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UNITED MITOCHONDRIAL DISEASE FOUNDATION®

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Quarterly publication
Volume 20, Issue 4, Winter 2016

A Home Run Friendship

by Tara Maziarz, UMDF Development Associate

This year the Chicago Cubs successfully put a 109 year curse to rest by winning the World Series. One team member who was instrumental in that momentous feat was LF/C Kyle Schwarber. There is more to Kyle than just being a World Series Champ, however. There's a desire to help others and do good in the world, and that includes his friendship with 10 year old Campbell Faulkner of Queen Creek, Arizona.

Campbell was born at 35 weeks old after a very difficult pregnancy for his mother, Carrie. She had sepsis at eight weeks and required an ultrasound every six hours to make sure she hadn't lost him. Her doctors told her Campbell wouldn't make it. Miraculously, Campbell came into this world at 6lbs, 7ozs. When Carrie held her newborn son for the first time, he was humming. She was so happy to hear that noise, telling a nurse, "Look, he's humming for me," but the nurse informed her that was not a good sign, and took Campbell spent time under watch in the NICU.

The Faulkners eventually took Campbell home, but he had constant struggles. They had difficulty maintaining his temperature and weight. A year later, Campbell had his first seizure, and then another at 15 months. He lost his ability to talk and started regressing.

Continued on next page...

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A Home Run Friendship

Continued from front page...

In particular, the Faulkners realized Campbell was silently aspirating his food, but never coughed. They enrolled him in a swallow study after he contracted pneumonia three separate times in one year. Campbell's neurologist suspected mitochondrial disease and suggested that the Faulkners see Dr. Fran Kendall across the country in Georgia as soon as possible.

Due to insurance issues, the Faulkners needed to raise money to travel and see Dr. Kendall. Campbell was 6 years old when the Faulkners organized the first Campbell's Crew fundraising event: a garage sale.

After finally meeting with Dr. Kendall and many years of unanswered questions, Campbell was diagnosed with mitochondrial disease at age 7.

The Faulkner's were invited to Sloan Park near their hometown in Arizona by a friend from church. Several club and farm teams for major league baseball teams play there. They were guests of Mike and Deb Berry who have a charity called "Steve's Dreams" in memory of their son Steve who passed away at 24 from Pericarditis. The family invites families like the Faulkner's for a tailgate to enjoy a day and forget your problems. Each year the foundation gives away 6 tickets to spring training.

That's when it happened, Kyle Schwarber was signing autographs after a game when he saw Kyle. He walked over to him and said "Hey dude, do you want me to sign your baseball?" Campbell said yes and introduced himself handing one of his Campbell's Crew wristbands to Kyle and asked him to join his crew. Kyle said that he would be honored and that he would wear it every game. In fact Kyle wears it everywhere! If you happen to catch a green flash during an at bat or a post-game interview there it is!

If you have looked into Kyle Schwarber's road to the World Series, it was not easy. At the beginning of the season he suffered a severe injury and was not sure that he would make it off of the disabled list. Through insurmountable hard work and dedication Kyle made it off that list and to the World Series.

He has stayed in touch with Campbell through the year and through the World Series, never taking his Campbell's Crew wristband off. Schwarber is sponsored by Dinger Bats, and now they all wear Campbell's bracelets while they are making the bats!

The Faulkners have experienced quite a life change since becoming friends with Schwarber, but they wouldn't have it any other way. They have brought hope and continued awareness to the mitochondrial disease community.

REATA LAUNCHES A MITOCHONDRIAL MYOPATHY CLINICAL STUDY

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

MOTOR
a study in mitochondrial myopathy

Spotlight: Life for Lila

My name is Julie Freed and I am the team captain for **Life for Lila**, part of the Charlotte Energy for Life walk since 2010. In seven years, Lila's team has raised $34,898.42. This is my story of how I got involved with the UMDF and EFL and how I work to raise funds. It's all for and because of Lila.

Five years ago, I responded to a message on a babysitting website and I had no idea how much it would change my life. Lila Richardson was only 3 at the time and I knew nothing about Mitochondrial Disease. I quickly learned the ins and outs of Lila, researched and read as many articles as I could about mito, and asked her parents, Dan and Eaddy, a million questions.

