



*Edward J. Lesnefsky presents before members of Congress*

## UMDF Advocacy in Action on Capitol Hill

**R**epresentatives from more than 30 house and senate offices attended the UMDF's latest Congressional Mitochondrial Caucus briefing, titled: "Causes and Consequences of Damage to Mitochondria on the Warfighter from Gulf War Illness to TBI." Presenting at this important briefing was Edward J. Lesnefsky, MD, FACC, FAHA, of Richmond, VA. Dr. Lesnefsky is with the Division of Cardiology, Professor of Medicine and Biochemistry at Virginia Commonwealth University and the McGuire Veterans Affairs Medical Center.

The briefing, held in the U.S. Capitol Building, enabled Dr. Lesnefsky to educate the members of Congress about the role mitochondrial dysfunction has in illnesses related to U.S. Service Personnel.

Evidence has revealed that mitochondrial dysfunction is at the core of many common illnesses and chronic conditions such as Alzheimer's disease, Parkinson's disease, diabetes, heart disease, obesity, osteoporosis and cancer. Most recently, a

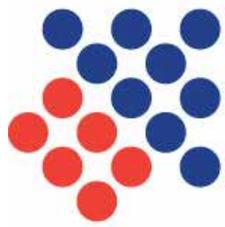
rapidly increasing amount of data shows that Gulf War Illness and Traumatic Brain Injury may have a mitochondrial basis. Additionally, mitochondrial function directly affects the energy levels and functional capabilities of the war fighter. Thus, mitochondrial energy production may provide ways to enhance active duty military capabilities. Dr. Lesnefsky focused on the implications of damaged mitochondria to the warfighter and how further research in mitochondrial disease and dysfunction could help lead to new treatments benefitting affected individuals – and new ways of protecting service persons and civilians.

While in Washington, D.C., UMDF staff was able to visit with key appropriations staff representing both the House and Senate in an effort to have mitochondrial disease and dysfunction added to the list of Congressionally Mandate Research funds within the Department of Defense. It is now up to the House and Senate to include this request in an appropriations bill to be sent to President Obama. Should mitochondrial disease/dysfunction be included, a new avenue of research funding for mitochondrial disease could open with benefits for all affected.

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# From the Chairman

Since this is my first "Chairman's Message," please allow me to express my thanks to the Board of Trustees for placing their faith in me as I continue to serve the United Mitochondrial Disease Foundation in this new capacity. I am honored to accept the position and want to take this time to recognize our previous Chairman, Dan Wright, for his tireless commitment to UMDF. I have had the pleasure of knowing Dan for many years and working closely with him the last several as a member of the Executive Committee. Of all his many qualities, the one that stands out to me is the way Dan always "leads by example" and thus inspires those around him to do the same. Dan assumed the Chairman's role in 2008 after the sudden passing of his friend and predecessor, Stan Davis, who was a compassionate and inspirational leader. Amidst a very difficult transition, and a looming financial crisis which would spell doom for many businesses and foundations, Dan quickly assumed his new role and, through his leadership, helped ensure a seamless transition. Not content to maintain the status quo, Dan provided the vision, leadership, and support for many of UMDF's most exciting and important initiatives. Although too many to list, a few of Dan's notable contributions include: the expansion of our Government advocacy efforts, the development of the Energy for Life signature fundraising events, the creation of a full-time Science and Alliance Officer position whose job is to facilitate the development and approval of treatments and cures for mitochondrial diseases and dysfunction, and, most recently, the establishment of the Mitochondrial Disease Community Registry (MDCR). This is only a small sample of the many tangible areas of progress that Dan has overseen during his tenure as Chairman. Please join me in recognizing and thanking



Dan for his leadership and commitment. I am grateful for his mentorship, advice and friendship and appreciate his on-going guidance in his new role as Vice-Chairman.

The one thing that hasn't changed during Dan's leadership is the commitment of the

Foundation to supporting those impacted by this disease. Like Dan and many of you, our family has experienced the challenges of searching for a diagnosis, the lack of physicians' knowledge of the disease, and the day-to-day problems of my son's (Patrick) fight with the disease. As challenging as this has been, I can't imagine what it would have been like without the support we have received from the myriad of UMDF staff, volunteers, and medical advisors. In the coming years, UMDF will aggressively push for effective treatments and cures. However, I am comforted and committed to ensuring that UMDF remains firmly grounded in its mission 'to provide support to affected individuals and families.'

As I was preparing this note and reviewing many of the past UMDF newsletters, I was struck not by the size of the challenge but rather by the progress and the rate of change we are experiencing. I am filled with a sense of optimism and hope for the arrival of effective treatments and cures in the coming years. In future newsletters, I look forward to sharing examples of the progress we are making, as well as an honest appraisal of the challenges we are facing and the areas where we need your help. I am confident that if we work together and "lead by example" as Dan has taught us, we will accelerate our path to a cure.

*Patrick Kelley*

Patrick Kelley, UMDF Chairman

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# Awareness Week Recap

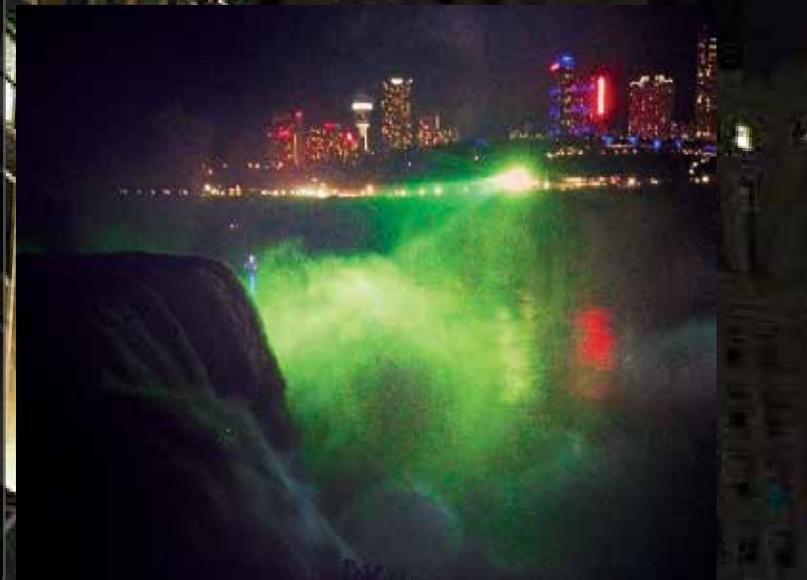
**U**MDF members, their families and friends, fanned out across the county September 14-20, 2014, to mark Mitochondrial Disease Awareness Week. The United Mitochondrial Disease Foundation received more than 20,000 requests for information designed to be used to help teach others about mitochondrial disease and its impact on the lives of those affected around the country. With the UMDF's help, a number of events were scheduled by members. Some events included participants educating teachers and students about the disease that affects a classmate. Key this year was an increase in physician education. UMDF provided hundreds of "Mito101" cards and "About Mito" brochures to members who wanted to connect with doctors and nurses in an effort to spread awareness within the medical community.

Several landmarks were turned green as part of the 'Awareness Week' activities held during the third week of September. MitoCanada was able to have the waters at Niagara Falls turned green in honor of those who are battling and those who have lost their battle with mitochondrial disease. In Cleveland, the historic Terminal Tower was bathed in green for awareness. There were also a number of proclamations passed during Awareness Week. UMDF Northwest Washington Ambassador, Joy Krumdiack, managed to have Governor Jay Inslee declare the third week of September as Mitochondrial Disease Awareness Week. Krumdiack also had the mayor of her hometown, the City of Bellingham, do the same. In Pennsylvania, Robin Bartle secured a proclamation from Governor Tom Corbett. There were several other proclamations sought and received by UMDF members across the nation.

UMDF worked alongside the Australian Mitochondrial Disease Foundation in creating a Global Mitochondrial Disease Facebook page. It was on that social media page that those affected and their families could post pictures and tell their story about mitochondrial disease. Hundreds of people from around the globe took part in sharing their stories as part of this 'Awareness Week' initiative.

In 2015, UMDF will celebrate 'Awareness Week' Sunday, September 20 through Saturday, September 26. Mark your calendars now and start thinking about how you would like to raise awareness!

*Above: The Terminal Tower in Cleveland, OH alight in green for Awareness Week. Below: Niagara Falls*





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# UMDF Joins Roundtable Discussion

The United Mitochondrial Disease Foundation was one of several advocacy organizations invited by Rep. Tim Murphy (R-PA-18) to participate in a public round table discussion called #Path2Cures.

The event, held in Pittsburgh on October 23, was organized by the Congressman to talk about ways to improve the discovery, development, and delivery of new medications and treatments. The UMDF was represented at the roundtable discussion by CEO/ Executive Director Charles A. Mohan, Jr.

Mohan was one of the leaders from 14 organizations chosen to participate. He urged representatives of the other organizations to become better advocates in order to move towards the advancement of treatment and cures.

