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Luke Krumich and friends sell lemonade at their stand in Freehold, New Jersey, in honor of Luke's little brother, Lincoln Ogonowski. Lincoln is diagnosed with Leigh's Disease.



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From the Chairman

by Brent Fields, UMDF Chairman

I hope you are having a wonderful summer. I know the hot or humid conditions in some parts of the country create unique challenges for patients so I am hopeful that all is well in your part of the world.



We, as members of the mitochondrial disease patient community, battle constant challenges.

Whether it is along the diagnostic journey or along a path to treatment, sometimes those challenges are hard to overcome. We are working to change that.

I was extremely excited to be part of the announcement about the Mitochondrial Care Network at the UMDF Symposium in June. You can read more about it in the pages ahead. MCN is a first-of-its-kind Care Network for patients and families. This is a collaborative effort on behalf of patient advocacy groups and the Mitochondrial Medicine Society.

The goals are clear. We want to unify clinicians who provide medical care to individuals with mitochondrial disease; to define, design and implement best practices in mitochondrial medicine; and to optimize management and care for patients with mitochondrial disease. There are more than 20 sites participating in this network and we expect to make significant announcements next year about their role in patient care.

Another challenge for patients and families is the lack of drug development. In the spring of 2019, UMDF will address this issue, but we need your help. UMDF will conduct an Externally-Led Patient Focused Drug Development meeting on March 29, 2019. The patient perspective is critical in helping FDA understand the context in which regulatory decisions are made for new drugs. Externally-led PFDD meetings give the FDA an important opportunity to hear directly from patients, patient advocates, and caretakers about the symptoms that matter most to them.

The impact the disease has on patients' daily lives, and patients' experiences with currently available treatments. This input can inform FDA's decisions and oversight both during drug development and during a review of a marketing application. We need your input and participation. See details about this meeting in the pages ahead, or visit www.umdf.org/pfddmeeting2019.

We had a very inspiring evening at our annual banquet. It was there that we honored Charles A. Mohan, Jr. for his years of dedication and service as our CEO and Executive Director. We thank Chuck for all he has done and for all he will continue to do for patients and families, now as Founder and Chair Emeritus. I also hope if you attended that you got to meet Brian T. Harman, UMDF's new President and CEO. I am sure you will join me in welcoming Brian to the UMDF family.

If you were able to attend Mitochondrial Medicine 2018 in Nashville, I hope you brought home with you more answers than questions. I was very happy to be able to talk with so many of you about your own stories and your own challenges. Most of all, I hope you enjoy the rest of your summer.

Energy to All!

From the CEO

by Brian Harman, UMDF President

Day 1: Attend Mitochondrial Medicine 2018: Nashville

It was such a pleasure being able to meet and speak with so many of you in June at Mitochondrial Medicine 2018 in Nashville. I can't think of a better welcome to UMDF. The convergence of clinicians, researchers, affected families, donors, volunteers and staff trumpeted the collective energy of our network. It is clear that UMDF is surrounded by so many good friends who are committed to advancing our mission. I left Nashville proud and honored to be part of the group.

While Pittsburgh is home for my family (my wife Melissa and our two sons, Mac and Graham) I've spent my career serving patients, families, and our most vulnerable populations. Each leadership experience, whether it was with American Cancer Society, Nationwide Children's Hospital or UPMC Children's in Pittsburgh, shaped me to help our mitochondrial disease community and to advance us towards to ultimate goal of a cure. But, I can't do it alone.

I need to hear from you. Very soon, I will begin what I am calling a "listening tour." I want to hear your thought and understand your ambitions for UMDF. I want you to feel free to share with us what UMDF means to you and where you hope to see us go. You are ourcareholders.

I am honored and take great responsibility in following the footsteps of our Founder, Chuck Mohan. But for Chuck's unwavering passion, the UMDF wouldn't be the multi-disciplined leader for the mito community that it is today. Chuck certainly gives everything he can to our mission. The most important gift Chuck has delivered to UMDF is the opportunity he created for others to give. Whether it through cutting-edge research discoveries, volunteering, providing patient support or making UMDF a philanthropic priority, we each have an opportunity to accelerate the mission. We are truly grateful for your unique contribution.

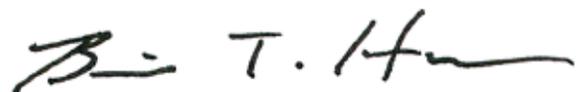
In my conversations with Chuck leading into his retirement he described the landscape of mitochondrial medicine and the status of UMDF as "tight coils" ready to be unleashed. I couldn't agree more and we are already starting to see this in a few key initiatives:

We have launched the Mitochondrial Care Network, together with our collaborative partners: Mitochondrial Medicine Society (MMS), MitoAction and the Foundation for Mitochondrial Medicine (FMM). The MCN will formally unify clinicians who provide medical care to individuals with mitochondrial disease; to define, design and implement best practices in mitochondrial medicine. As we move forward through the year, we will be telling you more about this important component to patient care.

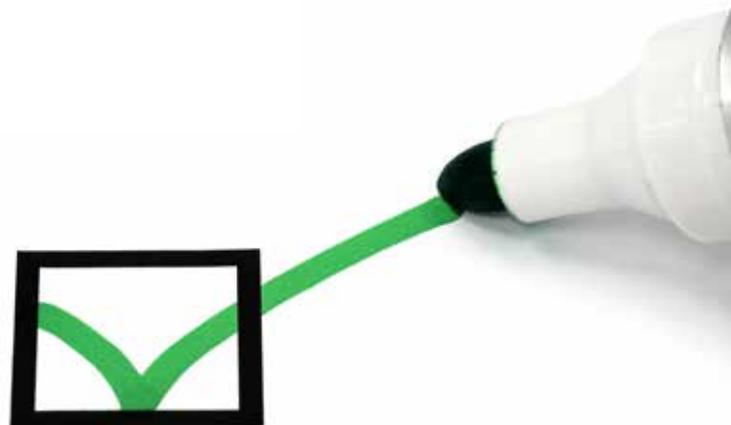
Additionally, we are collaborating with MitoAction, FMM along with the Muscular Dystrophy Association this spring for our first-ever FDA Externally-led Patient Focused Drug Development meeting. We look forward to bringing the patient perspective to the FDA as they weigh regulatory decisions for new drugs. We are very excited about this. I am personally asking you to stay engaged in this process. We need to have the voices of all patients and caregivers to be successful.

I hope you will agree with me that it is a great time to be a part of the UMDF. It is a great time to rally the mito community around the good work being within our community. Together, we are poised to do so many great things for the families we serve.

Onward,

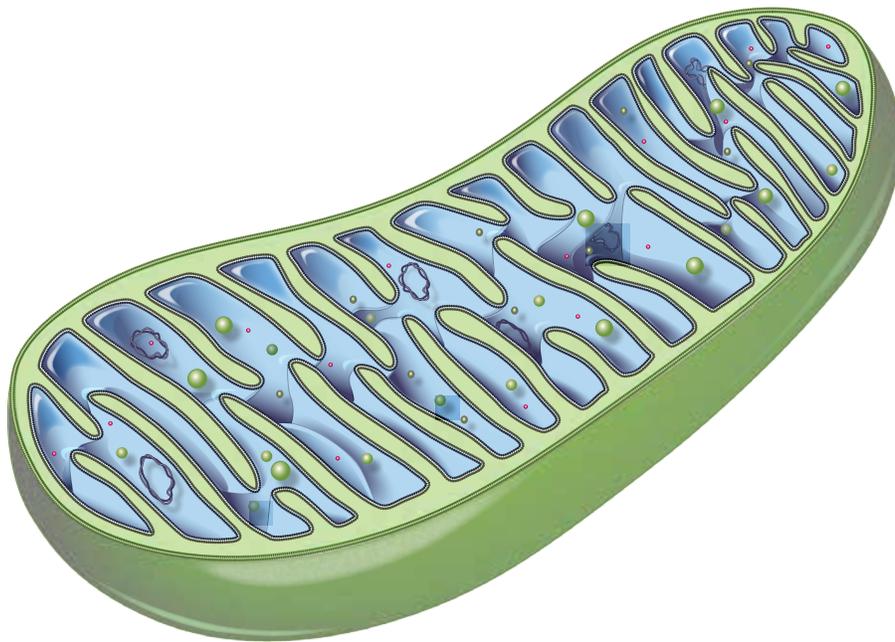


President and CEO
United Mitochondrial Disease Foundation



Stealth BioTherapeutics

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



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Medicine



Forming a Mito Care Network

On June 28, 2018 the formation of a first-of-its-kind Mitochondrial Care Network was announced at the UMDF Symposium in Nashville, TN. This collaborative effort on behalf of patient advocacy groups, the United Mitochondrial Disease Foundation, the Foundation for Mitochondrial Medicine, and MitoAction, as well as the mitochondrial disease clinician society, The Mitochondrial Medicine Society (MMS), has goals to formally unify clinicians who provide medical care to individuals with mitochondrial disease; to define, design and implement best practices in mitochondrial medicine; and to optimize management and care for patients with mitochondrial disease.

A Request for Application (RFA) was announced in January 2018 whereby any clinician in the United States who provides care to patients with mitochondrial disease could apply to join the pilot phase of the Network. Factors for consideration in the Network included, but were not limited to, current and prior patient volume, multidisciplinary approach and hospital/center support. The Mitochondrial Governance Board sought a diverse group of Centers for the pilot phase to determine the full scope, clinical priorities, implementation of standards of care and long-term desired outcomes of the Network. Based on expertise, experience, and geographic location the following leaders will bring a diversity of thought and perspective to the newly forming Network. The Network represents a significant and exciting step to address the unmet needs of clinical care for many patients and result in better care for the future. By working together, the groups plan to harmonize medical care by providing appropriate diagnosis and best practice care by expert clinicians, to patients and patient families throughout the U.S.