Lila, her parents, and her twin brother and sister, Ben and Hadley, are the kind of people that you meet and feel like you've known for years. They are completely transparent when it comes to Lila and their life with her. They do not sugar coat the struggles, but they also do not let the struggles define their lives. They find good in every day and if you were to randomly meet them, you would have no idea how much work they put into each day caring for Lila. It's their life, it's normal and they take it all one step at a time. They are the best people I've ever known and from the first day I met Lila and her family, I knew I wanted to do whatever I could help to them.

The first three years I was with the Richardson's, they held a Golf Classic in

Lila's honor to raise funds for the UMDF. Through their Golf Classic, they raised almost a quarter of a million dollars! To be a part of a fundraiser that successful was humbling and got my wheels turning. I was inspired to do my own. Bowling is one of the few organized activities Lila enjoys and it is fun for the whole family. To this day, I've held three Bowling for Lila fundraisers and have raised over $15,000 all to go to our Charlotte Energy for Life walk team.

Setting up the fundraiser was so much easier than I could have imagined. The bowling alley gave me a set rate per bowler which included two hours of unlimited bowling and shoe rentals. I then charged each bowler a flat rate which allowed 50% of the rate to go to the bowling alley and 50% to the UMDF.

Doing just the bowling fundraiser would have been enough, but I wanted to do more so we could raise more. First, I decided to become a Stella & Dot consultant, so I could host a trunk show which allowed me to donate all of my cash earnings from the trunk show to the fundraiser and use the jewelry credit earned to get pieces to raffle off at the fundraiser. Next, I reached out to local businesses (non-corporate/ local businesses are the easiest) to get donations for our raffle as well. I used any and all connections to businesses as I could. People are more likely to donate when they have a personal connection to the fundraiser! I did do a silent auction for any items I received that had a larger value. This past year, I added lane sponsorships to the event.

The best things about a bowling fundraiser is that they are easy to set up with little overhead and there are so many variations you can do. You can easily host your own bowling fundraiser for your EFL walk team and I'm happy to help! If you have any questions or would like help setting up a bowling fundraiser, you can contact me via email at *jmfreed1@gmail.com*.

Passing the Gavel

Leadership is the capacity to translate vision into reality.

Warren G. Bennis, US psychologist, management educator, and consultant, distinguished prof. at USC

I Googled "Transition in Leadership" and found 152,000,000 citations. I then I Googled "Volunteerism" and found 5,630,000 citations. Obviously there is more interest in being a leader than there is in being a volunteer!

The question I ask is, "What happens when you combine a desire to lead with the passion of a volunteer?" The answer is, "You get a UMDF Chairman of the Board of Trustees."

The UMDF Board Chair's gavel has been handed down five times since its inception and is now being handed for a sixth time from Patrick Kelley to another set of capable hands.

Our Past Chairman, Patrick Kelley, will be passing the gavel on to Vice Chairman, Brent Fields. We thank Patrick for his leadership and for being the spark behind the development of the UMDF Roadmap to Treatments and Cures. Patrick remains on the UMDF Board and will continue to facilitate community engagement and implementation for the Roadmap Project.

Brent Fields

Gavel recipient, Brent Fields, lives with his family in Central Texas where he works as the CEO of Big Brothers Big Sisters, a nonprofit mentoring organization that serves over 1,000 youth. Prior to his current role, he was an Administrator in the healthcare arena and then a Vice President with the American Heart Association. He has over 25 years of executive leadership experience in various industries ranging from education and counseling to healthcare and nonprofit services.

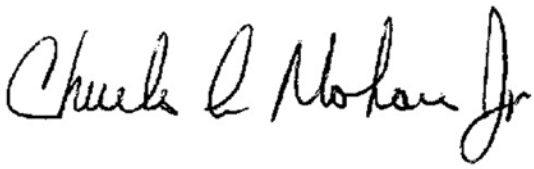
His educational background includes a Bachelors Degree in Communications, a Masters Degree in Education, a Clinical Residency, and a Certification in Health Promotion Management. He currently serves on a number of advisory boards and, in his five years at BBBS, he's led the organization to a position of national recognition, including the honor of National Board of Directors of the Year in 2012.

He and his wife, Suzette, have actively supported local UMDF efforts in the greater Austin area the past couple of years, including their involvement in the local Energy For Life walk. They have three children, and their youngest, Chloe, has a mitochondrial disease.