“We’re not getting the funding or the attention we need, often because we’re immobilized or stuck in a wheelchair or a bed,” Mohan said. “Remember: the ark was built by amateurs; the Titanic was built by professionals.”

Also attending the discussion was Dr. Pamela McInnes, Deputy Director of the National Center for Advancing Translational Sciences (NCATS), a division of the National Institutes of Health

dedicated to finding better ways to translate clinical observation into treatments, procedures, and medications. Dr. McInnes discussed plans by the federal government on how to bring new therapies to market. Dr. McInnes told attendees that fast tracking of drugs can only happen if more patients involve themselves in clinical trials.



“We have to start respecting patients as part of the process instead of simply the object of examination,” McInnes said, “but the problem is we need to start treating all diseases as having something in common; there are underlying factors to rare and common disease groups; let all boats rise to the top at the same time.”

The #Path2Cures meeting was part of the Energy and Commerce Committee’s 21st Century Cures Initiative, which was started in early 2014 to identify and develop solutions to problems in current systems, find ways that Congress can foster medical innovation, and work towards the optimal balance between speed and safety in the drug and treatment approval process. As part of the initiative, the Committee has hosted a dozen hearings and roundtables. Rep. Murphy is a member of the Energy and Commerce Committee and is also co-founder of the Congressional Mitochondrial Disease Caucus.

## Who’s on the Congressional Mitochondrial Disease Caucus?

We are frequently asked by UMDF members if their Congressman has joined the Congressional Mitochondrial Disease Caucus. Here is a list of the current caucus members. If your Congressman’s name is not here, call their office and ask them to join. The names that appear below are members of this important caucus because UMDF members in their congressional districts called and asked them to join!

### CALIFORNIA

- Rep. Jim Costa - (D-CA-16)
- Rep. Anna Eshoo - (D-CA-18)  
*Caucus Co-Founder*
- Rep. Devin Nunes - (R-CA-22)
- Rep. Adam Schiff - (D-CA-28)

### FLORIDA

- Rep. Ileana Ros-Lehtinen - (R-FL-27)

### LOUISIANA

- Rep. Bill Cassidy, MD - (R-LA-06)

### MASSACHUSETTS

- Rep. Niki Tsongas - (D-MA-03)
- Rep. William Keating - (D-MA-09)
- Rep. Jim P. McGovern - (D-MA-02)

### NEW HAMPSHIRE

- Rep. Ann McLane Kuster - (D-NH-02)

### NEW JERSEY

- Rep. Jon Runyan - (R-NJ-03)

### NEW YORK

- Rep. Christopher Collins - (R-NY-27)

### OHIO

- Rep. Marcy Kaptur - (D-OH-09)
- Rep. Tim Ryan - (D-OH-13)

### PENNSYLVANIA

- Rep. Joe Pitts - (R-PA-16)
- Rep. Tim Murphy - (R-PA-18)  
*Caucus Co-Founder*

### VIRGINIA

- Rep. Rob Wittman - (R-VA-01)
- Rep. Bob Goodlatte - (R-VA-06)
- Rep. Gerald Connolly - (D-VA-11)

# UMDF Families Spend Special Time at Retreat

**M**agical...  
 “Amazing...”  
 “A blessing...”

These are just a few of the ways that families described their experiences at the UMDF’s first Family Weekend Retreat at the Center for Courageous Kids (CCK) in Scottsville, Kentucky.

Passionate volunteers, UMDF staff and CCK recruiters had been discussing the idea of a weekend retreat specifically for families with mitochondrial disease since Spring 2013. When Nashville-area members Mendy and Tony Mazzo learned of the endeavor, they pledged full support from Josie Mazzo Children’s Charities. Four-year-old Josie Mazzo lost her battle with mitochondrial disease in 2006. Her parents, Mendy and Tony, founded Josie Mazzo Children’s Charities to provide resources to local families affected by mitochondrial disease and other rare diseases.

*“My husband Tony and I are so excited to honor the memory of our daughter, Josie Renae Mazzo, by helping other mito kids and their families. When the sponsorship request came to us for Camp for Courageous Kids, we knew this was a special opportunity to make a huge difference and we appreciate UMDF for including us.”- Mendy Mazzo, Co-Founder of Josie Mazzo Children’s Charities and Mom to Josie and Sam Mazzo.*

And what a special opportunity it was! On November 7-9, the Center for Courageous Kids hosted 27 UMDF member families from seven different states for a weekend retreat. Camp programming staff worked with UMDF staff and volunteers to tailor the weekend schedule, dining options, and volunteer support to the needs of families and patients with mitochondrial disease. According to the Delano family from Alabama, who had camped at CCK in the past, this weekend was the “best yet.”



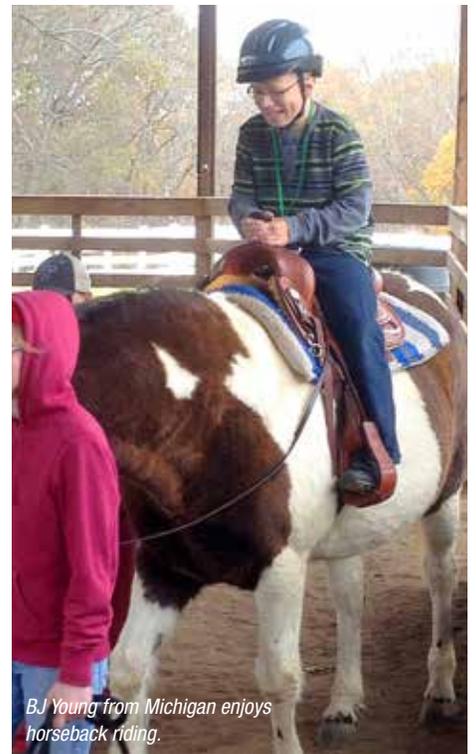
The Mazzo Family



Rebecca Simmons shows off the wooden palm she made in Wood Shop.



Kids and parents catch fish together at the fishing dock



BJ Young from Michigan enjoys horseback riding.

# UMDF members

Uplifting stories about our members

Families, each assisted by their own exclusive volunteer helper, caught fish, rode horses, shot arrows using assistive bows, and made numerous different crafts and wood projects. One of the most popular activity areas was the bowling alley and arcade, which came equipped with noise canceling headphones for patients with sensory sensitivity.

*"CCK is amazing! We had the chance to connect with other mito families and hear their stories. It gives us strength and hope. Amazing staff, food and activities! Great FAMILY WEEKEND!"*  
-The Kavan family from Kansas

Dr. Amy Goldstein, pediatric neurologist at Children's Hospital of Pittsburgh and UMDF Trustee, joined parents for an educational meeting on Saturday. Parents especially appreciated a special focus on ways to acknowledge and address other stresses--in the family, in marriage, in schools--that come along with a mitochondrial disease diagnosis. Dr. Goldstein also facilitated question and answer time, helping parents to understand the importance of genetic

testing, patient registries, and participation in clinical trials. At the conclusion of the meeting, Dr. Goldstein spent one-on-one time during dinner with parents who had additional questions.

*"THANK YOU! There are few words I can use to describe this opportunity and experience. HOPE, that one day this disease will no longer exist and that other families won't need to suffer through this. GRATITUDE, that organizations have this opportunity to share their passion to families so that they have a moment of normalcy."* -The Serrano family from Indiana

UMDF thanks Josie Mazzo Children's Charities and The Joshua Helfrich Memorial Fund for their generous funding of the UMDF Family Retreat at the Center for Courageous Kids. CCK staff members were very excited to have maximum enrollment for this first weekend dedicated to families with mitochondrial disease. Both organizations hope to make the weekend an annual event for all UMDF member families.



The Fitzgerald family from Charlotte pose in front of the weekend camp poster.



Arabella Prater and her volunteer helper paint a beautiful wood house.



UMDF member families from seven states attended the first retreat weekend!



## Leap for Life

by Tara Maziarz

**O**n August 11, 2014, Melissa Branch completed a unique feat as part of the UMDF's *Active-Ate* your Mitochondria initiative; she solved a Rubik's Cube during a sky dive!

Melissa has been solving 3x3 and 4x4 sided Rubik's Cubes for a total of one year. The Leap for Life was her first ever sky diving experience, and she is now hooked indicating there will be many more! She specifically chose this event so she could do something huge to raise awareness for Mitochondrial Disorders; the *Active-Ate* campaign was the perfect platform for her to achieve her goal.

I was fortunate enough to be able to interview her about this impressive accomplishment.

*TM : Why did you choose the UMDF as your charity of choice?*

MB: I decided to raise awareness for the UMDF after witnessing the devastating effects of mitochondrial disease first hand. My little cousin has been diagnosed with an unknown variety of mitochondrial disease. Additionally, my son has been undiagnosed for two years now -

mitochondrial disease has still not been eliminated as his underlying illness. The diagnostic and treatment processes for mitochondrial and metabolic diseases are lengthy, invasive, and difficult on families and patients. Raising awareness for the UMDF and mitochondrial disease can lead to much needed research and funding that can make treatments and diagnostics more effective.