MITOCHONDRIAL MEDICINE CENTERS

- Akron Children's Hospital, Bruce Cohen, MD
- Boston Children's Hospital, Irina Anselm, MD
- Children's Hospital Colorado and University of Colorado, Austin Larson, MD
- Children's Hospital of Philadelphia, Amy Goldstein, MD
- Children's Hospital of Pittsburgh, Jerry Vockley, MD
- Cleveland Clinic, Sumit Parikh, MD
- Columbia University Medical Center, Michio Hirano, MD
- Cooper University Hospital, Jaya Ganesh, MD
- George Washington University/Children's National Health System, Andrea Gropman, MD

- Icahn School of Medicine at Mount Sinai, Pankaj Prasad, MD & Brynn Webb, MD
- Johns Hopkins University and the Kennedy Krieger Institute, Hilary Vernon, MD, PhD
- Massachusetts General Hospital, Amel Karaa, MD
- Mayo Clinic, Ralitz Gavrilo, MD
- Seattle Children's Hospital, Russell Saneto, PhD, DO
- Stanford University, Gregory Enns, MD
- University of California, San Diego, Richard Haas, MD
- University of California, San Francisco, Renata Gallagher, MD, PhD
- University of Maryland School of Medicine and Medical System, Carol Greene, MD
- University of Texas McGovern Medical School, Mary Kay Koenig, MD

MCN AFFILIATE SITES:

- Children's Hospital Los Angeles, Alvaro Serrano, MD
- University of North Carolina School of Medicine Department of Pediatrics Division of Genetics and Metabolism, Muge Guccavas-Calikoglu, MD, MPH
- Children's Mercy Hospital, Jean-Baptiste Le Pichon, MD, PhD

MCN CONSULTANTS

- Fran Kendall and Mark Korson, VMP Genetics

NEXT STEPS

All sites will submit additional information including attestations of the site director, their institutions and subspecialists' commitment to the MCN effort

- An MCN coordinator will be hired
- An MCN Medical Advisory Board will be formed and convened to help prioritize and execute the goals of the launch phase

The MOTOR Study

A study of omeveloxolone (RTA 408) in mitochondrial myopathies

MOTOR is a double blind, placebo-controlled, multi-center Phase 2 study of the safety and efficacy of omeveloxolone (RTA 408) in mitochondrial myopathies

About the Study



Treatment: Omeveloxolone or placebo capsules taken by mouth once daily



Approximately 8 visits to the study site over 16 weeks



Primary endpoint: Change in peak workload, measured on a recumbent bicycle



Cost of travel may be reimbursed

Criteria for Participation



Between ages 18 and 75



Exercise intolerance with genetically confirmed mitochondrial disease (testing may be provided)



Willing to discontinue some medications



Not pregnant, planning a pregnancy, or breastfeeding

Recruiting Study Center Locations

United States



Los Angeles, California: UCLA
Perry Shieh, MD

Dallas, Texas: Institute for Exercise Medicine
Ronald Haller, MD

Houston, Texas: University of Texas Houston
Mary Kay Koenig, MD

Houston, Texas: Baylor College of Medicine
Fernando Scaglia, MD

Akron, Ohio: Akron Children's Hospital
Bruce Cohen, MD

Europe



Pittsburgh, Pennsylvania: University of Pittsburgh
Gerard Vockley, MD

Philadelphia, Pennsylvania: CHOP
Marni Falk, MD

Boston, Massachusetts: Mass General
Amel Karaa, MD

Copenhagen, Denmark: University of Copenhagen
Karen Madsen, MD



Contact information for participating study centers can be found on the clinicaltrials.gov listing



Go to www.clinicaltrials.gov/ct2/show/NCT02255422 for more information

Version 1; September 2016

In Memoriam

The UMDF is saddened to learn the following have lost their battle with mitochondrial disease. Below are the names of those who, according to our records, became Mito Angels between May 1, 2018 and July 19, 2018.

Mairi Davis
Lyndsey Eidinger
Taylor Harter
Kevin Honan
Aria Liyari
Shari Noland

Penelope Robledo
Martha Rossi
Debra Schoenwetter
Carol Seligman
Hattie Wright

UMDF has created a brick in memory of each on UMDF's Path to a Cure. To visit each path, go to www.umdfpathtoacure.org

Do It Yourself Fundraising - The Mito Way!



Become a fundraiser and start the process of raising funds to support the Roadmap to a Cure.

The steps are easy:

1. Come up with a fundraising idea
2. Create a fundraising page
3. Share with your family & friends
4. Watch your page as you reach your fundraising goals!

Let's Fundraise!

You want to fundraise - we have the place!

www.umdf.org/diyfundraising

Externally-Led Patient-Focused Mitochondrial Disease Drug Development Meeting

Join us for this groundbreaking meeting to share YOUR experiences living with mitochondrial disease with the Food and Drug Administration (FDA) and other drug development stakeholders. This important meeting is scheduled for March 29, 2019 at the College Park Marriott Hotel and Conference Center in Hyattsville, MD.

Among the many responsibilities of the FDA is to protect the public health by ensuring the safety, efficacy, and security of human and veterinary drugs, biological products, and medical devices.

Through this externally-led PFDD, YOU can help educate the FDA about:

- What it is like to live with a mitochondrial disease
- Your concerns as the disease progresses
- How you currently manage your mitochondrial disease
- What meaningful treatments look like

This is an opportunity to have YOUR VOICES heard.

ALL PATIENTS, FAMILIES, AND CAREGIVERS ARE INVITED TO PARTICIPATE!

Individuals living with mitochondrial disease and their caregivers and family members are invited to participate. Everyone who attends the meeting will have a chance to share his or her experiences and perspectives. If you cannot attend in person, you can stream the meeting online where you can participate in live polling throughout the day. Your input, both in-person or online, will be heard by FDA officials attending the meeting and will also be summarized in a report to the FDA. We will also send you surveys and other communications so that we can help you contribute your thoughts. Sign up on our website to receive these monthly e-communications!

WHAT IS AN EXTERNALLY-LED PATIENT-FOCUSED DRUG DEVELOPMENT MEETING?

The patient perspective is critical in helping FDA understand the context in which regulatory decisions are made for new drugs. Externally-led PFDD meetings give FDA an important opportunity to hear directly from patients, patient advocates, and caretakers about the symptoms that matter most to them, the impact the disease has on patients' daily lives, and patients' experiences with currently available treatments. This input can inform the FDA's decisions and oversight both during drug development and during review of a marketing application. UMDF, in collaboration with the Muscular Dystrophy Association, MitoAction and the Foundation for Mitochondrial Medicine, is excited to host this Externally-led Patient-Focused Drug Development meeting for the mitochondrial disease community on March 29, 2019!



HOW IS THIS MEETING DESIGNED FOR YOU TO BE HEARD BY THE FDA?

This Externally-led Patient-Focused Drug Development meeting will use multiple methods for soliciting YOUR thoughts and experiences about living with mitochondrial disease. EVERYONE who attends will have a chance to be part of the conversation. To allow us to hear as many different perspectives as possible, we have four main areas of focus for our panels:

- Burdens of the Disease for Pediatric Mitochondrial Disease
- Patients with Neurologic Manifestations
- Management of Care for Pediatric Mitochondrial Disease Patients with Neurologic Manifestations
- Adult Patients with Mitochondrial Myopathies

Following opening remarks by FDA officials and others, each session will include panel discussions made up of patients and family members. Mitochondrial disease patient advocacy groups will invite members of the community that reflect the diversity of mitochondrial disease experiences to be a panelist or a speaker. After the panels, everyone in the audience in-person or online will be able to answer live polling questions and we will be able to see the results in real time. In addition, all of YOU that can attend in-person will be invited to be part of a live discussion in the room where you can share your own experiences. The meeting will also be 'live streamed' online

for those who cannot attend in person. Select representatives of associated drug development stakeholders (researchers, clinicians, industry) will be invited to attend as well or may join the streamed presentation. After the meeting, all of this input, along with information collected prior to and after the meeting, will be summarized as a "Voice of the Patient" report, which our community will be submitting to the FDA.

WHY IS THIS EXTERNALLY-LED PATIENT-FOCUSED DRUG DEVELOPMENT MEETING IMPORTANT FOR OUR COMMUNITY?

For the mitochondrial disease community, this meeting is the first opportunity for a group of patients, families and other caregivers to speak directly to the FDA, and to share their experiences in their own words. It is also the first time a report on the patient experience will be completed and shared with the FDA. This input can inform the FDA's decisions and oversight both during drug development and during review of a marketing application. We need YOUR participation to make sure our collective community voice makes a positive impact.

To sign up for updates and to get the latest information, visit www.umdf.org/pfddmeeting2019





Member Spotlight: Kamaria's Krew

Kwasi & Christina Satcher learned the true meaning of extended family through their connections with Omicron Gamma Gamma chapter of Omega Psi Phi (Arlington, TX Chapter) and the Arlington Chapter of Alpha Kappa Alpha Sorority, Incorporated at the Dallas-Fort Worth Energy for Life Walk & 5k this past spring.

Christina's daughter, Kamaria, was smaller than most toddlers at her age, but after rounds of testing, misdiagnoses, and multiple doctors there was no definite diagnosis given to determine the cause of her failure to thrive.

"We were told that if we had any concerns in the future, we could always contact a metabolic geneticist," Christina said.

That moment came in 2011 when Kamaria began to lose her hearing. With no history that would seem to cause hearing problems, the ENT recommended an MRI, neurology visit and a visit with the metabolic geneticist.