The success of the UMDF is the result of engaging individuals, like Brent Fields, who have ability and dedication to mission. Many individuals may have ability and dedication, but UMDF Chairs' also have the single most important ingredient, without which, forward momentum and growth would stall; PASSION. Passion is the fuel that ignites dedication and ability.

So, as you can see, the UMDF gavel continues to land in the hands of very capable individuals. Brent is certainly capable of translating "vision into reality," and his passion will continue to lead the UMDF toward mission success by focusing on Coordination of Efforts, Communication of Need and Collaboration for the development of treatments and CURES!

Our hats are off to yet another unique volunteer and leader who is dedicated and willing to lead this great organization.



Chuck Mohan,
UMDF CEO/ED

Cousins for a Cure

On November 17, 2016, in New Jersey, the Breslow Family hosted one of the most unique sanctioned events to date. ***Cousins for a Cure*** was held at The Mansion on Main Street in Voorhees, New Jersey to benefit the Logan Sloane Aronson Family Research Fund in honor of Sydney Breslow. Thus far the event has raised over $150,000…. and they are still counting!

The Breslow family reached out to UMDF in March of 2016 with the idea to host a gala type event, one that would be unique to their hometown in Cherry Hill, NJ. With over 60 sponsors and guest speaker Michael Smerconish, the event had a local touch that focused on the importance of family, friends, energy, and the need for a cure.

The night opened with a beautiful cocktail hour and an amazing fisherman's and silent auction. The auction boasted two chairs from sponsor Global Furniture Group that were used by moderators in the 2016 presidential debates! Once the silent auction closed, guests were ushered over to a beautiful dinner.

The dinner began with an introduction by Alan Breslow, who highlighted the struggles of mitochondrial disease and the difficulty in finding a diagnosis and where a family goes once one is found. The guest speaker for the evening was CNN and Sirius XM host Michael Smerconish presenting his talk "The 2016 Presidential Election: What Just Happened?" From there, the event moved into the first live auction item of the night a special surprise package from Michael Smerconish. Guests had no idea what to expect, until he announced it would be a day with him at his studio to see how he produces his show.

The most poignant moments of the evening came from the speeches that followed. Debra Aronson, one of the chairs of this event, spoke of her son, Logan, for whom the research fund was established. Logan was taken too soon by a terrible accident, and Debra reminded us all to hold our loved ones tight and to cherish every moment. She then introduced her sister, Sherri Breslow.

Sherri is a woman who is determined not only to help her daughter, but all those around her. She spoke of their personal experience with mitochondrial disease, and how mito has affected many that face similar ordeals and struggles. The Breslow family wanted to highlight all those that suffer from mitochondrial disease. This made their event the perfect place for UMDF to premiere their new video highlighting our families, research, and hope for the future. Once the video aired, Brandon Breslow, Alan and Sherri's son and Sydney's older brother ,delivered a heartfelt introduction for his sister Sydney. Sydney spoke and highlighted her challenges, but noted that nothing could stop her from achieving her goals. Sydney will graduate with a Master's Degree from High Point University this December, and her goal is to help students with disabilities on college campuses. Her desire to help others was at the forefront of why she and her family decided to make this event a reality.

The night closed with a very exciting live auction, thanks to the Katz Family Foundation and auctioneer Jeff Hammond. The amazing prizes available included a stunning blue sapphire and diamond necklace donated by Jay Roberts Jewelers, as well as several vacations including stays at a penthouse in St. John, The Ritz – Carlton Aruba, Secrets at Puertos Los Cabos, and the Ongava Game reserve in Namibia, Africa!

Cousins for a Cure was a beautiful evening that showcased the love of a family, their friends, and an entire community.

Couple Spearheads Effort To Pass Mito Cocktail Legislation

Thanks to the efforts of David Faugh and Glenda McCoy of Lexington, KY, the state of Kentucky is the first to mandate that private insurance companies cover the vitamins and supplements prescribed by a physician for a "Mito Cocktail." The couple became frustrated that while Kentucky law mandated the coverage for their daughter, Katherine, and others with mitochondrial disease in the state, private insurers continued to deny the coverage. They managed to advocate on behalf of all mitochondrial disease patients in the state and worked to include a floor amendment into Senate Bill 18 that specifies that mitochondrial disease is an inborn error of metabolism or genetics to be treated by products defined as "therapeutic food, formulas, and supplements" and that health benefit plans that provide prescription drug coverage shall include in that coverage therapeutic food, formulas, supplements, and low-protein modified food products for the treatment of mitochondrial disease. The new law goes into effect on January 1, 2017.