*TM: What was appealing to you about our Active-Ate campaign ?*

MB: I loved the *Active-Ate* initiative! Let's all get out there and use some of our energy for those who can't!

*TM: Were you nervous?*

MB: I was more nervous about the cube than the jump! I was worried I would get too scared to finish or that I might drop the cube.

*TM: What was the most challenging part of your event?*

MB: Wind resistance! I was surprised at how difficult the Cube was to move with all the wind, I did not have enough strength to move it as fast as usual.



*TM: Did you need any special training?*

MB: I had no special training for the event, but I did have to develop a special tether for the cube in case I dropped it! It took a lot of work to figure out how to keep the cube connected to me without tangles, all while being approved as safe for the jump.

*TM: Is there any advice you would give to somebody starting their own Active-Ate activity?*

MB: Stick to it! Pledges may be difficult to collect, but we must remember that awareness is key; even if only one person walks away knowing about mitochondrial disease, you made a difference. The leap for life was one of the most rewarding things I have done (or will ever do) in my life, and I am happy to have made a difference for those fighting mitochondrial disease.

Melissa plans on hosting another Leap For Life next year with multiple leapers, only this time she thinks she'll go without the Cube.



# Through Mito Eyes: Awareness... It's All in a Day's Work

by Liz Kennerly

Last summer, I found myself in a situation that necessitated a trip to the ER. This trip was different. I had to go to a hospital I had never been to. I was scared. I was anxious. Most of my apprehension and fear stemmed from the fact that I would be seeing doctors who didn't know me. Not only that, but I wasn't sure how they would react to a very complex patient. There was no way around this. I had to go! My seizures weren't going to improve on their own without some sort of intervention. Not only this, but I was alone.

As nervous as I was, there was a silver lining. I was in a position where I could advocate for myself! The situation could have been far worse.

Once I was settled in a room, the doctors came in to do their exam and evaluate. I recited my entire medical history from memory. I provided them with spelling my doctor's names as well as their phone numbers, also from memory. I told them, "I have Mitochondrial Disease. I'm not sure if you know about it or if you have heard of it." They responded, "Of course we have! We're doctors!" I was flabbergasted. My jaw hit the floor and I was rendered speechless. My mind was racing. Who? Where? When? I could have kissed them! I felt a tremendous sense of relief. I knew I would be okay. I'm not sure how many ER docs are familiar with it.

I was admitted and the next morning 10 neurologists came into my room, including one doctor who was barely awake and leaning against a wall. I hollered from my bed, telling him to wake up, because I was probably one of the most complicated patients he would ever see.

Fast forward to Thanksgiving Day. My youngest cousin, who is about 13, noticed I was looking at my phone a lot. The day before, I glanced at it a couple times, but I acknowledged to her that, yes, I was looking at it more frequently. I come from a large extended family. Both of my parents are the oldest of six. There were at least a dozen people at my uncle's house. I thought I could get away with looking at it as regularly as I was without being caught.

After we went to our shared bedroom, she asked why I was paying such attention to my phone. I immediately felt guilty and awful because she noticed my mind was elsewhere. Then, I understood that she brought it up because she cares. I explained I had to check on some friends of mine who were very sick with the same disease I have. She asked and I told her that

I have Mitochondrial Disease. "Mito what???" YES!!! You just asked my favorite question!

I first explained how our mitochondria are the "powerhouse of the cell", along with the "brown out" analogy we are all familiar with. Once she understood the basics, I dove deeper. I described how energy is made, and that their purpose is to produce ATP, but in Mito they cannot make enough. I also told her about the multitude of ways Mito affects not only myself, but also those I love. To facilitate my explanation and elaborate, I showed her a YouTube video a friend of mine made a few years ago. In addition to displaying pictures of others with Mito, as well as their interventions needed to sustain life, it also provides the statistics. My cousin read the words as the video played. It broke my heart to hear her not only read aloud what I already know and experience, but also realizing she was grasping our reality.

A few months ago, I was sitting in a nearly empty hospital waiting room across from a pair of siblings. After exchanging pleasantries, the young girl asked why I was there. Instead of being caught off guard by the question, I embraced it. Instead of viewing it as a child being nosy, I saw it as a chance to raise some awareness! I told her that I have Mitochondrial Disease and asked if she had ever heard of it. "Oh yes, a friend of mine has it!" While I was upset to hear about her friend, I was also pleased that she was familiar with the disease.

I always take every opportunity I have to raise awareness. After all, the more who know, the better. Sometimes it happens at the hairdresser. Other times, the chance presents itself in a taxi or on a plane. I have learned that in some situations, nosy is synonymous with curiosity. I challenge each person I educate to tell another. Knowledge is power!



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*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, but will move out of her parent's house once she gets a job!*

# Community Registry Update

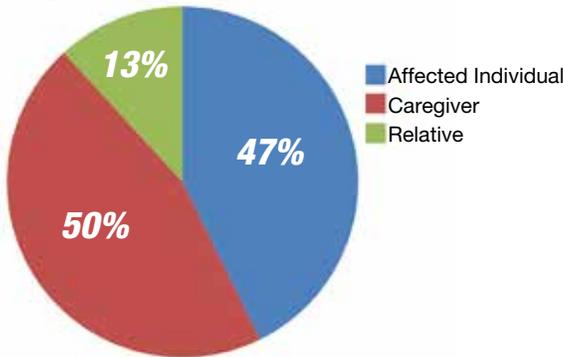
by Phil Yeske, PhD, UMDF Science & Alliance Officer

The Mitochondrial Disease Community Registry (MDCR) is a UMDF-stewarded, patient-populated databank of health information meant to facilitate the development of treatments and cures for mitochondrial disease. MDCR is now just over three months old and currently on track for 1,000 registrants by the end of 2014. This is a phenomenal result in such a short period of time and truly a testament to the desire of this disease community to play an active role in therapeutic development.

Before discussing what we have learned to date, first it is important to remind everyone that UMDF is only able to see anonymous data for those registrants that have specifically allowed UMDF to see their de-identified data. Neither UMDF, nor any other party, will ever be able to see identified data - registrants are completely anonymous.

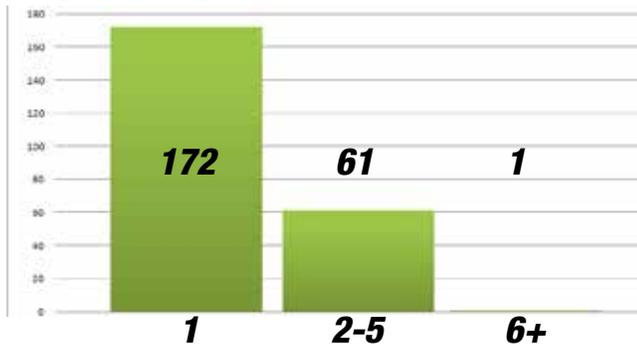
With that in mind, the first survey is really meant to capture baseline demographic information more than anything else, although a handful of questions regarding diagnostic state and opinions on research are also presented. So far, we are getting a nice mix of affected individuals, caregivers and relatives.

## Registrant Segmentation



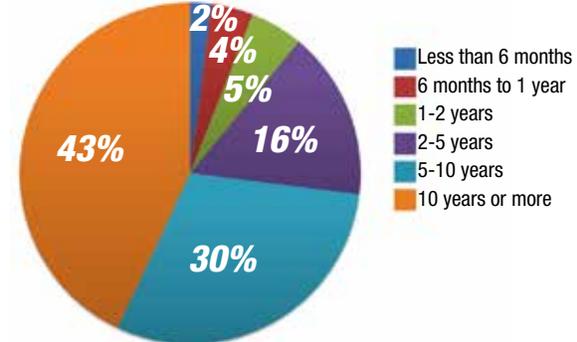
Amongst the 234 caregivers who responded, most are providing care for one individual, although some are caring for a larger number.

## Caregiver Responsibilities



The vast majority of caregivers are taking care of a son or daughter (95% combined), with parents, siblings and other family members making up the remaining 5%. Interestingly, care is being provided over extended timeframes - evidence of the long-term stress involved in mitochondrial disease patient care.

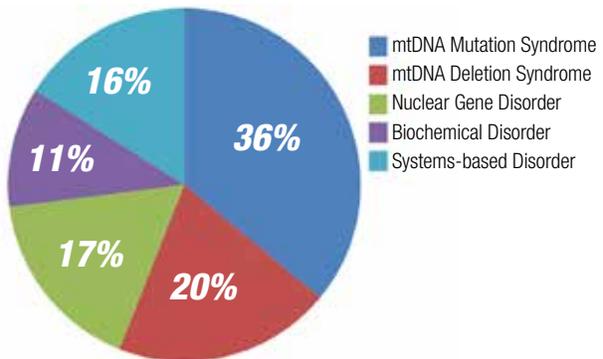
## I have been a caregiver for...



With respect to affected individuals, the responses highlight the challenges that remain around diagnosis. Only 63% of affected individuals reported a definitive diagnosis of mitochondrial disease by their doctors, although another 27% categorized themselves as probable based on their doctor's opinion. Obviously, we all want and hope for higher levels of definitive diagnoses in the future.