"We always indicated the metabolic disorder when providing her medical history. Her small stature, ptosis (droopy eye lids) and now hearing loss finally led to the testing that revealed the mitochondrial disorder," Christina recalls.

Kamaria received bilateral hearing aids, but by 2014, her hearing loss had worsened to the degree that cochlear implants were now necessary. That year, Kamaria underwent five surgeries in a 6-month span (feeding tube, ptosis correction, two cochlear implant surgeries). During the pre-op for the second cochlear implant, doctors discovered Kamaria had a A/V heart block and needed a pacemaker. With that discovery, Kamaria's mitochondrial disorder was able to be narrowed down to a specific diagnosis: Kearns-Sayre Syndrome.



Kamaria is now 14 years old. She has two older sisters, Corae' and Khirstian. Christina is a full-time speech pathologist and Kamaria's primary caregiver, with a lot of help from dad and older sisters. Kamaria requires assistance with walking, and Kwasi is her at-home physical therapist, encouraging her to practice walking, balance and strength activities. Corae' and Khirstian keep the normalcy of being a teenager a priority for Kamaria, by listening to the latest hip hop music, teaching her the latest dance moves and encouraging

her strong fashion sense. The family manages work, school, and extracurricular activities - along with multiple doctors' visits. Mom spends countless hours taking Kamaria to various specialists throughout the year, which now also include a retina eye specialist and a nutritionist.

members

The family got involved with the planning committee of the annual Energy for Life Walk & 5k Run in the Dallas/Fort Worth area this past year. With Kamaria's family, friends, and teachers, Alpha Kappa Alpha Sorority, Xi Theta Omega Chapter and Omega Psi Phi Fraternity, Omicron Gamma Gamma Chapter joined forces to support Kamaria's Krew.

"It's important we continue to bring awareness to this dreadful disorder," Christina said.

Lisa Thompson, a long-time Satcher family friend, teaches Kamaria and her older sister at her Step by Step Dance Studio. "I encouraged Christina to reconnect with our Sorority, the Arlington Chapter of Alpha Kappa Alpha Sorority, Incorporated, many years ago," Lisa said. "I feel it has allowed Christina to receive additional support and encouragement that she needs to manage as a caregiver. This past year the entire chapter supported Kamaria's Krew and 2018 United Mitochondrial Disease Foundation (UMDF) Walk in Arlington, and we served in many capacities from raising the funds toward Kamaria's goal, to working as a volunteers directing the walkers and guests to registration and parking. When I served as President of the Sorority, I supported Christina in every way possible, including visiting Kamaria in the hospital, giving Christina personal time, and even learning how to feed Kamaria using her feeding tube. I'm sure I can't fully understand what Christina has to do for Kamaria, but I pray for her and try to support her whenever or however I can. I love and care deeply for Kamaria and will be there for her every fight and battle. Like the song says: *I hope you never fear those mountains in the distance / Never settle for the path of least resistance / Livin' might mean takin' chances, but they're worth takin' / And when you get the choice to sit it out or dance / (Kamaria), I hope you dance!*"



Kwasi's fraternity brothers also stepped up to support the family. "Kamaria is the daughter of Kwasi and Christina, but she is a part of the Omega family," David Washington, Jr. said. "Our fraternity has a sacred bond and share each other's joys and dreams. The men of Omega didn't look at this as a walk, we were supporting a family and a bringing awareness to a great cause. As members of the Omicron Gamma Gamma chapter of Omega Psi Phi (Arlington, TX Chapter), it was our DUTY to support our brother and his family. We were honored to be a part of it."

Kamaria was surrounded by support from this extended family, who helped raise over \$6,000 as well as volunteering to help make the event a success. Their involvement enriched the event and brought awareness to the impact that mitochondrial disease has in the Dallas-Fort

Worth community.

The Satchers say they will continue to focus on quality of life and balance, for themselves and with the help of their extended family. Kamaria told her teacher that she enjoys shopping, traveling (New York is next on her wish list) going to dance class (she just completed her 11th year of dance with a standing ovation at her recital and there wasn't a dry eye in the audience), eating out (crab legs are her favorite) and volunteering with her mom at AKA Sorority events. Kamaria aspires to be a debutante in 2021 (she did the math) and wants to be a fashion designer. Her support network will surely support and cheer her on towards all of these aspirations.



When Life Hands You Lemons...

These Sweet Kids Make Fundraising



LINCOLN'S SUNSHINE STANDS

Lincoln Ogonowski is 5 years old and was diagnosed with Leigh's Disease when he was just three. Lincoln lives in Freehold, NJ, with his parents, Dyna and Robert, and big brother, Luke. Lincoln's smile is like sunshine to his friends and family, which is why Lincoln's Sunshine lemonade stands are so special!

In the summer of 2015, Luke and neighbor friends, Nora, June & Henry, decided to set up a lemonade stand to raise money for the Energy for Life Walkathon in Delaware Valley. Dyna added mini funnel cakes from a deep fryer to the menu. The kids did so well - raising over \$400 - that they decided to make the stand an annual tradition. In preparation, Robert built the Lincoln's Sunshine Stand. After promoting the stands on Facebook, family and friends asked if they could host one in their neighborhoods. So on July 9, 2016, five stands were set up around New Jersey and Virginia in honor of Lincoln and Team Linkoholics.

The stands sold lemonade, summer treats (like watermelon, cookies or funnel cakes) and distributed UMDF bookmarks and brochures. On July 15, 2017, Team Linkoholics had a Sunshine Stand at their family's church, selling lemonade, green ribbon cookies and Fight Mito bracelets.

They have had families host stands during garage sales, and friends with toddlers help make signs and sell lemonade to their neighbors. They have even had other mito-fighters stop by the stand, such as Michael Friedberg, a member of UMDF's Board of Trustees, and his family.

This year they plan to hold the stands on August 11 in as many neighborhoods as they can. The official Lincoln's Sunshine Stand will be at the Little League Baseball Regional tournament in Freehold Twp, NJ on August 4-5. Lincoln makes an appearance at as many stands as he can. He loves to see kids smiles and hear their laughter and lemonade on a summer day definitely brings a lot of smiles and laughter.



Dyna and Lincoln, with Rhonda and Zachary Friedberg

...Make Lemonade



NATHANIEL & MICHAEL: THE SWEETEST OF FRIENDSHIPS!

For Nathaniel Pakuris, helping out his best friend, Michael LoPresti was easy peasy lemon squeezy! The story begins when Nathaniel (almost 11 years old) and Michael (11 years old) met at school. Nathaniel knew that Michael didn't have that one "really good friend."

"I felt I could be that to Michael," Nathaniel said, "and that I could learn some things from him. Now my best friend." Even though Michael can't speak, Nathaniel has learned ways to communicate with Michael and spends every school day interacting with him.

Nathaniel had the idea to set up a lemonade stand, because it was a hot summer and he knew people would want some good lemonade! He also read about how successful other lemonade stands were. With the help of his family, he made some signs and put them along a local intersection by their house, hung them on telephone poles, made some lemonade and poured his heart out. For \$1 a glass, Nathaniel sold his tasty lemonade - and told customers all about Michael.

"We were so touched by the outpour of love and support that our family, friends and perfect strangers showed towards our cause," Gina, Nathaniel's mother said. "Our hearts are full of gratitude for each and every one of you."

Love came from a five-year-old, who donated his \$3 weekly allowance, to a neighborhood mom who packed up her minivan full of kids from her street, to Nate & Michael's teachers, who show love and encouragement every day. Even Michael enjoyed some of the sweetness, as his siblings filled his feeding tube and swabbed some of the lemonade into his mouth.

"Michael is just like us," Nathaniel said, "but without the energy."

Nathaniel's Lemonade Stand raised over \$800 for the Michael Angelo LoPresti Research Fund!



Nathaniel, Gina and Noah Parkus with Michael Angelo LoPresti



Ambassador Spotlight: Ryan Eberly

Have you ever considered becoming a UMDF Ambassador? Our Ambassadors help people impacted by mitochondrial diseases, hold support meetings and are our eyes and ears in the community. If you are interested please contact Margaret Moore at Margaret.moore@umdf.org or 412-354-1553.

Ryan Eberly has been a UMDF Support Ambassador since 2017 and has been a superstar! He helps newly diagnosed patients, shares UMDF resources on our Facebook page and has even helped the UMDF update our online resource guide.

Here is Ryan's story:

I have primary mitochondrial myopathy with CPEO+ and ataxia neuropathy spectrum (ANS) caused by a novel POLG mutation. I started out life as a healthy baby but at 2 years of age I developed bilateral cataracts which were removed and I've been aphakic ever since, wearing glasses and then contacts since age 12. I had a normal active childhood and teenage years being involved in competitive gymnastics, soccer, baseball, track, golf and Boy Scouts earning the Eagle Scout award.

My first major medical issue as an adult was at age 28 being diagnosed with avascular necrosis (AVN) with no known cause which led to a total hip replacement 5 years later. I had no other significant medical issues until age 35 when I first experienced left bicep weakness while carrying groceries or holding a plate of food. After 6 months of weight lifting failed to strengthen the bicep, my PCP referred me to a sports medicine doctor. Beside the bicep weakness the doctor immediately noticed bilateral ptosis, absent vibration sensation in toes and scapular winging. A MRI of the cervical spine was normal and the doctor suspected a possible muscular dystrophy and an EMG was ordered. My first EMG showed a myopathy and suggested a possible myotonic dystrophy and I was referred to neurology at OSU Medical Center in Columbus, OH.