Will You Be Part Of Our 3rd Day On The Hill?

The United Mitochondrial Disease Foundation is gearing up for our third 'Day on the Hill'. The date next year falls during the same week as Mitochondrial Medicine 2017: Washington DC. Affected individuals, their families and friends will be able to participate in Day on the Hill on June 29, 2017. It will be an opportunity for you to meet with your Congressman and your two U.S. Senators to educate them about mitochondrial disease, how it impacts your life, and to advance our specific agenda items that will lead to more governmental funding for research towards treatments and cures.

Very soon after the first of the year, UMDF will send information via eblast and social media on how to register for the 2017 Day on the Hill. If you do not have computer access, please contact our office at 888-317-8633 and we will send you the registration information you will need to return to our office. Let's make this our largest "Day on the Hill" ever!

Genetic Testing Pilot Program

A few months ago, UMDF and Courtagen Life Sciences announced a new pilot program designed to provide genetic testing for patients who have been unable to access testing because of financial barriers. On a quarterly basis, Courtagen is offering a complimentary mtDNA analysis (mtSEEK) or a nuclear gene analysis (nucSEEK Standard). Both physicians and patients must participate. Patients meet the criteria and be registered in the Mitochondrial Disease Community Registry. Physicians must register for the program on the UMDF website. Tests will be awarded quarterly. The physician selected for our first random drawing on September 29, 2016 was Samuel P. Tang, MD, of the Providence Genetics Clinic in Spokane, WA.

If you are a patient or physician and would like to learn more about enrolling in this program, visit *www.umdf.org/freetest*.

CDMRP Awards $11M for Mitochondrial Disease Research

Through the efforts of families impacted by mitochondrial disease, the United Mitochondrial Disease Foundation is excited to learn that more than $11 million dollars for eight mitochondrial research projects are being funded this fiscal year by the Department of Defense Congressionally Directed Medical Research Program (CDMRP). The CDMRP recently released the names of the researchers and award amounts.

UMDF and members of the mitochondrial disease community played a vital role in the process to secure these important research dollars. In June, 2014, affected individuals and their families participated in a "Day on the Hill". In meetings with their House and Senate representatives, they asked if mitochondrial disease could be added to the list of research priorities funded by the Department of Defense CDMRP.

"We were told this would be very difficult to do and that it would take years to be included," said Charles A. Mohan, Jr., CEO/Executive Director. "However, when keys members of Congress met with our families and heard their stories, mitochondrial disease was added to the list and we are grateful for that inclusion," he added. "We worked very hard on the Hill to reinforce what our families were telling Congress and to recruit researchers and members of the affected community to sit on the panels that reviewed proposed research projects under the CDMRP program, so we are incredibly excited with the awards this year and the impact they may have on treatments and cures," Mohan said.

Programs such as the CDMRP that focus on mitochondrial research are important because they attract a broad range of topics of interest to the affected community. Projects funded in the current fiscal year range from basic science to therapeutic development and the Department of Defense is providing the mechanism by which scientists active in all stages of life science research can participate.

According to UMDF Science and Alliance Officer Phil Yeske, PhD, "The CDMRP-funded projects are all very relevant to the UMDF mission of facilitating research toward the development of treatments and cures for mitochondrial disease. Importantly, the size of the CDMRP awards are larger than the typical UMDF research grant, which allows investigators to explore broader topics. One could argue that the CDMRP research program has effectively grown the size of the UMDF grant program by a factor of 10!"

Yeske says the UMDF will continue to aggressively advocate to make mitochondrial disease its own research program within the CDMRP. "The evolution from 'topic of interest' within the Peer Reviewed Medical Research Program to a stand-alone "Research Program" would guarantee a certain level of annual funding long-term, further securing this important complimentary funding mechanism for our research community," he said.

The CDMRP originated in 1992 via a Congressional appropriation to foster novel approaches to biomedical research in response to the expressed needs of its stakeholders-the American public, the military, and Congress. The CDMRP fills research gaps by funding high impact, high risk and high gain projects that other agencies may not venture to fund. While individual programs are unique in their focus, all of the programs managed by the CDMRP share the common goal of advancing paradigm shifting research, solutions that will lead to cures or improvements in patient care, or breakthrough technologies and resources for clinical benefit. The CDMRP strives to transform healthcare for service members and the American public through innovative and impactful research. The Department of Defense is the largest funder of medical and scientific research. In the current fiscal year, the CDMRP will provide $247.5 million in peer reviewed medical research covering 41 diseases and illnesses.