The exact nature of the reported diagnoses of mitochondrial disease is predictably diffuse. Here is a breakdown by major category:

## Diagnostic Category



As an example, the mtDNA Mutation Syndrome category has cases of AID, LHON, LHON Plus, MELAS, MERRF, MIDD, MILS and NARP reported. This same breadth of variation is observed in all of the categories, which is good, since we want to capture the broadest picture possible of mitochondrial disease.

This is just a snapshot of the more than 80,000 data points collected since the launch. We are working with our PEER partners to develop better data analysis tools, which will allow us to share even better data summaries. Looking to the future, we are preparing the registry to accept data over time, i.e. "longitudinal data." With robust longitudinal capabilities in hand, future surveys will be deployed on topics such as quality of life and dietary supplement usage that will allow registrants to update their data as frequently as they like.

The community sends a big "THANK YOU" to everyone that has already registered. To these folks, please answer as many questions as possible, and consider sharing your anonymous data as broadly as possible. Only through sharing can we translate the patient perspective into treatments and cures.

## Ask the Mito Doc<sup>SM</sup>

Living with mitochondrial disease presents many twists and turns, and a maze of questions. UMDF is pleased to offer answers to some of those questions as taken from Ask the Mito Doc<sup>SM</sup> at [www.umd.org](http://www.umd.org). Please note that information contained in Ask the Mito Doc<sup>SM</sup> 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 was diagnosed with Mitochondrial Myopathy 2 years ago. I have the OPA-1 gene mutation. I suffer with fatigue. I get worn out very easily and some days I struggle to get out of bed because I am so tired and sleep doesn't make me better; food also doesn't help (mostly I'm even worse after eating). It effects my work and social life, and I'm in my early 20s. My doctor says that it's not part of my condition. I was wondering if you believe that it is? I can't see how general fatigue wouldn't be caused by my mitochondria so it's frustrating every time it's rejected as it affects me greatly. I've tried looking for other causes but every time a doctor reads mitochondrial myopathy, they ask if it could be due to that.

**A:** Fatigue is a common problem in mitochondrial disease and one of the most difficult issues to treat. It can be worsened by sleep apnea and other sleep issues, poor hydration and nutrition, dysautonomia and other problems such as anemia. Some patients lessen their fatigue by addressing some of these co-morbid problems, and others use medications to "rev up" their systems such as Vyvanse or other ADHD drugs or Provigil, used typically for narcolepsy but helpful in some mito patients. However, many patients "crash" after using such medications, paying the price of pushing their bodies too hard and not pacing themselves appropriately. As such, I personally recommend using such medications cautiously. I would suggest that you address this issue with your mito specialist and determine what, if any, additional measures can be taken to help improve your fatigue. - *Fran Kendall, MD*



*Fran D. Kendall, MD*

**Q:** My husband has MELAS and was recently diagnosed with diabetes. His doctor has changed his medicine to Januvia (sitagliptin) because he has been able to become stable with his numbers. Are there any known complications with MELAS?

**A:** As a matter of fact, there's evidence that sitagliptin decreases oxidative stress by acting as an antioxidant and preventing mitochondrial dysfunction.

Please read: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3696328/pdf/bph0169-1048.pdf> and <http://joe.endocrinology-journals.org/content/218/1/1.full.pdf+html>

There shouldn't be an adverse effect of sitagliptin on mitochondrial function; however, this drug is relatively new and we still don't know potential long-term effects. - *Dmitriy Niyazov, MD*



*Dmitriy M. Niyazov, MD*

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.umd.org](http://www.umd.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.

# Check Presentation



Nicole Shanter, UMDF Northeast Regional Coordinator, was presented with a \$1,000 check from the company, ARI, in Mount Laurel, NJ. They participated in a charity softball game every year and this year chose to donate the funds to the UMDF in honor of Dave Chiusano's daughter, Becca. Dave is the gentleman holding the big check!

## Mitochondrial Medicine & Industry Job Openings?

The United Mitochondrial Disease Foundation is committed to publishing information that grows and supports the mitochondrial research community. In order to advance science and the development of new therapies for mitochondrial disease, UMDF will post open positions from around the world at all levels in academic mitochondrial research as well as relevant industrial positions.

The UMDF is delighted to help you reach a broad audience. To list your posting here, please submit the following information:

- Job Title
- Employer (*Name and location of the position*)
- Working Environment (*Institution, type of industry, focus of the laboratory or group*)
- Activities (*Specific focus of the position, type of work to be performed on a daily basis*)
- Expectations/Requirements (*Provide required core competencies, goals, required expectations*)
- Contact (*Provide name and contact for more information or to apply*)
- Website or link to job posting

Employers with open positions that fit these guidelines are encouraged to contact the UMDF Science and Alliance Officer, Phil Yeske, PhD, at [mitojobs@umdf.org](mailto:mitojobs@umdf.org).

### MRT Updates

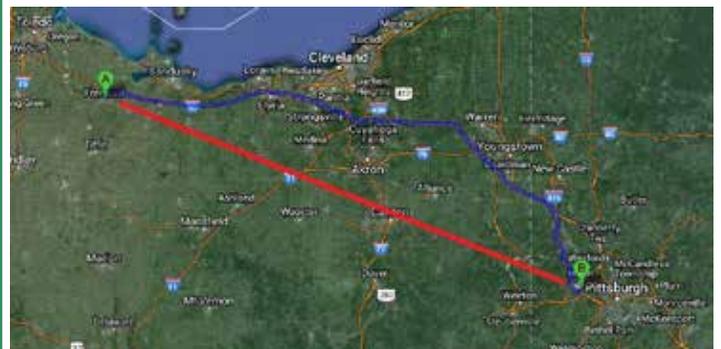
If you are interested in learning more about Mitochondrial Replacement Therapy, visit the UMDF website at [www.umdf.org/replacementtherapy](http://www.umdf.org/replacementtherapy) for the latest information about the therapy and current trials and studies.

## Balloon of Hope

There was an interesting find made at the Pennsylvania Air National Guard 171 Air Refueling Wing based at Pittsburgh International Airport. One of the officers from the headquarters was patrolling the grounds when he stumbled upon an odd find. At first glance, it could have been a candy wrapper or a tossed plastic grocery bag. But on closer inspection, the officer saw that it was a deflated balloon and attached to a string appeared to be a card of some sort. When the officer picked it up, he noticed that the card read, "In Memory of Brody Stephen Bivens." Nearly three years old, Brody Bivens lost his battle with mitochondrial disease on February 28, 2014.

After taking the balloon and the card back to the base, it was determined that the balloon was released as part of the Bivens' family battle against mitochondrial disease and in honor of Brody. Those who found the balloons were instructed to report their locations on Brody's Facebook page. This balloon was released in Fremont, Ohio, and traveled more than 200 miles to land in the field at the 171st.

The 171st Airman's Council not only wanted the Bivens family to know they found the balloon, but Council Vice President Elizabeth L. Simoneau, TSGT, PA ANG, sent the United Mitochondrial Disease Foundation a generous donation in honor of Brody.



# UMDF national

News from the national office.

## Welcome Tara!

Please help us welcome Tara Maziarz to the UMDF. Tara joined the UMDF's special events staff in October 2014. She has a Bachelor's degree in Mass Communications with a concentration in Public Relations and a Theatre minor from Bloomsburg University of Pennsylvania.

Before joining the UMDF, she was the Public Relations Coordinator for CANDLE Inc. and Reality Tour, a parent and child drug prevention system. She interned with The Cooley's Anemia Foundation in New York City helping those affected by Thalassemia. Tara is very motivated to bring her skills to the UMDF: "What the UMDF does is huge, for their patients and the medical community. Mitochondria affects so many aspects of everyday living!"

In her spare time, she enjoys going to concerts, Netflix, and hanging out with her friends, family, and cat. This quote by Princess Diana encompasses what she hopes to accomplish at UMDF: "Everyone needs to be valued, everyone has the potential to give something back."



## UNITED MITOCHONDRIAL DISEASE FOUNDATION STAFF

### Executive Staff

**Charles A. Mohan Jr.**

*CEO/Executive Director*

**Janet Owens**

*Executive Administrative Assistant*

**Philip Yeske, PhD**

*Science & Alliance Officer*

### Finance

**Mark Campbell**

*Chief Financial Officer*

**Donna Nameth**

*Data Entry Manager*

**Barbara Podowski**

*Administrative Assistant*

### Communications

**Clifford Gorski**

*Director of Communications*

**Jeff Gamza**

*Multimedia Coordinator*

### Member Services

**Kara Strittmatter**

*Meeting Event Director*

**Jean Bassett**

*Research Grants Coordinator*

**Liz Weiss**

*Special Events & Member Services*

*Associate*

### Development

**Leslie Heilman, JD**

*Associate Director of Development*

**Tania Hanscom**

*Special Events Coordinator*

**Tara Maziarz**

*Special Events Associate*

**Cassie Franklin**

*Gift Officer*

### Regional

**Crissy Harris**

*Regional Coordinator - Central*

**Margaret Moore**

*Regional Coordinator - Southeast*

**Nicole Shanter**

*Regional Coordinator - Northeast*

**Anne Simonsen**

*Regional Coordinator - Great Lakes*



HOPE. ENERGY. LIFE.