Around the same time I was experiencing insomnia and a sleep study diagnosed mild obstructive sleep apnea. At age 36 I was first seen by a neurologist. A new EMG/NCS revealed sensory neuropathy, myopathy and along with clinic symptoms the first time I read the words "a possible mitochondrial disorder should be considered."

One year after initial symptom onset a left bicep muscle biopsy showed a mitochondrial myopathy with ragged red fibers, COX negative fibers and multiple mitochondrial DNA deletions. A blood test was negative for mtDNA common mutations and deletions. At this point the doctors knew I had a mitochondrial myopathy but the cause was still unknown. Later that year at age 37, I started experiencing extremely itchy blisters and a skin biopsy and genetic testing were positive for dermatitis herpetiformis (DH) the skin manifestation of celiac disease.

From age 37-38 I lost at least 15lbs, my legs were getting weaker and I first started noticing a lot of overall fatigue doing ordinary tasks. Due to a new job offer I moved from OH to NC and what I know was fate, ended up in the Duke Health system which has a great neurology department, one of the few mitochondrial disease specialists in the country and I had an amazing internal medicine doctor that coordinated my care. An endocrinologist quickly discovered that I had hypogonadism and a DEXA scan revealed low bone density for my age.

At age 38 my first neurology appointment

at Duke and collaboration with the mito specialist, tested for MNGIE, myotonic dystrophy 2 and myasthenia gravis which were negative. However a POLG blood panel was positive with heterozygous novel VUS. A third EMG/NCS confirmed chronic myopathy and severe sensory neuropathy. Reviewing all the prior testing and clinical symptoms my mito specialist diagnoses was primary mitochondrial myopathy with CPEO+ likely due to a POLG mutation.

Around 39 years old dizziness became an almost constant issue, I started limiting my driving to short trips around town and I had trouble with memory/concentration. A referral to an ENT doctor and a pulmonary function test said the results were consistent with neuromuscular disease. I was seen routinely by the Duke

MDA clinic who monitored my growing symptoms. Around age 40 extreme fatigue, weakness along with increasing memory/concentration problems were affecting my ability to work and I later was unable to maintain employment.

At 41 years old I was no longer able to drive and independent living was becoming challenging so I returned home to PA to live with family. Living in PA put me close to the Mitochondrial Medicine Center at Children's Hospital of Pennsylvania (CHOP) where I will continue to be a patient under the expert care of 3 outstanding mitochondrial specialists and their staff.

The UMDF website was one of the first resources I found to learn about my new diagnosis in 2013. I was also eager to

sign up for their Mitochondrial Disease Community Registry (MDCR) so I could help advance diagnosis and treatment. My family also reached out to the UMDF to get free advocacy material and distribute to local doctor offices and radio stations during Mito awareness week in 2014. I continue to refer my medical specialists to the many resources UMDF provides like "Mito on Call".

Having a rare disease has many daily challenges but I try to keep a positive attitude which is easier with my faith and very supportive family. I enjoy helping those affected by mitochondrial disease through the UMDF, CPEO/KSS and POLG Facebook groups. In 2017 I volunteered to be a Support Ambassador for UMDF and enjoy helping them on small projects as needed.

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SPECIAL EVENT HIGHLIGHT:

TEAM HOPE ENERGY LIFE CHICAGO MARATHON



Jacob Pletcher and Aashni



Jeannie Dickens and River

This upcoming October, 26 Mitoans will join runners from all 50 states and over 100 countries as the UMDF's Charity **Team Hope Energy Life** participates in our 8th Bank of America Chicago Marathon. Since securing their entries in the Marathon last fall, members of Team Hope Energy Life have been holding fundraising and awareness events throughout their local communities and raising funds through an online Crowdrise page. We'd like to introduce you to a few members of our team:

Jacob Pletcher of Redwood City, California is running and fundraising for his daughter **Aashni**. Jacob says sees the struggles his daughter faces and he is inspired by her every day. "Despite the past 4 years being a relative roller coaster, Aashni remains a vibrant, spunky, wickedly smart and determined young girl. She faces and overcomes challenges on a daily basis and our goal is to provide her with everything she needs to succeed in this world." Jacob has been overwhelmed by the support of friends and family for his Marathon campaign. "I have a fantastic group of family and friends. I want them all to know that supporting and donating to UMDF is one way to help investigate new treatments and even a cure to this debilitating class of diseases." Jacob has currently raised \$6,504!



Tom and Michelle Lewis

Jeannie Dickens of Seymour, Indiana is running for her daughter **River**. When Jeannie decided to run the Marathon, she reached out to two family friends and recruited them to join her. **Tom and Michelle Lewis**, along with Jeannie, make up a contingent of EFL Indianapolis walk team "River Strong" who will be running the Marathon. Jeannie says that River is her little warrior. "River has always been my running buddy and we have run many races

together. She loves feeling like she's flying when we go fast so training for this marathon together has been our ultimate dream." Jeannie and team River Strong had a Fools 5K fundraiser held to benefit their Marathon campaign by a local fitness gym Fitness 1440. This event alone raised \$2,150! "Our dream is that through running and helping the UMDF we can bring more awareness to this progressive disease", says Jeannie. Jeannie, Tom & Michelle have collectively raised \$4,290!

Team Hope Energy Life is national – 11 states represented! Team Hope Energy Life is flexing mito-mom power – 17 runners are female and 4 are moms of affected kiddos. UMDF board, staff, families, friends, doctors, pharma companies and researchers -- all running to bring awareness at this world-class event!

You can find out more about the team and learn how to support them by searching Chicago Marathon on the UMDF Event Calendar.



EFL Team Spotlight: Erin's Energy

Meet the Kolodziejski Family and Team “Erin’s Energy”! The Kolodziejski Family walks at the Energy For Life Walkathon in Charlotte to honor Erin Kolodziejski. Erin has a working diagnosis of Mitochondrial Disease and her family works every day to provide the best for her.

ABOUT ERIN

Erin had feeding issues right from the start but the Kolodziejski’s did everything they could to be sure she got as much nutrition as possible. Despite their efforts, Erin was diagnosed as “Failure to Thrive” at three months. It was a very difficult time for the family and they were not sure that Erin would survive this struggle. She spent two years experiencing an assortment of seemingly unrelated symptoms, such as requiring feeding tube placement and having a 45 minute febrile seizure. At the time, there was no “reason” that the symptoms were happening, but, in 2014, they finally heard the words “mitochondrial disease.” At that time, they initially reached out to the UMDF to find a physician and traveled to Atlanta, GA, to see Dr. Fran Kendall. The gene causing her symptoms has not yet been identified, but the Kolodziejski Family holds out hope that it will be identified in the future.

ABOUT TEAM “ERIN’S ENERGY”

The Kolodziejski Family formed their first Team “Erin’s Energy” in 2016 but they were apprehensive, because they didn’t know which “gene” was causing her disease. They walked, but they thought they were the only family that did not have a genetic diagnosis. By the next year, they learned that they were part of a large group of families unable to secure a genetic diagnosis. They decided to jump into UMDF’s Energy For Life Walkathon Charlotte’s fundraising effort with two feet.

After some thought, Erin’s father, Mike decided to focus some of his fundraising efforts at the workplace. Mike works at Wells Fargo and knew he could get support from his colleagues if he targeted Wells Fargo’s “Giving in the Community” period.

He started out by sending an educational email about mitochondrial diseases to all of his colleagues. Mike had carefully crafted this document being sure to include only the most up to



date information. He even asked Chuck Mohan, UMDF Founder and Chair Emiratis to proof-read and edit it. He sent it out and had good response.

But Mike decided that he wanted to kick things up a notch, and he knew he would need to use humor to get his colleagues attention and set his efforts apart. He tried to think of something that would be both personal and meaningful to his colleagues. He tailored each email outreach to highlight that recipients Alma Mater. He would craft an email that “appeared” to come from a famous alumni. For instance, if a person attended the University of Pittsburgh they might get an email that said, “Mike Ditka here. Why don’t you score a touchdown and donate to Erin’s Energy?”

The creativity and personalization worked. The donations came in quickly.

But Mike didn’t stop there. He secured a \$2500 sponsorship through Wells Fargo. He reached out to local TV News personality Molly Grantham who featured Erin on her Facebook page. He also invited good friends from Kemp Karate Studio to Walk on Erin’s Team.

All of this effort led to SUCCESS!! Team Erin’s Energy raised \$33,373!!!

Mike said, “All of this was out of our comfort zone. We are not a family that puts ourselves out there like this. But this is for my daughter and I have a network. I knew I had to try.”

UMDF Says THANK YOU Team “Erin’s Energy”!!!!





Symposium Recap

More than 600 people representing the patients and families, caregivers, and the scientific and medical community, gathered the last week of June for Mitochondrial Medicine 2018: Nashville. This was the highest attended symposium in the more than 20 years that UMDF has provided this international educational event. In fact, mitochondrial disease community members from 31 states and 15 countries participated.

The focus for patients and families this year was preparation for the Externally-led Patient-Focused Drug Development Meeting on mitochondrial disease. UMDF conducted this important preparation session that included the testimony of patients, families and caregivers. They detailed their struggles with mitochondria disease and its impact on their lives, and families. “This was a very important practice session for our community,” said Kara Strittmatter, Director of Meetings and Events. Strittmatter, along with Science and Alliance Officer, Philip Yeske, PhD, are charged with organizing the EL-PFDD that is scheduled for March 29, 2019 in Hyattsville, MD. “I know it wasn’t easy for our panelists to share their stories. But their testimony and the testimony of others at this critical meeting next year could help move us towards drug development. So, it is crucial for our entire community,” Strittmatter added.

Patients, families and caregivers were also updated by members of industry on the status of clinical trials. Currently, there are 25 clinical trials underway.