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From left to right, Senator John Mulroe, Andrew Lawson, Cheri Lawson testifying at the state

ADVOCACY IN ACTION: ANDREW LAWSON

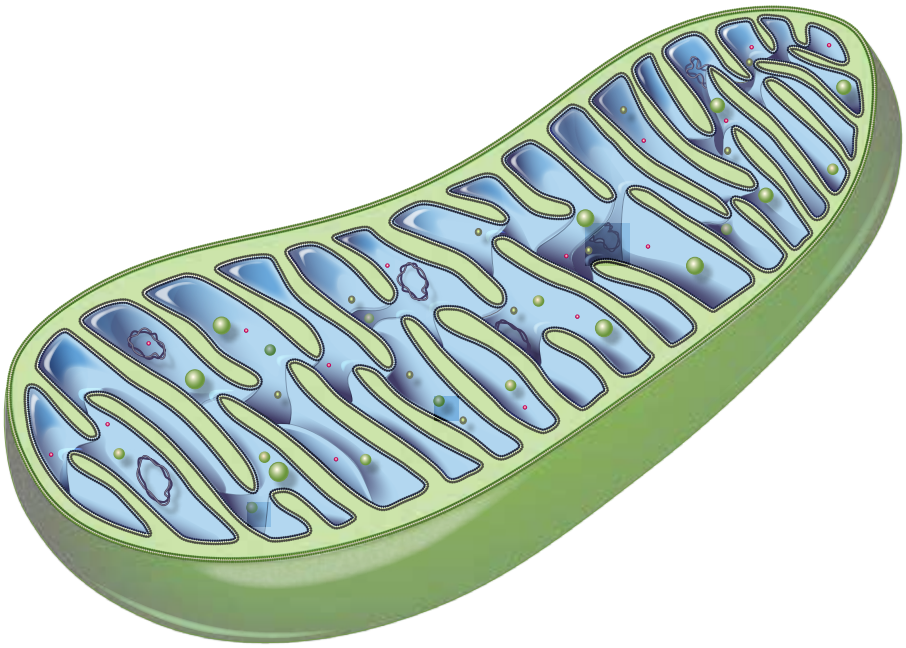
Advocacy continues to be the mission of Andrew Lawson, of Chicago Illinois. In addition to the numerous visits he made both to state and federal representatives, Andrew has managed to draw attention to the needs of the affected community in the state of Illinois. Over the last few years, Andrew has made numerous visits to the state capitol in Springfield. He's engaged his own state representatives in educating them about mitochondrial disease and how it impacts his life as well as having them issue proclamations for Awareness Week. Due to his advocacy efforts he was asked by Senator John Mulroe (D-IL-10) to speak to the Senate Matters Committee regarding getting the supplements covered under insurance for all persons affected with Mitochondrial Disease. Andrew was very happy Sen. Mulroe accepted his invitation and participated in the 2015 Energy for Life Walk in Chicago. Andrew also met on the federal level with Rep. Mike Quigley (D-5-IL). He educated the Congressman about mitochondrial disease and persuaded him to join the Congressional Mitochondrial Disease Caucus.

In February 2016, Andrew traveled to Springfield where he participated in Rare Disease Day. Because he made several trips, many elected officials remembered him and mitochondrial disease. The only way to get attention from our elected officials is to ask them to help and to ask them to participate. Andrew did a great job with both and continues to help everyone in Illinois with his advocacy effort.

UMDF Great Lakes Regional Coordinator Anne Simonsen, UMDF Board Chairman Patrick Kelley, Senator John Mulroe, Andrew Lawson, Cheri Lawson at Energy for Life Walk 2015 in Chicago.

Stealth BioTherapeutics

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



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

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UMDF Holiday Card Contest

A few weeks ago, we asked you to submit your favorite, original artwork design that visually answered the question “If I had more Energy, I would…..”.

This year, the artwork chosen by the judges is “If I had more Energy, I would skate on a pond”. The original artwork was created by 11 year old mito patient Kelly Beyea, of Eden, New York.