## 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.

# Supergirl's Guide to Living With Mito

by Jennifer Schwartzott

**M**ito what? That was my reaction when I was diagnosed. It was 1990 and very few doctors even knew about the disease. I had been sick off and on for years and was relieved to get an answer, but so little was known and I was scared. I have learned, along with the medical world, throughout the years and have changed my way of living and thinking and have discovered how to have quality of life. I have seen friends get diagnosed and lock themselves in their homes and give up. It is important to make the conscious decision to choose to live.

## LEARN YOUR CEILING

I was the classic overachiever. In college, I took on a heavy class load, worked and belonged to half the clubs at school. I was Supergirl and beginning to pay for it. I started having stroke-like episodes because my body couldn't handle the stress. After the birth of my daughter and the subsequent diagnosis of mitochondrial myopathy, the symptoms got worse, and I was in real trouble. I was still in school, had a young child, and still couldn't say no to activities that came my way. It wasn't until I lessened my load that things started to improve. I went down to part time college, went on Social Security disability, and rested. The SLEs became less frequent and life improved.

It is very important to learn your ceiling. What can you accomplish during your day without overdoing it. Google "The Spoon Theory" for a great analogy. Prioritize what is most important to you. I never have a day without having some pain or discomfort, but I have an idea of how much I can do without putting myself in bed for days to come. Learn to delegate at work and at home. If you can, hire a person to do the heaving cleaning. If work becomes too difficult, go down to part time or go on disability. Don't wait too long because it can be a long process. This can all be difficult to do but if you regularly overdo it, you will put your health at risk. It just isn't worth it.

## GET PLENTY OF REST

Mito is an energy zapper. Most of us require extra rest in general and after activities. If your body is telling you to rest, do it. I get increased numbness and tingling when my body isn't happy. That is my queue to lay down. Listen to your body. You will get more out of your day and your life if you take it easy. Meditation is a great way to relax. You don't have to go out and hire a guru. Lay down and focus on relaxing each muscle and put yourself in a happy place. This is also how I get through MRIs and other unpleasant tests. If you are finding daily errands tiring, get a handicapped parking permit or use a mobility cart in the store or mall. Save your energy for what is important.

## MAKE A BUCKET LIST

What makes you happy? What do you want to accomplish in life? Making a list of these goals, big and small, puts life into perspective. This is where you will find your quality of life. Be optimistic but realistic. Most of us will never be able to climb Mt. Everest but, depending on our personal medical conditions, we can still do activities that give us something to look forward to. I love taking cruises. They are very relaxing but have plenty of low key activities and excursions. Is there a hobby you would like to try? It is difficult to give up things we love and changing your lifestyle can lead to depression and regret. It is important to choose to LIVE your new life.



## DON'T SWEAT THE SMALL STUFF

Watch sunsets. Listen to children giggle. Savor your favorite food, even if you can only have one bite. Have a long talk with a good friend. Happiness can come out of little things. You just have to learn to recognize them. Triumph in the little victories. Smile and laugh. The dust bunnies and cobwebs can wait.

## DEVELOP A RELATIONSHIP WITH YOUR DOCTOR

When you visit the doctor's office, bring your list of questions and issues and make the most of your visit. Tell your doc about your family, your goals, and what makes you happy. Let them know that you have a life to live and that they are a key to making that happen. Give them a reason to remember you, and they are more likely to go that extra step. Remember to thank them. You might find that a doctor is not right for you. Sometimes switching doctors or getting a second opinion is the answer.

## FIND SUPPORT

Join a support group or an online group. Ask for help when you need it. Vent. Keeping it all inside is stressful. There are people out there that are like you and others that want to help you. Educate yourself. Knowledge is power.

There is hope. Researchers are searching for treatments and a cure. While we wait, we must take care of ourselves and enjoy our lives. Hate the mito, but love yourself. Choose life.

## AACT Update

The Adult Advisory Council Team recently added five new Council members. Please join us in welcoming them to the AACT:



**M**y name is **Devin Shuman**, and I live in Bellevue, WA (right outside Seattle). I was diagnosed with mitochondrial disease in 2010. In 2014, I joined the Adult Advisory Council Team as the Young Adult Coordinator. I have also been a Youth Ambassador for UMDF since 2010.



**M**y name is **Kailey Danks**, and I live in Toronto, Canada. I was diagnosed with CPEO+ (Chronic Progressive External Ophthalmoplegia), a form of Kearns Sayre Syndrome, in 2008 after over 10 years of testing. I am new to the Adult Advisory Council Team and joined in 2014. I am also a Peer Support Volunteer for MitoCanada and am very excited to be a part of the Adult Advisory Council Team.



**M**y name is **Terry Livingston**, and I live in Seminole, FL (Tampa Bay area). I was clinically diagnosed over 35 years ago with Chronic Progressive External Ophthalmoplegia (CPEO) Plus / Mitochondrial Myopathy. I joined the Adult Advisory Council Team in 2014.



**M**y name is **Christy Koury**, and I live in the suburbs of Charlotte, NC. I have a clinical diagnosis of mitochondrial disease. Two of my children are affected as well. I have worked with the UMDF in various capacities since my oldest daughter was diagnosed in 2006.

The AACT also welcomes **Mary Ann Piazza** of Williamsville, New York.

### Adult Advisory Council Team (AACT)

Jennifer Schwartzott, AACT Chair, New York  
Gail Wehling, AACT Co-chair, Illinois  
Devin Shuman, YA Coordinator, Washington  
Bob Brief, New York  
Kailey Danks, Canada  
Whit Davis, Pennsylvania  
Rev. David Hamm, Maryland  
Pam Johnson, MD, Missouri/Kansas

Christy Koury, North Carolina  
Joy Krumdiack, Washington  
Terry Livingston, Florida  
Deb Makowski, Arizona  
David McNees, Ohio  
Mary Ann Piazza, New York  
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 and will assess and evaluate, provide advice and guidance, and make recommendations to UMDF on adult-related issues.

# UMDF events

The energy providing education,  
support and research.

## Fundraisers Benefitting the UMDF



**Summer 2014** Brock Hudkins of Team Indiana (*above*) pledged to “Takedown Mito” at all of his summer wrestling tournaments and donate \$1 per takedown in honor of his sister, Kyliegh. Brock went 47-0 and finished with 135 takedowns.

**July 1** Run, Walk, or Roll with Wyatt, a virtual run in which anyone nationwide could sign up and participate raised over \$1500! The unique event was held by the DeStefano Family in honor of Wyatt DeStefano.

**July – August 2014** Hairdressers United at Level Spa Salon hosted a fundraising event at their salon in Cumming, GA. The salon sold coupons for haircuts and hosted a 50/50 raffle at their salon until August 14 and raised \$1900!

**July 25** Justin Loncar selected the UMDF as his non-profit pick for AETNA Inc’s company-wide Jeans Day in Cranberry Township, PA.

**July 26** The Carter Buffum 5k was held at Cascades Park in Jackson, MI, in support of the Carter Buffum Research Fund with the UMDF. The event featured a 5k walk/run with glowing accessories and raised over \$2500!

**August 2** The 7th Annual Run for Raley event was held in Philo, IL. This annual event is held in memory of Raley Kirby and raised nearly \$20,000 for the UMDF! Thank you to the Kirby family for your continued support!

**August 6** The annual Splish Splash for the UMDF pool party held at the Crooksville pool in Crooksville, OH, raised funds to support the UMDF in honor of Baylee Thompson.

**August 9** Sweet Faith McColl sold her sweet Lemonade again this year for the UMDF! Faith is in Marietta, GA, and has raised over \$10,000 for the UMDF in the last 5 years!! Thank you Faith for your amazing Lemonade Stand this year raising over \$3,000!!

**August 9** Team ‘Slippery When Wet’ participated in the Mudathon- Cincinnati in Hamilton, OH, in memory of Leslie Whitt-Williams.

**August 15** The DeStefano Family and the Octorara School District of Atglen, PA, hosted ‘Stick it to Mito’ in honor of Wyatt DeStefano. The junior high school, high school, and alumni field hockey players participated in games to raise awareness for Mitochondrial Disease, raising \$1300 for the UMDF!

**August 16** The 5th Annual EFL: **Minnesota** was held Normandale Lake Bandshell in Bloomington, MN. Over \$73,718 was raised by the amazing 27 teams who came out in support of the UMDF!

**August 16** Baylee’s Ball bash Softball tournament in honor of Baylee Thompson was held in Crooksville, OH, benefiting the UMDF.

**August 19** The Applebee’s in Cincinnati, OH, held a restaurant night in honor of Leslie Whitt-Williams. The money raised supported the Leslie Whitt-Williams research fund with the UMDF.