New this year for patients, families and caregivers, was information presented on social security and disability issues; managing sleep issues; physical, occupational and speech therapy for mitochondrial disease patients. When asked what they liked most about the symposium, a first-time attendee noted the following: “Availability of pharma information, research information, co-mingle with all involved and most important to no longer feel like we are on an island alone.” “This is what we strive for each year...taking away the alone factor. We are all in this together.” said Strittmatter

While patients, families and caregivers joined the scientific and medical community for the annual Friday Night Banquet, more than 40 teens and young adults gathered for their annual prom. This year’s attendance was the largest ever. “This prom allows our teens and young adults to break the chains of the disease, dance, and just have a good time,” said Strittmatter. Portion of the teen and young adult program are made possible because of the generous support of the Edith L. Trees Charitable Trust.

Next year, the annual symposium moves back to Washington, DC. Patient and Family meetings will be held June 28-29, 2019.





LHON Summary

Leber's Hereditary Optic Neuropathy (LHON) is unique among mitochondrial disorders in that it usually involves only one symptom: sudden-onset legal blindness. Since 2013, the annual UMDF Symposium has included a special program specifically for individuals affected by LHON and their loved ones. Created and led by LHON Ambassador Lissa Poincenot, the LHON Conference includes sessions on the science behind LHON, the latest on clinical trials, lifestyle resources for the visually impaired, patient journey stories, and LHON community updates.

This year in Nashville marked the sixth convening of the LHON community at the UMDF Symposium, and over 100 people attended. Thursday afternoon's sessions included a presentation on assistive technology options for the visually impaired, a discussion of the many sports and fitness activities in which those who are visually impaired can become involved, and a powerful and courageous sharing of stories by affected community members. One of the key messages expressed during the LHON Journeys panel came from Daisy Polk, recently affected by LHON, who implored the audience to simply "choose joy." After the panel concluded, one attendee remarked that "there wasn't a dry eye in the room."

On Friday morning, LHON attendees joined with mito families, doctors and scientists for a session on scientific developments and clinical trial updates. Dr. Nancy Newman, Director of Emory University Eye Center's Neuro-Ophthalmology section and UMDF Scientific and Medical Advisory Board (SMAB) member, discussed mitochondrial vision disorders. She then invited representatives from Stealth BioTherapeutics, GenSight Biologics, and Santhera Pharmaceuticals to provide updates

and findings from their LHON clinical trials, then moderated a panel with representatives from the three companies. Dr. Barrett Katz, CMO of GenSight, imparted this inspiring message, "We are at the beginning of this journey. In the long term, we will win this battle." Next, she met with the LHON group for an LHON-specific Q&A session. Dr. Newman's expertise and breadth of knowledge on neuro-ophthalmology and mitochondrial vision disorders - especially LHON - is remarkable, and it was an immensely beneficial opportunity for LHON community members to be able to ask Dr. Newman about a wide range of LHON topics.

To close the LHON event, Lissa Poincenot led an LHON Community Update panel discussion, sharing information about the LHON community in the United States and around the world. Notably, LHON Canada recently became an official group and will be holding its first symposium on September 16, 2018 in Ottawa, Canada.

One of the best parts of attending an LHON conference is the opportunity to meet new friends and reconnect with old ones, who all understand the unique challenges that come

with sudden-onset legal blindness. The LHON community is often described as a "family you never knew you had!" Following the LHON conference, many in the group headed downtown to explore Nashville and enjoy a local restaurant together, while others attended UMDF sessions and the Banquet.

There are many ways to continue connections within the LHON community. On the first Wednesday of each month, the LHON group holds a live phone call with a different guest speaker each month. Speakers share their journey, and those who call in have an opportunity to ask questions and share their thoughts. There are also LHON Facebook groups, including a Global group and regional/state groups specific to where you live. Local group meetups and Team LHON's at EFL Walks also bring the community together during the year. LHON sessions at the annual conferences are captured on video and can be viewed on the LHON page of the UMDF website.

If you have questions about LHON or LHON community activities, please contact the UMDF's LHON Ambassador, Lissa Poincenot (LHONpoince@aol.com).



Dr. Nancy Newman moderates a panel with industry representatives

Symposium Awards

At its annual symposium, Mitochondrial Medicine 2018: Nashville, the United Mitochondrial Disease Foundation honored several volunteers for their efforts and dedication in supporting the organization and the patients and families it represents.



The Heartstrings award is presented to an individual under the age of 18 who has invested their time, demonstrated their talents, effectiveness and generosity in raising money or donations to enable the UMDF to continue its mission. The winner is chosen based on related criteria of age, time invested, talents demonstrated, effectiveness, and generosity and how the individual has “tugged at the heartstrings.”

The 2018 Heartstrings Award Winner is **Catherine “Cadie” Wolf**. Cadie is a 12 year old from Lake City, Minnesota. Four years ago, Cadie’s younger brother, Nathan, was diagnosed with mitochondrial disease. Cadie hosted a “Muffins for Mito” fundraiser. She baked muffins, sold t-shirts and brought a lot of awareness to her local community about mitochondrial disease. For the past four years, Cadie has organized a “Go Green” day at her school to raise awareness about Mitochondrial Disease. She has also been an inspiration to others in her family, encouraging them to keep up and match her Energy. Cadie also volunteers for her church, several organizations in her community and at Give Kids the World. Cadie truly has a true heart for service.

The UMDF Energy Award recognizes an individual who embodies the spirit of the UMDF mission, to promote research and education for the diagnosis, treatment and cure of mitochondrial disorders and to provide support to affected individuals and families.

We are proud to recognize **Angie Nunn** of Millington, TN as the 2018 Energy Award recipient. Angie has led the Jackson Culley MitoWhat 5k since 2010. Having never met the Culley’s before, Nunn had a crazy idea to hold a 5k race in honor of Jackson. That first 5k back in 2010 raised over \$22,000. For nine years, Nunn, along with help from Cindy Kraft, has successfully marketed the event locally with signs and posters in the community and by maintaining an online presence. Nunn’s leadership as chair of the Jackson Culley MitoWhat? 5k, is tireless. “Angie is the most passionate person about finding a cure for mitochondrial disease that I have ever met that DOES NOT have a family member with the disease,” said Emily Culley, Jackson’s mother. Over the course of those 9 years, Nunn not only successfully raised over \$190,000, she also raised awareness in Millington, TN. Nunn always dedicates 100% of herself to the UMDF through the Jackson Culley MitoWhat? 5k.



The LEAP Award stands for Living, Encouraging, Achieving and Persisting. The award is presented to an individual who is age 14 or older living positively with mitochondrial disease. The Awardee overcomes daily challenges to achieve goals in career, family, and volunteer service. The individual demonstrates a positive attitude, hope for a brighter future, and an enthusiasm that inspires others.

The 2018 LEAP Award Winner is **Andy Garrison**. Garrison was four years old when he was diagnosed with Leigh's Disease. He wanted to do everything his active brothers did. When there were obstacles that he couldn't overcome, he pushed others to find a way to help. As a result of his persistence, he has gone river rafting, kayaking, and snorkeling, camping, and even surfing. He attained the rank of Eagle Scout with the help of an encouraging scoutmaster. He has participated in therapeutic horseback riding for over 20 years. He attended college, living on campus for two years. And when that ended, he knew he wanted to live independently, which he now does with help from roommates and aides.

Life for Garrison has never been spent on the sidelines. He lives near downtown Franklin where he wheels nearly every day. He's made friends with the downtown merchants, residents and the many tourists who come to town. He's proud to ask every one of them for support to fight this disease.

The prestigious Stanley A. Davis Leadership Award is presented to a volunteer leader who exemplifies dedication to the UMDF. The award honors the organization's late Board Chairman, Stanley A. Davis.

Gail Wehling truly exemplifies the spirit of the Stanley A. Davis award. In fact, this recognition is long overdue. Gail is a leader that put others before herself. She has made a difference in the Chicago area and nationally for the mito-community.

Gail first connected with the UMDF in 2000 as an affected adult although she was diagnosed with CPEO as a teenager. She established the first UMDF Chicago Support Group in 2003 and served as the leader up until 2017. She also helped to form the UMDF Chicago Chapter in 2006. Under Gail's leadership, UMDF Chicago held consistent support group meetings for over 13 years straight. She arranged numerous guest speakers for special family educational meetings and helped to arrange Grand Rounds at a number of Chicago's top hospitals. She has also been involved in many other local activities, including the Energy for Life Walkathon, where Team Gail has raised over \$7,000.

In 2006, Gail was selected as a founding council member of the UMDF Adult Advisory Council Team (AACT) and continues to serve as co-chair. The tireless work of Gail and fellow council members has furthered UMDF's mission and AACT's purpose of representing and serving the adult & young adult mito-community.

"It is an honor and a privilege to represent, support and serve the adult & young adult mito-community," Gail said. Education, raising awareness and advocacy is a driving focus for her, especially enrolling in patient registries and participating in clinical trials and studies. "(It) begins with us and now up to us, the mito-community, who have battled this disease for so long to take the first big step. Otherwise, we cannot reach our ultimate goal - finding treatments and cures for mitochondrial diseases and disorders. As long as I am able, my mission and lifework will be UMDF's."



Sharon Shaw displays the artwork



Teens and Young Adults present Chuck with their artwork



Adrienne and Chuck Mohan



Dr. Anne Murphy, Anu Wartiovaara & Carlos Moraes lead a group sing-along

Honoring our Legacy

It was a night of laughs and tears as we honored the legacy of Charles A. Mohan, Jr. This was Chuck's last symposium as Executive Director/CEO of the UMDF. To honor him, artist Nancy Ostrovsky worked with the teens and young adults in attendance to create an original piece of artwork entitled, "Tree of Life."