Kelly enjoys skating, but because of her fatigue and muscle pain, she can never skate as long as she would like. Kelly has had health issues since birth and was diagnosed with mitochondrial myopathy at age 3. Not long after that, she received a g-tube for nutritional support. She is the youngest of four sisters. Two of her older sisters are also affected by mitochondrial disease.

Kelly loves life and does not let her health challenges stop her from trying new things. She loves to hang out with her miniature horse, Buddy, to play military marches on her trumpet and to read mystery novels. Her grandmother is a painter, and she has been teaching Kelly how to paint. The subjects of her paintings are most often dolphins, sunsets and waterscapes, and her favorite color to use is cobalt blue. Above all, Kelly hopes that her artwork will inspire smiles and happiness for all who see it.

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Great Job Kelly! Her artwork will be placed on the 2016 UMDF Holiday Appeal Card that will arrive in your home shortly after Thanksgiving.

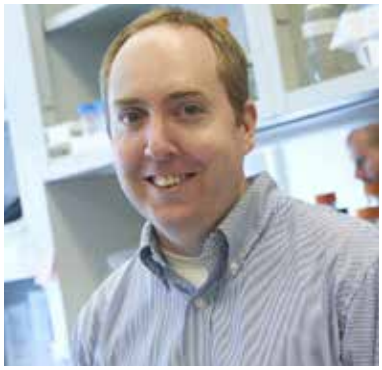
First Baby Born by MRT

Researchers say the first baby has been born through Mitochondrial Replacement Therapy (MRT). MRT allows parents to have a child after the mitochondrial DNA from a healthy woman is replaced in the egg of a woman who carries the gene for mitochondrial disease. The now 6-month old baby boy born after the procedure is healthy and doing fine. The child does not have Leigh Syndrome, the mitochondrial genetic disorder carried by his mother. The unidentified couple already lost two older children to Leigh Syndrome.

Scientists from a New York fertility center carried out the experimental procedure in Mexico because it is forbidden by the Food and Drug Administration in the United States.

The Kids are OK

More than a decade ago, Dr. Jacques Cohen performed an initial experimental procedure as infertility treatment. Cohen injected a donor's cytoplasm that contained mitochondria into the natural mother's egg. This may have been the first procedure to produce a baby technically from three parents. This procedure is different from the procedure known as MRT. Recently, the journal, BioMedicine Online, reported on the children born as a result of this procedure. The children, now between the ages of 13 and 18 are living relatively normal and healthy lives. The initial procedure developed by Cohen and his colleagues was used for a short period in two other fertility clinics in the US. However, after the FDA imposed stricter regulations, the procedure was stopped as Cohen wasn't able to obtain the necessary funding to continue while trying to obtain a permit from the FDA.



Gates Foundation Funds Mitochondria Research

Cole Haynes, Ph.D., an associate professor of molecular, cell and cancer biology, is the recipient of $900,000 in grants from the Howard Hughes Medical Institute (HHMI), the Simons Foundation and the Bill & Melinda Gates Foundation. He is one of 84 other scholars awarded an early-career scientists prize. The funding will enable Dr. Haynes to investigate how deletions in mitochondrial DNA accumulate over time and may lead to aging. He is currently investigating the sensors and tools used by cells to monitor mitochondria and, when defective, the strategies cells use to ensure cell survival and mitochondrial recovery. Dr. Haynes recently joined Memorial Sloan Kettering Cancer Center in New York City.

Study May Show Ways To Correct Mitochondrial Dysfunction

Researchers at Washington University School of Medicine and Albert Einstein College of Medicine, while investigating potential treatments for Charcot-Marie-Tooth disease (CTMD) and other mitochondrial diseases, may have found a way to correct mitochondrial dysfunction. In their study, the researchers prepared novel molecules able to correct mitochondrial dysfunction. They say testing on mouse models added new insight into the structure and function of the disabled protein responsible for the mitochondrial dysfunction. The researchers examined the mitochondrial protein mitofusin 2. They found that folding and fusion between two mitochondria is controlled by mitofusin 2, which allows both units to exchange genetic information that plays a role in healthy function of mitochondria. The researchers believe these small peptides that activate and deactivate mitofusin 2 protein are promising new routes to pursue future searches for novel therapeutic agents for mitochondrial diseases. The study, "Correcting mitochondrial fusion by manipulating mitofusin conformations" was published in Nature.