**August 23** Party for Mitochondrial Disease Research was held in Buffalo, NY, at Snyder Bar and Grill, with all funds raised going to the John Geraci Research Fund. The event included all-you-can-eat wings and pizza along with all-you-can-drink beer, wine, and pop; plus raffle baskets and a silent auction.

**August 30** The relaxed atmosphere All Star Car Show was held at the USA Stadium in Millington, TN. A portion of the proceeds went to the UMDF, this year’s charity of choice!

**September 6** The 3rd Annual EFL: **Detroit** was held Dodge Park in Sterling Heights, MI. Over 23 teams came out in support of the UMDF and raised over \$23,000! Thank you to everyone who made the event such a success!

**September 13** The 4th Annual EFL: **Indianapolis** was held at Hummel Park in Plainsville, IN this year! The change of venue and season brought in over \$19,643 with over 28 teams! Thanks to our walk committee & teams for your hard work!



**September 13** The first annual “Fight Mito for Maddix” Energy Walk took place at Coal Miner’s Park in Pekin, IL, in honor of Maddix Carter.

**September 13** The 5th Annual EFL: **Kansas City** was held at Community America Ball Park in Kansas City, KS. Over \$21,000 was raised by nine teams this year! Thank you to our amazing teams & walk committee!

**September 15** Chelsey May held a Jammin’ for Mitochondrial Disease Awareness benefit where she offered her services as a Jamberry Nails consultant for the month of September with proceeds benefiting the UMDF.

**September 15** Michelle Schwarz and her family celebrated her birthday by fundraising for the UMDF instead of gifts in honor of her cousin Anne Juhlmann and nephews Zach and Sam Juhlmann.

**September 19** The Carlos Alberto Memorial Golf Outing was held at the Gem City Golf Club in Fairborn, OH and raised over \$9,000!

**September 20** The 2nd Annual EFL: **Columbus, GA** was held at Golden Park Baseball Field in Columbus, GA. The growing group raised over \$13,000 and had 8 teams come out in support of the UMDF! Thank you to our walk committee & teams for a great year!

**September 20** The Idaho Mito Group came together again this year for their 8th Annual Mito Bowl at Big Al’s! The annual event is organized and attended by the many members of the Idaho Mito Group!

**September 20** The 1st Annual EFL: **New Orleans** was held at La Salle Park in New Orleans, LA. Nearly \$26,000 was raised by an outstanding 28 teams!! Thank you to our teams & walk committee for an excellent first year NOLA!

**September 20** The 1st Annual EFL: **Omaha** was held at Miller’s Landing in Omaha, NE. The event brought in over 16 teams raising over \$17,000 for the UMDF! A special thank you to our teams & walk committee for a great first year!

**September 20** The 4th Annual EFL: **Western New York** was held at Cheektowaga Town Park in Cheektowaga, NY. Over \$28,000 was raised by 25 teams! Thank you to our walk committee & teams on a great walk year!

**September 20** The Jaxon’s Warriors 5k and Little Warrior Fun Run in memory of Jaxon Sharma was held at Highland Church of Christ in Robinson, IL. The 5k / fun run raised over \$15,500 in support of the Jaxon Sharma Research Fund with the UMDF.

**September 20** The 2nd Annual Walk and Awareness Day was held in Anderson, SC, in support of the Samuel Cutliff Research Fund with the UMDF! The Fund was established in memory of Samuel Cutliff. Thank you to the family & friends of the Cutliff family!

**September 21** The 5th Annual EFL: **Chicago** was held at Katherine Legge Memorial Park in Hinsdale, IL. 24 teams from the Chicago community raised over \$109,000! Thanks to our teams & walk committee on another great year!

## Special Campaigns

### COINS FOR A CURE

- Melinda Edwards is participating in the Coins for a Cure Campaign in the Solsberry, IN area for the Jack Edwards Research Fund.

### LIGHT BULBS

- Leslie DaCosta is partnering with Kean University and participating in the Light Bulb Campaign in the Union, NJ, area.
- Jesi Janey is participating in the Pray for the Fighters, Remember the Fallen, and Fight for a Cure Light Bulb Campaign in honor of Kristin, Joshua, and Nick Gruber, in the Lodi, WI, area.
- Melinda Edwards is participating in the Light Bulb Campaign in the Solsberry, IN, area in honor of Jack Edwards.
- The Fayette Elementary School in W. Terre Haute, IN, will be participating in the Light Bulb Campaign School wide!

### ACTIVE-ATE YOUR MITOCHONDRIA!

**August 11, 2014** Melissa Branch became the first woman to solve a Rubik’s Cube while skydiving! She participated in the jump in Maine to raise awareness for Mitochondrial Disease. (See page 10)



**September 20, 2014** The Redman Triathlon in Oklahoma City, OK, was completed by Joanne Kovac – Roberts in honor of Bennett Hanneman.

**September 27** The 5th Annual EFL: **Delaware Valley** was held at Campbell's Field in Camden, NJ. This year over 37 teams came out in support of the UMDF and raised over \$97,000! A special thank you to our walk committee & teams for helping us reach our walk goal!

**September 27** The 3rd Annual EFL: **Milwaukee** was held at Greenfield Park in Milwaukee, WI. Over \$24,000 was raised by our 22 amazing teams! Thanks to our teams & walk committee on a great year!

**October 3** The Bobby Rahal Automotive Group hosted their annual company picnic with their dunk tank event benefitting the UMDF!

**October 3** John Kobunski held a quilt raffle in North Royalton, OH, with all proceeds benefitting the UMDF.

**October 4** The 3rd Annual EFL: **Akron** was held at Lock 3 in Akron, OH. Over 32 teams came out and braved the freezing rain to raise over \$27,000 for the UMDF! A special thank you to our walk committee & teams for all of your hard work this year!

**October 5** A glow in the dark 5k run/walk, Shine On Corynna, was held at the Darke County Fairgrounds in Greenville, OH. This event was held in support of the Corynna Strawser Research Fund with the UMDF. The fund was set up in memory of Corynna Strawser and her courageous battle with mitochondrial disease.

**October 5** Kaitlyn Chermak ran in the Rock n' Roll Half marathon in San Jose, CA, in memory of Lauren Francis.

**October 12** Team Hope Energy Life participated in the Bank of America Chicago Marathon in support of the UMDF. Thank you to Gary Moberly for organizing the team.

**October 18** The 5th Annual EFL: **Charlotte** was held at Freedom Park in Charlotte, NC. The Charlotte community came out with 47 teams and brought in over \$135,000 for their 5th year! Thank you to our amazing teams & walk committee for such a great year!



**October 18** The 1st Annual EFL: **Birmingham** was held at Railroad Park in Birmingham, AL. The first year was a smashing success with over 13 teams raising over \$27,000! Thank you to our teams & walk committee. Congratulations on your first year, Birmingham!!

**October 19** The 3rd Annual EFL: **Central Texas** was held at Old Settlers Park in Round Rock, TX. Over 22 teams came out and raised over \$45,000 for the UMDF! Thank you to our teams & committee for another successful walk in Central Texas!

**October 25** Jess Grabow ran in the Cape Cod Half Marathon in Falmouth, MA, in memory of Zach and Sam Juhlman. She far exceeded her goal of \$500 by raising \$1025 for the UMDF!



**October 25** The Bruster's of Ingomar, PA, hosted their annual Halloween Costume Contest for the UMDF (above). There were games, face painting, prizes, and, of course, ice cream!

**November 1** The Will Woleben Family Fun Day was hosted by the Woleben Family in their hometown of McKinney, TX to benefit the Will Woleben Research Fund!

**November 3** The Will Woleben T-shirt fundraiser was hosted in an online event benefitting the Will Woleben Research Fund!

**November 11** The Vanscoy /Rahmany Family of Indianapolis, IN hosted the Sophie Strong Bracelet Sale in honor of Sophie Rahmany and raised \$1200 !



**November 15** The Fall into A Cure wine tasting and silent auction at Breaux Vineyards was held in the D.C. Metro Area and raised over \$25,000! (above)

**November 21** The Cloverdale High School Student Council collected donations at their Fall Homecoming dance in honor of Andrew Nees!