Trustee Sharon Shaw presented Chuck with a hardbound book of pictures and memories shared about Chuck, from founding UMDF through the years. She also presented Chuck with a link to all of the online memories patients and families from around the world submitted.

Jack Black made a surprise video drop in to wish Chuck well as he moves into retirement. Black is a member of the UMDF's Honorary Board of Trustees.

UMDF also announced the Chuck Mohan, Jr. Legacy Award program. More than \$50,000 was raised for this ongoing development effort that will be used for programming that is part of UMDF's Roadmap to a Cure.

Chuck will remain active for the UMDF. He currently serves as Founder and Chair Emeritus of the Board of Trustees.

Living the Mission

The UMDF Staff—they organize Symposia and educational meetings, they connect you with your representatives in Congress for advocacy, they work with researchers and doctors to find and fund incredible research, and they coordinate Energy for Life Walkathons across the country. They dedicate not only their professional time, but also their personal time and family time to spreading awareness and finding a cure for mitochondrial disease. In short, UMDF staff members live the mission of UMDF!

What you might not know about your UMDF staff members: they have contributed almost \$35,000 to UMDF in the last ten years just through their payroll deductions! They not only live toward a cure; they give toward a cure!

The majority of UMDF staff participates in charitable payroll deductions, automatically giving back to the mission of UMDF out of every paycheck. Many of them also donate to Walkathons, Research Funds, and appeals throughout the year in addition to their payroll gifts. Those gifts over time add up to incredible impact toward a cure.

Employee giving gives you the opportunity to make a sizeable difference through small recurring donations. If you are interested in participating in payroll deduction at your own workplace, speak to your human resources or payroll departments. If your employer does not provide charitable payroll deductions, sign up for recurring giving with UMDF online. Visit www.umdf.org/donate, enter your preferred billing information and have your donation, at whichever level you choose, deducted or charged monthly. You can also sign in anytime and change your monthly giving amount or stop donations. Please reach out to the UMDF office directly at 1-888-317-UMDF (8633) with any questions. Recurring donations, big or small, add up over time and create huge impact!

DOUBLE YOUR IMPACT WITH DOUBLE THE DONATION!

Many corporations match employee donations (or the tax deductible component of your membership) to our organization. If you volunteer with us, your employer may also provide us with a grant as a way to recognize your ongoing support.

Find out if your employer offers matching donations or visit <https://doublethedonation.com/umdf>.

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ADULT ADVISORY COUNCIL TEAM

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**Joy Krumdiack, Co Chair
Washington**

**Gail Wehling, Co Chair, Illinois
Devin Shuman, Young Adult Chair,
Nevada**

**Kailey Danks, Toronto, Canada
Whit Davis, North Carolina
Nicole & Lillian DeJean, Louisiana
Debra Fox, Arizona**

**Rev. David Hamm, Maryland
Christy Koury, North Carolina
Terry Livingston, Florida
David McNees, Ohio**

**Linda Ramsey, New York
Jennifer Schwartzott, New York
Sharon Shaw, Arizona
Gregory Yellen, Maryland**

MEDICAL ADVISORS

**Bruce Cohen, MD
Amy Goldstein, MD**

AACT Purpose

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/or needs.

www.umdf.org/AACT

connect@umdf.org

AACT- ADULT CORNER PAGE

SUMMERTIME TIPS



Kailey, Toronto, Canada

Summertime cool beverage; Passion Fruit Iced Tea Lemonade. Use passion fruit tea (caffeine free). Brew tea and cool. Add lots of ice and a splash of organic lemonade.



Whit, North Carolina

When traveling to other time zones I've found it helpful to adjust yourself to the new time zone a day or so before you leave home, e.g. wake time, meal times, bed times, etc. It lessens the shock to your system once there. Summertime travel can be a little more stressful...bigger crowds so don't forget to pack your patience! With warmer weather I also eat lighter meals and more frequently than otherwise to help digestive challenges.



Nicole & Lillian, Louisiana

We live in the deep South where heat and humidity are worn like a part of our wardrobe! This is also the time of the year when we see the greatest decline in mine and Lillian's activity level. To maximize our functioning we do some of the following:

We do our shopping early in the morning before the asphalt can heat up. Shopping in the afternoon or evening is out of the question because the sun has heated the asphalt all day. At stores we don't always use the handicap parking spots because we choose spots that are under trees (unfortunately, those are rarely near the door). We drop Lillian off at the door to avoid the additional walking and heat exposure.

In our area, we do a lot of traditional cooking outdoors. In order for Lillian to enjoy being outside with us, we use a portable AC. This allows her to be part of the traditions of our family and community.



Deb, Arizona

If you have to go outside, be cautious. Stay out of the heat and in the air conditioning.



Rev David, Maryland

Great time to take up six-string guitar! Helps to improve brain function by learning new things like notes and chords. Helps to improve hand coordination by playing the instrument with both hands. Take the guitar outside while practicing but remember;

Sit under an umbrella on hot, sunny days and drink plenty of water for hydration; wear a wide-brimmed hat for additional protection of the face from the sun; wear sunglasses for protection of the eyes from the sun's harmful rays; use suntan lotion with an SPF rating of 40 to protect the skin from the sun's harmful rays.



Joy, Washington

For a treat to keep cool, freeze watermelon or other fruit in ice cube trays and you can use them to chill your drinking water. The frozen fruit could also be put in an infuser bottle.



Terry, Florida

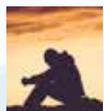
Use cooling towels/headbands similar to the kind used by athletes.



David, Ohio

The Buddha said: *"in the end, only three things matter: how much you loved, how gently you live, and how gracefully you let go of things not meant for you."*

Our common processes with mitochondrial disease unfurl our capabilities to love and be loved, while also nudging us toward a gentle life that we can sustain.



The long daylight hours of summer are conducive to sitting in the shade, watching nature flourish and gracefully letting go of what has been difficult for us. Ponder this, and realize what blessings have been gained through your journey!



Linda & Jennifer, New York

Stay in AC if possible. Stay extra hydrated. IV hydration with electrolytes if possible. Eat watermelon. More frequent naps. Cooling neck wraps. Self-assess.



Sharon, Arizona

Hydrate and schedule your outings around the hot sun!



Devin, Nevada

If cooling vests are too heavy/expensive, try using a simple bandana with an icepack wrapped inside of it around your wrists and the back of your neck. It's cheap, and if the icepack is small enough you can simply spin the bandana around between your hands to secure the icepack within and tie it to your wrist/neck.



Gail, Illinois

Growing up and living in the Chicagoland area, our summers are short, too short. Summer is a time for me to reset and reinvigorate my body, mind and spirit. Depending upon Mother Nature, I love to do some of the following things...

Parks: All of us have many local area parks to enjoy. Sit and/or walk along their paths, pack a picnic, and/or use them as a powerful place and time to connect with nature (meditation, journaling, etc.)

FYI...The National Park Service oversees over 400 natural and historic areas, and offers free admittance to any U.S. citizen or resident with a permanent disability via its Access Pass. Parks and the great outdoors are accessible for people with disabilities no matter our mobility level.

Fairs & Festivals: I love to attend with family and friends. They are always lots of fun and a great way to spend a day outside. It's also a wonderful opportunity to connect with and support your local community.

Farmers Market: Simply, the best! There is nothing better than selecting healthy locally grown and sourced goods. Plus, it's a great way to support our local area farms and businesses.

Travel: Do not be afraid to travel - long or short trips! It's important at times to get away. Plan ahead and be well prepared for expected and/or unexpected situations. To help, make a detailed list of all things you will or may need, including local area hospital contact information.

Summertime has so many benefits for us to enjoy, including being more active - on any level - which helps our mitochondria! And, it's a great time to naturally boost our Vitamin D levels. Many of us have low or deficient Vitamin D levels which can cause fatigue, on top of our chronic fatigue. Next time you see your doctor, you may want to have your Vitamin D level checked.

Happy Summertime... Get Outside... Have Fun & Enjoy!



Greg, Maryland

Plant a small garden. Many benefits include helpful occupational therapy, enjoying your grown goods, and a great way to spend some time outside.



Amy Goldstein MD, Pennsylvania

CHOP & AACT Medical Advisor

Make your own cooling vest. Buy a fishing vest with many pockets from a sporting goods store and place lightweight freezer packs in every pocket.

Visit www.UMDF.org/AACT soon for links to symposium recordings.

AACT CO CHAIR HONORED



Gail Wehling of Wayne, IL, was awarded the prestigious Stanley A. Davis Leadership Award. The award is presented to a UMDF volunteer leader who exemplifies dedication to the UMDF. The award was created to honor the organizations late Board Chairman, Stanley A. Davis. Wehling truly exemplifies the spirit of the award. She is a leader that put others before herself. She has made a difference in the Chicago area and nationally for the mito community.

LEAP AWARD



At Mitochondrial Medicine 2018, the United Mitochondrial Disease Foundation recognized Andy Garrison of Franklin, TN, with the UMDF Leap Award. The award is presented to an individual who is living positively with mitochondrial disease. As a result of his persistence, he has gone river rafting, kayaking, and snorkeling, camping, and even surfing. He attained the rank of Eagle Scout with the help of an encouraging scoutmaster. He has participated in therapeutic horseback riding for over 20 years. He attended college, living on campus for 2 years. And when that ended, he knew he wanted to live independently, which he now does with help from roommates and aides.

UMDF events

The energy providing education, support and research.

Past Fundraisers Benefitting the UMDF



Chicago supporters of Kristen's Angels playing bingo!

April 2018 Becker & Poliakoff, P.A.'s held a dress down day for the UMDF! Over \$430 was raised to support our mission! Thank you so much for your support!