Pittsburgh is the home of UMDF. For the second time in as many years, UMDF has asked that the Iconic Gulf Tower blaze green during Awareness Week.

Awareness Week 2016

Thanks to everyone who participated in the Mitochondrial Disease Awareness Week, September 18-24, 2016. Patients, families, friends and co-workers planned and participated in a number of events designed to raise awareness for mitochondrial disease. This year, UMDF supplied more than 8,000 pieces of collateral for use in a variety of activities. While many awareness activities included education for the general public, the majority of activities focused on patient education of physicians this year.

Affected individuals worked hard in their communities to launch larger scale awareness activities. Many sent state and local proclamations designating the week as Mitochondrial Disease Awareness Week. Other managed to have landmarks in their communities turned green in honor of those battling mitochondrial disease. It's not too early to think about next year when Awareness Week will be held September 17 -23, 2017.

The State of Washington

Proclamation

Joy Krumdiack asked Washington State Governor Jay Inslee to issue this proclamation for Awareness Week in 2016. The Honorable Kelli Linville, Mayor of the City of Bellingham, issued a similar proclamation thanks to Joy!

The Manning Family of Galloway, OH helped students at Brown Elementary participate in a 'Green Out' day in honor of Myles Manning. His father, an employee of Columbus, Ohio based American Electric Power (AEP), asked for the Sky Band on the AEP Building to be lighted green. Myles lost his battle with mitochondrial disease this year.

Member Spotlight – Sally and Halina

There are so many moments in the past four years of working for the UMDF that have impacted me. In September at the Chicago Energy for Life walk, I witnessed a beautiful friendship that crosses oceans and generations between Sally Taylor and the Moreno family. I'm so happy they have agreed to share their stories with our entire mito-community.

- Anne M Simonsen, Great Lakes Regional Coordinator

CONNECTING FROM AFAR

by Sally Taylor

I consider myself part of the legacy families in the UMDF's Chicago Chapter. I currently live abroad in Scotland with my family, but I have been back to the states for my care multiple times in the past years. I have always enjoyed reconnecting with the Chicago families, many have visited me in the hospital or at my parent's home and we keep in contact through Facebook. But this past year, I struck up an online friendship with a newly diagnosed family in Chicago that has helped me feel I am continuing to give back, even after a massive regression.

Sally and her husband David

In 2013-2014, I had a shunt placed in my brain that failed multiple times. I went downhill quickly, lost my ability to walk and most of my speech. I was sleeping about 18-20 hours a day. I was put on a ventilator via face mask and I was told that most likely I would wake from my shunt surgery with both a feeding tube and tracheostomy in place. I was petrified of getting a trach, as the idea of breathing and speaking differently freaked me out, but knew in my head it was the right step in order to wake up again. I went into the surgery very weak and I spent six weeks in the ICU.

A year and a half into being trached, I was connected to a mom in the Chicago area with a baby who was doing quite poorly. Diane was living in the PICU with her daughter Halina. Halina had been trached a month before and we started emailing constantly. Diane was worried about caring for Halina. The hospital tries to teach you to handle every crisis that can happen, but that is not any reassurance for actually being on your own. In caring for myself at home, I had major issues with aspiration which led to infection. I developed my own techniques that worked for me, and tried to reassure Diane that she would be able to support and care for her daughter at home.

Sallay and Halina met for the first time at the EFL in Chicago this September.

Throughout our correspondence, I have grown very attached to Diane, Halina, and their whole family. When I found out it was going to be possible for me to attend the Chicago walk, I was so emotional about the thought of finally meeting them in person. Getting to hold Halina, my trach buddy, at the Chicago EFL Walk was amazing!

OUR STORY

by Diane Moreno

"Our medical journey has been a complicated, emotional and confusing experience. Yet along the way there have been tiny miracles that shine when there was nothing but gray clouds ahead of us. Sally Kukla Taylor was one of those miracles."

- Diane Moreno

My daughter, Halina, was diagnosed with Leigh Syndrome in August 2015 at the age of 13 months. Things were going "okay". Outside of some feeding issues, we didn't realize any real complications and naturally doubted the diagnosis all-together since we were still in the "denial" phase of this whole process. Things were going so well, we decided to take a family trip to Cancun, Mexico for 12 days over the week of Thanksgiving. Then our lives changed forever.

