Saturday, April 30 – St. Louis
www.energyforlifewalk.org/stlouis
- Saturday, May 1 – New England
www.energyforlifewalk.org/newengland
- Saturday, May 14 – Nashville
www.energyforlifewalk.org/nashville
- Saturday, May 14 – Cincinnati
www.energyforlifewalk.org/cincinnati
- Saturday, May 21 – Pittsburgh
www.energyforlifewalk.org/pittsburgh
- TBD – Houston
www.energyforlifewalk.org/houston
- TBD – Shreveport/Bossier City
www.energyforlifewalk.org/sbc
- TBD – Evansville
www.energyforlifewalk.org/evansville

www.energyforlifewalk.org/birmingham



UMDF national

News from the national office.

WHAT UMDF REGION DO YOU LIVE IN?

Below are the UMDF's current regional coordinators and their email addresses.

We also encourage you to stay up to date in your region by visiting the regional webpages listed below!



Northeast Region 2

Nicole McCaslin

Nicole@umdf.org

www.umdf.org/northeast

Southeast Region 3

Margaret Moore

Margaret.Moore@umdf.org

www.umdf.org/southeast

Great Lakes Region 4

Anne Simonsen

anne.simonsen@umdf.org

www.umdf.org/greatlakes

CONGRATULATIONS, NICOLE!



Congratulations to Nicole McCaslin, UMDF Northeast Regional Coordinator, and Jason McCaslin on their marriage on Saturday, July 25th!

UNITED MITOCHONDRIAL DISEASE FOUNDATION STAFF

Executive Staff

Charles A. Mohan Jr.
CEO/Executive Director

Janet Owens
Executive Administrative Asst.

Philip Yeske, PhD
Science and Alliance Officer

UMDF Symposia

Kara Strittmatter
Meeting Event Director

Finance

Mark Campbell
Chief Financial Officer

Donna Nameth
Data Entry Manager

Barbara Cullaj
Administrative Assistant

Communications

Clifford Gorski
Director of Communications

Jeff Gamza
Multimedia Coordinator

Development & Member Services

Beth Whitehouse
Director of Development

Tania Hanscom
National Walk Manager

Cassie Franklin
Gifts Officer

Julie Hughes
Development Associate/
Grants

Tara Maziarz

Development Associate/
Social Media

Nicole McCaslin
Regional Coordinator -
Northeast

Margaret Moore
Regional Coordinator -
Southeast

Anne Simonsen
Regional Coordinator -
Great Lakes

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.

The UMDF focuses on coordination, communication and collaboration.

We bring people and resources together to make an impact on diagnoses, treatments and a cure for mitochondrial disease.

Remember the UMDF this Holiday Season

Full Season is in full swing and the holiday season is right around the corner. In other words, a lot of running around, meal planning and holiday shopping. And, yes, UMDF asks you to remember us this holiday season, too. But we want you to know there are many ways to give and support our mission. Please consider some of these creative ideas:

Share your story with us and others

Tell others why you support UMDF by posting your story or video on social media and/or through email. Be sure to tag #UMDF and include this link to donate to us – www.umdf.org/donate

New Year's Resolution

Starting out the New Year oftentimes comes with a resolution that is hard to keep. In 2016, make a resolution to make a recurring monthly gift to UMDF. Visit www.umdf.org/donate and select the option, "I would like to make a recurring gift."

Holiday Gifts from the UMDF Store

Give commemorative UMDF gifts this holiday season! Visit the UMDF Store for gifts, holiday cards and more!

Online Shopping and Search Options

AmazonSmile

AmazonSmile is a simple and automatic way for you to support the UMDF every time you shop, at no cost to you. You'll find the exact same low prices, vast selection and convenient shopping experience as amazon.com with the added bonus that Amazon will donate a 0.5% of the purchase price to the UMDF! Visit smile.amazon.com and select UMDF to receive donations from eligible purchases before you begin shopping.

GoodSearch.com

Set your default browser to GoodSearch.com and every time you search the internet at GoodSearch.com, the UMDF earns \$.01. The more you search, the more dollars we earn to find better treatments and cures. Type <http://www.goodsearch.com/?charityid=806412> into your browser to contribute to the UMDF.

iGive.com

The www.iGive.com feature on the UMDF website allows you to shop online and have part of your purchases donated to the UMDF. Register at iGive.com and support the UMDF at the same time.

FundPhotos

FundPhotos is an online photo printing and personalized photo merchandise retailer dedicated to supporting community groups and non-profit organizations just like the UMDF. FundPhotos will donate 10% of the purchase of all prints and personalized photo merchandise to the UMDF. Join for free at www.FundPhotos.com. Create photo galleries that you can share with friends and family. Select the UMDF as your photo gallery's contribution recipient and when you or anyone you share your photos with, makes a purchase, the UMDF will receive your 10% donation!



HOPE. ENERGY. LIFE.

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Donate today!
Every dollar counts.
Visit www.umdf.org.