April 23, 2018 This past April, four amazing Mito Artists were chosen by PaperClouds Apparel to be UMDF's representation in our 2018 campaign! These pieces were then sold and raised nearly \$400 – plus, you were able to score some pretty amazing articles of clothing! Thank you PaperClouds for selecting UMDF and for those who made purchases!

May 2018 Jenevieve Woods donated a percentage of her book sales to the UMDF! Thanks, Peach!

May 2018 Tyler Byrd of California held a Coins for a Cure fundraiser at his school in the month of May! The students raised funds in honor of Tyler's brother! Thank you Tyler!

May 3rd-6th, 2018 Cadie Wolf and Wolf Pack vs. Mito held a Muffins for Mito event during the 100 Mile Garage Sale in Red Wing, Minnesota. They raised \$1,000 to support their EFL walk team!

May 4, 2018 A Kendra Scott Gives Back event was held in Chicago to benefit the Energy for Life Walkathon in Chicago, raising \$330.45.

May 10, 2018 A Panera Fundraiser was held in Chesterfield, Missouri by St. Louis EFL team Olivia and Liam's Crew. They raised \$155.35 at this event.

May 30, 2018 The James Kenan High School held a fundraiser in honor of Emily Quinn. \$477 was raised during their event! Thank you so much for being such great supporters!

June 2018 Kristen's Angels of the Chicago Energy for Life walk held Bingo each Thursday evening in June to raise money for their EFL team.

June 8, 2018 Go Pro for Mito Golf Tournament in Columbus, GA was held at the Maple Ridge Golf Club. An outstanding year for Go Pro, as they raised over \$76,000 for the UMDF! Amazing work, Wendy & Chelsea Loyd & committee!

June 15, 2018 The 6th Annual Thomas Golf Tournament took place in Bridgewater, MA. The event was held at Olde Scotland Links Golf Course and had a great turnout! Over \$10,000 was raised in honor of Thomas Schmid! Thank you, Uncle Jason for your continued support!

June 22, 2018 Wolf Pack vs. Mito held a Thirty One Gifts fundraiser and raised \$158.50 towards their Minnesota EFL walk team. Thank you Wolf Pack!



Members of the Ruhana-Smerek family at the Torpey Golf tournament.



Adam Kohr at Paulie Gees Pizza

June 23, 2018 The 6th Annual Nicholas J. Torpey Butterfly Golf Classic was held Sycamore Hills Golf Club in Macomb, MI. It was a great day of family and friends raising money to benefit the Nicholas J. Torpey Research Fund through the UMDF. The event raised a total of \$18,306!

July 2018 Adam Kohr of Chicago EFL team Futureof645 has designed t-shirts for Paulie Gees Pizza in Logan Square. The shirts are hanging in Paulie Gees with Adam's story for mitochondrial disease awareness. A percentage of each shirt purchased will go to the walk team.

July 11, 2018 Brayden Lane celebrated his birthday, by collecting donations for the UMDF! You are such a gift to us, Brayden! Happy 11th Birthday, buddy!

July 14, 2018 A 'Charity Bowl' event was held in Brooklyn, NY for the UMDF in memory of Grace Caruso. Over \$2,700 was raised for the UMDF! Thank you so much, Alan Leber & Committee for your amazing support! We call that one a STRIKE!!!



Chelsea Loyd with dog Aspen & Golf Participants

Upcoming Educational Activities

September 14, 2018

Lansing, MI

Michigan Association of Genetic Counselors (MAGC) Annual Education Conference

UMDF will represent the Mitochondrial Disease Community

September 21-22, 2018

Rochester, MN

UMDF and Mayo Clinic Collaborate for Educational Conference for Clinicians/Researchers

Organizer: Ralitz Gavrilo, MD

Visiting Speakers: Douglas Wallace, PhD; Amy Goldstein, MD; Amel Karaa, MD; and Sumit Parikh, MD

Families are invited to a two hour meeting with Drs. Gavrilo, Goldstein, Karaa, and Parikh – as well as others from the Mayo team – on Saturday, September 22 from 10am to 2pm.

For more information, visit <http://www.umd.org/events/2018-09/>

October 16-18, 2018

Chicago, IL

UMDF Family Meeting with Dr. Saneto

October 16, 2018

Details to come – visit <http://www.umd.org/events/2018-10/>

Northwestern Neurology Grand Rounds

October 18, 2018 at 7:30am

Joint GR between Adult and Pediatric Neurology Departments



Grace Caruso Charity Bowl



Upcoming Events

July 28, 2018 Team Fighting for Aliyah Faith is holding a Dance for Mitochondrial Awareness in Red Wing, Minnesota.

August 4, 2018 The Carter Lackey Memorial Miles is a virtual event with a closing ceremony held in Athens, PA. You can learn more at: www.tspt.biz/CarterLackeyMemorialMiles. Thank you to Liz Terwillinger & the Lackey Family!

August 10, 2018 EFL Chicago Walk Chair Maureen Galezkiewicz is selling tickets for the Friday August 10th Chicago White Sox game to raise money for the Chicago walk.

August 10, 2018 The 11th annual Run4Raley will be held in Philo, Illinois by the Kirby family.

August 11, 2018 Jamming with the Morris Bros will be held at General Admission Sports Bar 7:00-11:30pm. Joe Atchley's Energizers are fundraising for their EFL Kansas City team with music, raffle and a silent auction.

August 14, 2018 Minnesota EFL Corporate Partner Staples Oil Inc. Co. will hold their annual Expressway BP and Dairy Queen fundraiser in Jackson, Minnesota. 100% of DQ sales and 10 cents of every gallon of gas are donated to EFL Minnesota.

August 24, 2018 Join Aiden's Red Wagon at Primp Boutique in White Bear Lake, Minnesota for a Primp Gives Back fundraiser. 10% of sales for the day will be donated to their walk team for EFL Minnesota.

August, 2018 Beth Wolf of Wolf Pack vs. Mito will be holding "Jeans Day" fundraisers at her workplace to fundraise for the Minnesota EFL.

September 7, 2018 Team Zoe will hold their annual "Concert for a Cure" at Rock & Brew restaurant from 6:00-10:00pm in Overland Park, Kansas. The event will feature the band Wednesday's at Hermans and proceeds will benefit EFL-Kansas City.

September 8, 2018 The Nathan Mowrer Memorial Horseshoe Tournament will take place on September 8th. Prizes, basket raffles and horseshoes are on the menu! Thank you for supporting the UMDF for over 10 years!

September 21, 2018 The 5th annual Carlos Alberto Memorial Golf Outing will be held in Miamisburg, OH at the PipeStone Golf Course. Shotgun start at 1pm, followed by dinner, raffles and awards at 6:00pm. Join in as a single, or a team of two at www.umdf.org/golfforcarlos. Contact Cristina Rue (cristinarue@gmail.com) with any questions!

October 8, 2018 Team Hope Energy Life will be represented at the Bank of America Chicago Marathon. The team currently has 25 members. If you would like to learn more about our runners or support their efforts visit <https://www.crowdrise.com/o/en/team/bank-of-america-chicago-marathon-2018>.

November 15, 2018 The 2nd Cousins for a Cure Gala in honor of Sydney Breslow and in memory of Logan Sloan Aronson will be held at the Woodcrest Country Club at 6pm. The gala will benefit the Logan Sloan Aronson Research Fund in honor of Sydney Breslow. You can purchase tickets, or sponsor the event at www.umdf.org/cousinsforcure18!

For a full list of events, visit www.umdf.org/events!



Energy for Life Walkathons



It is FALL Walk season!! Our amazing volunteer planning committees are working hard on planning Energy for Life Walkathons in your town. You can be a part of an EFL by being a team captain, registering to walk, becoming a donor or sponsoring a walk! Contact events@umdf.org to see how YOU can be involved!

We would love to see YOU at a walk....

August 18, 2018 – Minnesota

www.energyforlifewalk.org/minnesota

September 8, 2018 – Indianapolis

www.energyforlifewalk.org/indianapolis

September 8, 2018 – Delaware Valley

www.energyforlifewalk.org/delval

September 15, 2018 – Western New York

www.energyforlifewalk.org/westernnewyork

September 15, 2018 – Kansas City

www.energyforlifewalk.org/kansascity

September 15, 2018 – Detroit

www.energyforlifewalk.org/detroit

September 16, 2018 – Chicago

www.energyforlifewalk.org/chicago

September 29, 2018 – Southern Wisconsin

www.energyforlifewalk.org/southernwisconsin

September 30, 2018 – Seattle

www.energyforlifewalk.org/seattle

October 13, 2018 – Central Texas

www.energyforlifewalk.org/centraltexas

October 13, 2018 – Charlotte

www.energyforlifewalk.org/charlotte

The following cities hosted an EFL Walkathon this past Spring!
Watch for 2019 dates coming soon....

Houston

www.energyforlifewalk.org/houston

Nashville

www.energyforlifewalk.org/nashville

San Francisco Bay Area

www.energyforlifewalk.org/sanfrancisco

Tampa Bay

www.energyforlifewalk.org/tampabay

Dallas/Fort Worth

www.energyforlifewalk.org/dallasfortworth

Atlanta

www.energyforlifewalk.org/atlanta

New England

www.energyforlifewalk.org/newengland

Columbus

www.energyforlifewalk.org/columbus

St. Louis

www.energyforlifewalk.org/stlouis

Pittsburgh

www.energyforlifewalk.org/pittsburgh

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!

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: My son has MERRF, he is 29 and diagnosed at 21. He continues to have myoclonic movements - they are getting worse. He currently is on Keppra and clonazepam, and Xanax as needed. I am concerned that he is building a resistance to these meds. Are there other medications available for MERRF? Any and all help is appreciated.