**November 22** The 2nd annual Bowling for Mito event was held at Pleasant Hill Lanes in Wilmington, DE!



EFL: Birmingham



# Upcoming EFLs

## **EFL Walkathon: Houston**

February 7, 2015  
Sam Houston Park, Houston, TX  
[www.energyforlifewalk.org/houston](http://www.energyforlifewalk.org/houston)

## **EFL Walkathon: Atlanta**

March 28, 2015  
Piedmont Park, Atlanta, GA  
[www.energyforlifewalk.org/atlanta](http://www.energyforlifewalk.org/atlanta)

## **EFL Walkathon: Nashville**

March 28, 2015  
Centennial Park, Nashville, GA  
[www.energyforlifewalk.org/nashville](http://www.energyforlifewalk.org/nashville)

## **EFL Walkathon: Dallas-Fort Worth**

March 28, 2015  
Downtown Garland Square, Garland, TX  
[www.energyforlifewalk.org/dallasfortworth](http://www.energyforlifewalk.org/dallasfortworth)

## **EFL Walkathon: Tampa Bay**

March 29, 2015  
Al Lopez Park, Tampa, FL  
[www.energyforlifewalk.org/tampabay](http://www.energyforlifewalk.org/tampabay)

## **EFL Walkathon: Shreveport-Bossier City**

April 11, 2015  
Airline High School, Bossier City, LA  
[www.energyforlifewalk.org/sbc](http://www.energyforlifewalk.org/sbc)

## **EFL Walkathon: San Francisco Bay Area**

April 18, 2015  
Bishop Ranch Business Park, San Ramon, CA  
[www.energyforlifewalk.org/sanfrancisco](http://www.energyforlifewalk.org/sanfrancisco)

## **EFL Walkathon: Pittsburgh**

April 25, 2015  
Heinz Field Great Lawn, Pittsburgh, PA  
[www.energyforlifewalk.org/pittsburgh](http://www.energyforlifewalk.org/pittsburgh)

## **EFL Walkathon: St. Louis**

April 25, 2015  
Tower Grove Park, St. Louis, MO  
[www.energyforlifewalk.org/stlouis](http://www.energyforlifewalk.org/stlouis)

## **EFL Walkathon: Cincinnati**

April 25, 2015  
Eden Park, Cincinnati, OH  
[www.energyforlifewalk.org/cincinnati](http://www.energyforlifewalk.org/cincinnati)

## **EFL Walkathon: Evansville**

May 9, 2015  
Burdette Park, Evansville, IN  
[www.energyforlifewalk.org/evansville](http://www.energyforlifewalk.org/evansville)

## Upcoming Events & Fundraisers

**December 6** Carter's Christmas to benefit the Carter Lackey Research fund will be held at the Sayre Elks Club in Sayre, PA from 10am to 3pm. This unique event is a holiday craft show featuring local area vendors! For more information please contact Brittany Lackey at [Brittanylackey23@gmail.com](mailto:Brittanylackey23@gmail.com)

**February 14** Dance Your Cares away for a Mito Cure is an adult prom and fundraiser that will be held at the Brookston Elementary School in Brookston Indiana from 8-11pm EST. For more information please contact Tammy Poore at [pooksticks47923@gmail.com](mailto:pooksticks47923@gmail.com).

**February 21** The UMDF is partnering with the NHL's New Jersey Devil's for a night of family fun and awareness! The Devil's will play the Carolina Hurricanes at the Prudential Center in Newark, NJ. Tickets at a discounted price will be available for purchase at [www.newjerseydevils.com/umdf](http://www.newjerseydevils.com/umdf) using promo code UMDF. A portion of the ticket sales goes to the UMDF. For any other questions please contact Zach Johnston at (973)-757-6122 or by email [zjohnston@prucenter.com](mailto:zjohnston@prucenter.com).

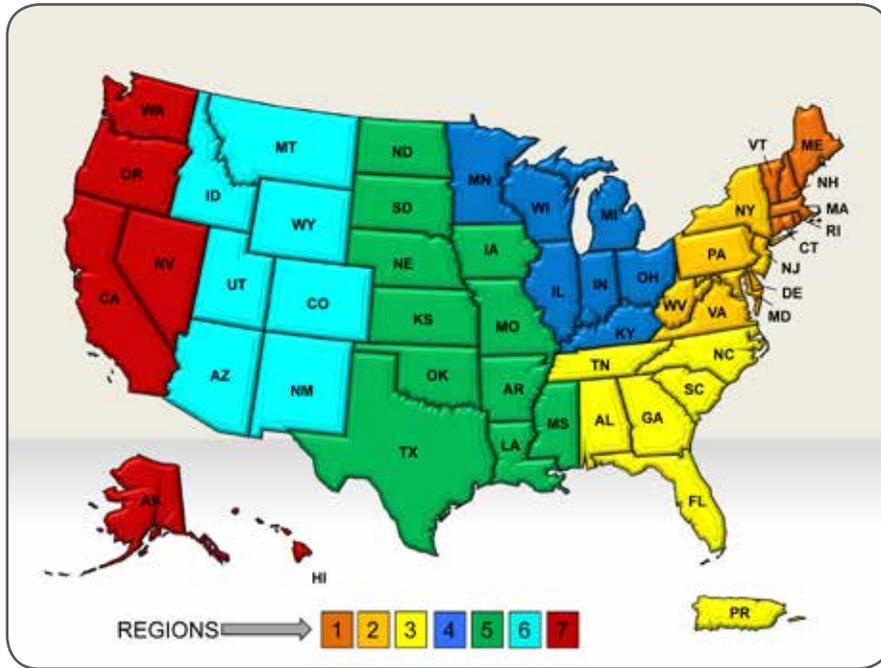
**March 21** The 6th annual Jackson Culley Mito What ? 5k will be held at the USA stadium in Millington, TN. For more information please contact Angie Nunn [angienunn73@gmail.com](mailto:angienunn73@gmail.com) .

**April 18** The 12th annual Bet on Bailee event in honor of Baylee Thompson will be held at the Perry County Fairgrounds in New Lexington, OH. For more information please contact Jody Thompson [buff2506@hotmail.com](mailto:buff2506@hotmail.com) .

**May 30** The UMDF Bike Run will be held in memory of Conner Hadden at the Ford City Eagles club in Ford City, PA. The event will include a Motorcycle Poker Ride, Dinner, and a Chinese Auction! For more information please contact Rachele Hadden at [all4conner@yahoo.com](mailto:all4conner@yahoo.com).



In addition to the support staff at the UMDf National Office, help is available to you nationwide 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 [connect@umdf.org](mailto:connect@umdf.org). *When sending an e-mail, please include the leader's name or city/state in the subject line for us to best serve your needs.* Interested in getting involved? Call 1-888-317-8633 or visit [www.umdf.org/volunteeropps](http://www.umdf.org/volunteeropps)!



**Southeast (3)**

Margaret Moore, Regional Coordinator

**ALABAMA**

- Marissa Benjamin, Leeds

**FLORIDA**

- Amber Ferrell, Gainesville, Central FL
- Kimberly Gray, Tampa
- Garry Krueger, North Central Florida
- Joan Morris, Titusville
- Denise Richardson, Fort Lauderdale
- Holly Schneider, Coconut Creek
- Jennifer Slauter, Orlando, Central FL
- Sophie Szilagy, North East Florida
- Marla Tobia, Tampa
- Becky Yu, Tampa

**GEORGIA**

- Amy Blackwell, Kennesaw
- Hannah Bossie, Athens
- Sebastien Cotte, Atlanta
- Mary Beth Morris, Atlanta
- Cheryl Porter, Atlanta
- Gail LaFramboise, West Central Georgia
- Shelly Lorenzen, Sugar Hill
- Wendy Clegg, Loyd, Columbus
- Tiffany Tuggle, Stockbridge
- Erin Willis, Valdosta

**NORTH CAROLINA**

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

**SOUTH CAROLINA**

- Christine Golden, Greenville/Spartanburg
- Hillary Miller, Charleston
- Karis Mott, Chapin

**TENNESSEE**

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

**New England (1)**

**MAINE**

- Amber Taylor, Bangor
- Heather Field Ruggiero, Lisbon

**VERMONT**

- MaryBeth LeFevre, Williamstown

**CONNECTICUT, NEW HAMPSHIRE, RHODE ISLAND**

- Contact the National Office to Connect

**MASSACHUSETTS**

- Julie Gortze, North Attleboro

**Northeast (2)**

Nicole Shanter, Regional Coordinator

**DELAWARE**

- Kathleen Stapleford, Magnolia
- Judy Weeks, Dover

**MARYLAND**

- Dawn Murphy, DC/Baltimore/Northern Virginia

**NEW JERSEY**

- Laurel Smith, Meford
- Carrie Mullin, Pittsgrove

**NEW YORK**

- Kim Zuzzolo, NY Metro Chapter
- Linda Roesch, Buffalo, Western NY SG
- Jennifer Schwartzoff, Buffalo, Metro NY SG
- Erica Beyea, Buffalo
- Sandy Sallaj, Buffalo
- Sherri Schultz, Buffalo SG
- Jacqueline Perrotta, Albany
- Lori Piccirilli, Binghamton
- Kimberly Dedrick, Utica

**PENNSYLVANIA**

- Jillian Austin, Cranberry Township
- Daria Grabowski, Erie
- Jessica Myers, Erie
- Kim Olenderski, Central Pennsylvania
- Heather Pallas, Pittsburgh
- Karen Wilson, Pittsburgh

**VIRGINIA & WASHINGTON DC**

- Heather Meyer, Lynchburg
- Judi Bartle, Central Virginia SG
- Sharon Hoffert, Central Virginia
- Sharon Goldin, DC/Baltimore/Northern Virginia
- Anne Tuccillo, DC/Baltimore/Northern Virginia