A: Myoclonus in MERRF can be very difficult to treat. Medications can help but will not stop these movements. A good epileptologist is needed. There are other medications that can be tried if felt appropriate by your medical team including zonisamide, primidone, piracetam and lamotrogine.

Sumit Parikh, MD

Q: I had a child pass away from Pearson Syndrome that turned into Kearns Sayre Syndrome. My question is if I were to have more children would they also have this disorder. What are the chances of that happening again?

A: Pearson syndrome and KSS are caused by sporadic mtDNA deletions typically isolated to the affected patient. As such, there should be no recurrence risks for you with subsequent pregnancies. I would recommend that you speak with a genetic counselor to review this information in detail.

Fran Kendall, MD

Q: This question is regarding a 19 month old who is in hospice. Hair is falling out and new skin rash, suspect vitamin D deficiency based on food intake. It is safe to supplement with vitamin D and if so how much? The patient is 5.06 kg. Thank you!

A: Vitamin D levels should be checked. It is a cheap and easy test. Dosing for vitamin D deficiency is based on age and how low the level is. The hospice team should be able to assist with this.

As an aside - vitamin D deficiency does not typically cause hair loss or a rash. The team should look for other causes for this.

Sumit Parikh, MD

Q: My two children have been recently diagnosed with a TWNK mutation. My oldest is 5½ and my youngest is 22 months. Our symptoms are global developmental delay, ataxia and optic nerve atrophy. My oldest child has experienced vision loss. Is there anything else I can do to prevent this from happening to my younger child?

A: I am sorry to hear that your children have TWNK related mitochondrial disease. It is not easy to answer the question as to whether the vision loss is preventable without knowing more medical information. I would recommend that you see a mitochondrial specialist if possible. A list of sites with mitochondrial specialists is available at the Mitochondrial Medicine Society website under the section of "Care Networks." - <http://www.mitosoc.org/clinics/>

Sumit Parikh, MD

Q: Is there any connection between mito and prostate cancer or enlarged Prostate?

A: In terms of prostate cancer, mutations in the gene ELAC2 in autosomal dominant inheritance can lead to prostate cancer. When autosomal recessive can cause a Mitochondrial cardiomyopathy.

Amy Goldstein, MD

Q: Why isn't ATP a part of our Mito cocktail? Could taking ATP supplements help Mito patient?

A: ATP is not available directly although you might be able to find supplements labeled as ATP enhancers. Some of these include creatine, D-ribose and other components of the mito cocktail. There is a new review of supplements provided by the NIH - <https://ods.od.nih.gov/factsheets/PrimaryMitochondrialDisorders-HealthProfessional/>. None of these have been proven or approved by the FDA.

Amy Goldstein, MD

Corporate Partnership Spotlight



Who are they?

Solace Nutrition prides itself on its main reason for existence – the advancement of disease management through nutrition. Their products are designed by healthcare professionals specialized in the area of disease for which their products are intended. The team at Solace Nutrition is consistently developing scientifically proven products that fill the unmet need of the many people struggling with chronic disease management.

Their mission is to develop medical nutritional products with strong scientific background that target diseases which can be better managed through nutrition and thus promote quality of life. A continual program of technology analysis, licensing, and acquisition is the mission for the success of Solace. Their program maintains close ties with major research institutions and organizations

worldwide who are involved in chronic disease. All relevant technologies are considered as candidates for synergy with the corporation. Through incorporating novel technology, Solace will continue to take a leadership role in fields pertaining to chronic disease and nutritional management.

What do they do for UMDF?

Solace Nutrition has been generously supporting UMDF since 2008 in the fight against mitochondrial disease. They not only support our National and Regional symposia, but also support our educational and scholarship fund, the New England Energy for Life walkathon and our Grand Rounds program.

Solace says...

Our team is committed to supporting UMDF and all those effected by mitochondrial disease. We are thankful for the opportunity to meet families and practitioners each year at various UMDF events and learning about how our products continue to make a difference in the lives of our customers. We look forward to supporting UMDF for many years to come!

UMDF Staff says...

The team at UMDF enjoys working the Solace Nutrition team. Tom Clough, Kate Murtaugh and Andrew Sanford have been so pleasant to work with and we always look forward to seeing them at our events. We appreciate everything they do to support our cause and make a positive difference in the lives of all who live with mitochondrial disease.





UMDF advocacy

IN DISTRICT MEETING SET FOR PATIENTS/FAMILIES IN SEPTEMBER

During Awareness Week (September 16-22) patients and families will fan out across their congressional districts for an advocacy awareness event. UMDF will arrange meetings for patients and families with their congressional office and the offices of their two U.S. Senators. More than 50 patients signed up online to participate in this in district advocacy event.

During their meetings with elected officials, patients and family members are encouraged to share their personal stories with mitochondrial disease. They will also ask their House Members to co-sponsor two pieces of legislation – HB 5115 and HB 5062.

HB 5115 is known as the RARE ACT. The measure supports improvements to rare disease treatments, education, federal awareness efforts, and diagnosis and ramps up federal efforts to alert more health professionals to related diagnoses and treatments. HB 5062, also known as Advancing Access to Precision Medicine Act, directs the Department of Health and Human Services to enter into an agreement with the National Academy of Medicine to recommend how the federal government can support the use of genetic and genomic testing to allow for better delivery of precision medicine.

Patients and families will ask their U.S. Senators to co-sponsor S. 1194, which is the Medical Nutrition Equity Act. Coverage of medically necessary foods, vitamins for digestive and inherited metabolic disorders under federal health programs and private health insurance.

CONGRESSIONAL BRIEFING UPDATE

The Diagnostic Odyssey for Mitochondrial Disease Patients was the topic of the briefing UMDF Presented to the Congressional Mitochondrial Disease Caucus. The briefing, attended by more than 25 congressional offices, was presented by Michio Hirano, MD. Dr. Hirano of Columbia University, will discussed the results of his efforts to survey over 200 patients diagnosed with mitochondrial disease in the National Institutes of Health (NIH)-funded Rare Diseases Clinical Research Network, learnings that may be applied to rare diseases more broadly. He told members of Congress, that in many cases, patients see up to 20 physicians before they are accurately diagnosed with mitochondrial disease.

In addition, Dr. Hirano discussed the challenges of diagnosing patients in the context of his work on the Charlie Gard case last year, a case of a British boy diagnosed with a rare form of mitochondrial disease that drew attention from the international community, Congress, and the Administration.

WELCOME TO THE CAUCUS

UMDF Is excited to report that we gained another Congressional Mitochondrial Disease Caucus member. The Honorable Fred Upton (R-MI-6) is our newest member. Congressman Upton is a member of the House Energy and Commerce Committee, where many of the issues affected our patients and families are heard.

UMDF national

News from the national office.

Are you looking for someone to connect with? Connect with a UMDf Ambassador, an affected individual/family member who would be happy to network with you. To get started, email info@umdf.org or call us toll-free at 1-888-317-8633.

WHAT UMDf REGION DO YOU LIVE IN?

East Region

Nicole McCaslin

nicole@umdf.org

www.umdf.org/regions/east

Central Region

Anne Simonsen

anne.simonsen@umdf.org

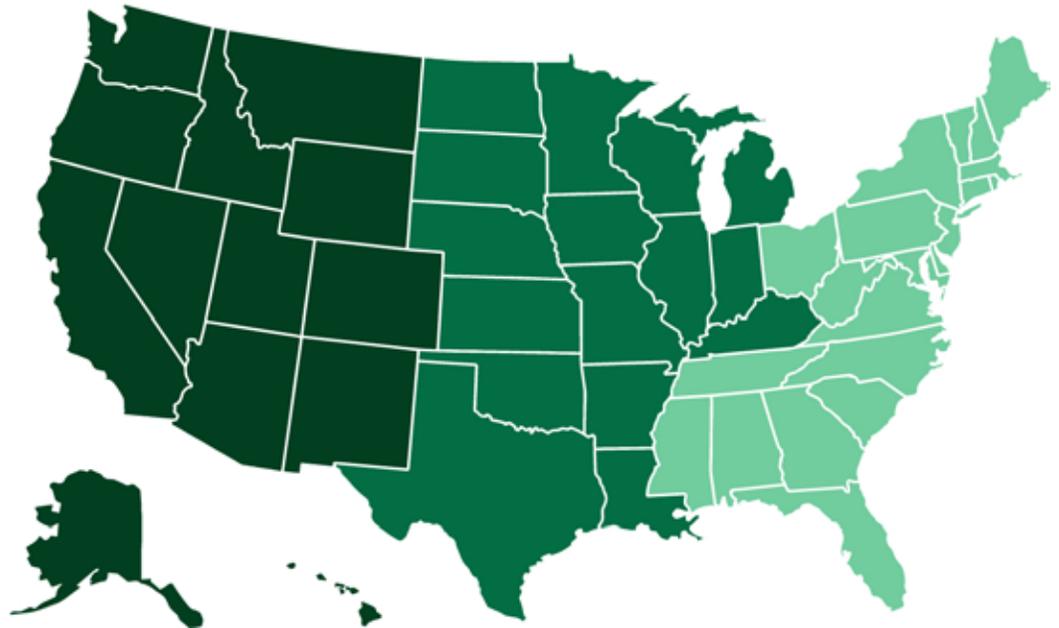
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UMDF MISSION

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

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.

ADVANCING MITOCHONDRIAL MEDICINE

We are a Swiss specialty pharmaceutical company committed to developing medicines to meet the needs of patients living with mitochondrial disorders and other rare diseases.

Our focus is on the development of treatments for neuromuscular and neuro-ophthalmological diseases that currently lack treatment options and our passion is on improving patients' quality of life.