**WEST VIRGINIA**

Contact the National Office to Connect

## Great Lakes & Midwest (4)

Anne Simonsen, Regional Coordinator

### ILLINOIS

- Christine Carter, Pekin
- Cherie Lawson, Chicago Area SG
- Vicki Ternberg, Chicago Area
- Gail Wehling, Chicago Area SG
- Luke and Leslie Kirby, Philo
- Victoria Helms, Southwest Area/St. Louis SG

### INDIANA

- Melissa Edmondson, Evansville Area
- Kaitlin Thompson, Evansville Area SG
- Jackie Parrish, Indianapolis Area

### KENTUCKY

- Krystena Richards, Lexington & Cincinnati
- Mandy Salensky, Lexington & Cincinnati

### MICHIGAN

- Carrie Gervasone, East Michigan/ Detroit Area
- Missy Leone, East Michigan/Detroit Area SG
- Genevieve Angeloff, Upper Peninsula
- Holly Worden, West Michigan/Grand Rapids

### MINNESOTA

- Stacey Pieper, Minneapolis/St. Paul
- Atom Wolff, Minneapolis/St. Paul

### OHIO

- Ruth Gerke, Central Area/Columbus
- Elyse Latella, Hilliard
- Kristi Strawser, Greenville
- Jody Thompson, Central Area/Columbus
- Darcy Zehe, Northeast Area/Akron, Cleveland
- Chris & Alisa Rawski, Northwest Area/ Toledo

### WISCONSIN

- Mindy Welhouse, Central Area/Appleton, Green Bay
- Terilyn Musser, Central Area/Eau Claire
- Jaqueline Bohne, Northern WI/Rhineland, Tomahawk, Minocqua Area
- Josh Bartz, Southeast Area/Madison
- Karen Loftus, Southeast Area/Milwaukee SG

## Central Region (5)

Crissy Harris, Regional Coordinator

### ARKANSAS

- Lacie Moore, Rogers

### IOWA

- Emmanuel Atanga, West Des Moines
- Ronda Eick, Northern Iowa
- Kim Novy, Des Moines SG

### KANSAS

- Anne Tramposh, Kansas City Area

### LOUISIANA

- Nicole DeJean, Lafayette
- Rhonda Mailhos, New Orleans SG
- Mandy Poche, Baton Rouge
- Tammy Reyna, Bossier City
- Anna Stewart, Bossier City
- Chantel Wooley, Covington

### MISSISSIPPI

- Tracy Shedd, Vicksburg

### MISSOURI (see also Illinois)

- Matt Bishop, Kansas City Area
- Keli Stone, St. Louis Area SG

### TEXAS

- Stephanie Callahan, Houston
- Shamayn Kennedy, Wichita Falls
- Jamie Buryanek, Houston
- Melissa Knight, Houston
- Trisha Kranz, Houston
- Kari Richardson, Houston
- Crystal Lopez, Dallas/Fort Worth
- Shawna McElveen, Dallas/Fort Worth
- Heather McNair, Dallas/Fort Worth
- Laura Torres, San Antonio
- Kristen Wilson, San Antonio

### ND, SD & MONTANA

- Marty Campbell, Beach, ND

### NEBRASKA

- Dana Ritterbush, Omaha

## West (6)

### ARIZONA

- Marin Pelletier, Phoenix

### IDAHO

- Jennifer Pfefferle, Boise, Idaho SG

### NEW MEXICO

- Stephanie Cassidy, Albuquerque

## UTAH

- Laura McCluskey, Orem

## COLORADO & WYOMING

- Jamilyn Teske, Johnstown, CO

## Pacific and Northwest (7)

### CALIFORNIA

- Norma Gibson, California Chapter
- Cheryl Burge, Inland Empire
- Cory Greenlee, La Verne
- Dan Francis, Oceanside
- Sharon Reeder, Aliso Viejo
- Kathy Saenz, Sacramento SG

### HAWAII

- Kimo Phan, Honolulu

### OREGON

- Kimberli Freiling, Monmouth SG

### WASHINGTON

- Maresa Henderson, Spokane
- Joy Krumdiack, NW Washington

### ALASKA & NEVADA

Contact the National Office to Connect

### INTERNATIONAL

- Rob Ryan, Australia
- John Carreiro, British Columbia
- Atanga Emmanuel, Cameroon
- Andrew Alexander, Hungary
- Nilam Agrawal, India
- Saijad Haider, Pakistan
- Anne Hansen, Norway
- Vidar Hunstad Vik, Norway
- Rowland Dicker, United Kingdom
- Keely Schellenberg, Winnipeg

### YOUTH AMBASSADORS

- Hannah Eichner, Chapel Hill, NC
- Emily Swinn, Stone Mountain, GA
- Briana Garrido, Wahiawa, HI
- Haley Wroth, Massachusetts/Connecticut
- Alexandra Simonian, New York, NY
- Tyler Liebegott, Pittsburgh, PA
- Colleen Powell, Horsham, PA
- Devin Shuman, Medina, WA
- Jordan Schmeer, Richmond, VA
- 

### PDCD AMBASSADORS

- Melissa James, Bernardston, MA
- Michelle King, Lima, OH
- Jillian Austin, Cranberry Township, PA

\* "SG" indicates an established Support Group

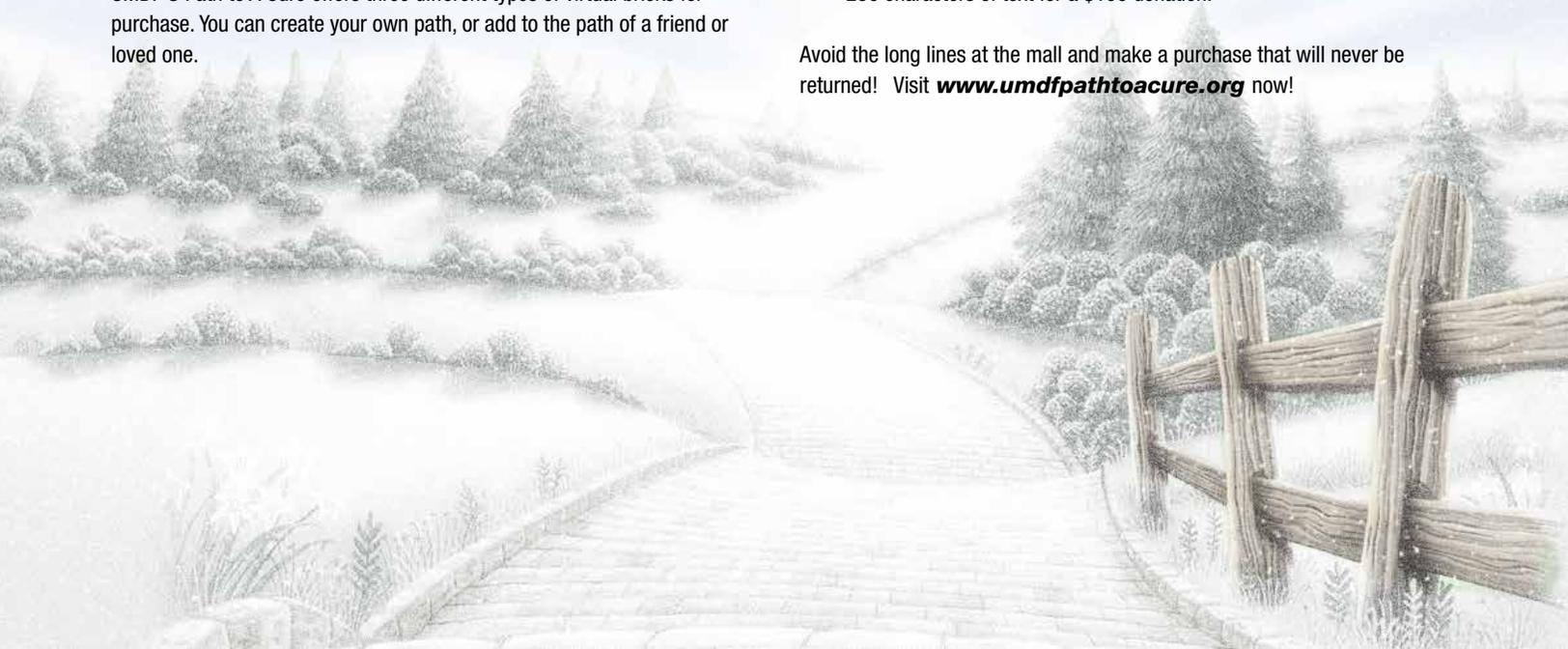
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UMDF'S Path to A Cure offers three different types of virtual bricks for purchase. You can create your own path, or add to the path of a friend or loved one.

- The "**Hope**" brick allows the purchaser to add up to 75 characters of text for a \$25 donation.
- The "**Energy**" brick allows the purchaser to upload a JPEG picture and allows for up to 125 characters of text for a \$50 donation.
- The "**Life**" brick allows the purchaser to upload a JPEG picture, an online video (from You Tube or Vimeo and can be any length), and up to 250 characters of text for a \$100 donation.

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