Five days into our trip, Halina ended up in the ICU of a small Mexican hospital and was then Aero Ambulanced to Miami for eight days. She was intubated and due to the extent of her illness, we were advised we needed to fly back home immediately, since we had a long road ahead of us.

On December 1, we arrived at Lurie Children's Hospital in Chicago. After a few trial extubations that failed, we were advised that in order to provide quality of life we would need to trach our daughter. We only knew one person previously with a trach, who was not a child. We were alone and confused on what it meant and the resources we would need to make it home.

My boss at the time who was familiar with Halina's situation had us on the prayer list at her church and knew a mutual friend of Sally's. Sally and I connected on Facebook, and I was so relieved to have a resource familiar with doctors in the Chicagoland area as well as having first-hand experience with mitochondrial disease and a trach.

From the point of introduction to current day, Sally has been invaluable to me as a resource and friend. Sally gave me the strength and courage to know that it's okay to leave the hospital. Life will be okay at home. Life will be different, but manageable at home. Coming home with a child on a trach is not the everyday normal and is very scary if you have no idea what to expect. Sally Facebook messaged me resources, real-life experiences of what to expect, and connected me with other moms of children with Leigh's. The list goes on and on.

Sally also helped me advocate for Halina in our weakest moments in the hospital when we were ready to go home, but had no nursing care lined up. Sally once again came to the rescue with information and resources, and we eventually got home. Sally was literally there every step of the way checking in with me daily to see how things are going, providing advice on rehab locations, and what to expect during the nights with the vent settings and alarms.

Diane, Halina and Sal Moreno

This year's Chicago Energy for Life walk was the day we finally got to meet Sally in person. Although I felt like I already knew her, it was such a great feeling to finally meet in person. Sally helped us get to the place we are today. Thank you UMDF and Thank you, Sally! We are eternally grateful for having met you and pray always that we find a cure!

Meet your UMDF Ambassadors

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

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

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

How long have you been an Ambassador with the UMDF?
I just recently became an Ambassador this year. When I was forced to give up work because of my Mitochondrial Disease I wanted to find a way to volunteer in a place that there was truly a need in my community.

How are you connected to mitochondrial disease and the UMDF?
I was diagnosed with MCAD in 1988. Up until a few years ago I had never heard of the Mitochondrial Disease classification. Truly, my family and I were living in a bubble and were unaware of the many other conditions that had been discovered as well as the resources available such as the UMDF.

Describe how you are active as a UMDF Ambassador.
Being new to this role, I am taking things slow and trying to learn as I grow. I know in speaking with families that there is a large population of families affected by Mitochondrial Disease in my area and my goal is to connect with them and let them know they are not alone. In addition to building connections, I would like to create activities for families to connect. I have also created a research fund through the UMDF and am working on various fundraising events for this as well.

As you know, mitochondrial diseases are very challenging. What advice would you give to a newly diagnosed family?
Mitochondrial disease is very much in its infancy. Many diseases were discovered HUNDREDS of years ago while many Mito diseases are only 20-30 years if not younger. The interesting, yet troubling, concept of Mito is that truly everyone is different. There is no 'textbook' case. As the patient ages, he/she will need to listen to their body. What is easy for one person may be next to impossible for another. I have learned the hard way to listen to my body. You should also know that you are not alone.

During your time as an ambassador, what has been the most rewarding?
I recently was connected, through a friend of a friend, to a family who has a daughter with the same diagnosis as me. I have spoken to many people online but never met someone in person. It was rewarding to meet someone else and make a face-to-face connection with them. I hope to have more of these.

Update: Jenevieve's Room

This past spring the UMDF featured an article on Jenevieve Woods. A young woman from the Pittsburgh area with mitochondrial disease. Jenevieve and her family were partnered up with the Forbes Road Career and Technology Center and its students to create a living space all her own. They had help from numerous charitable partners such as Lowe's Home Improvement, Lowe's Liberty Roofing Center, and the Massaro Construction group just to name a few. We caught up with Jenevieve's mom once the project was completed to get her thoughts.

"The Room is a physical place, but that's not all it was. Realizing mito has taken a lot away from her, the room gave her the ability to have a space that is safe. It is so much more than boards and nails. When you are the mom of disabled children you have to advocate the best that you can even if it's an unusual request. Getting this room gave her the confidence to pursue other ideas and dreams. The CTC and Principal Barr as well as all the faculty and agencies that helped were vital to this success. It could not have happened without them and we are so grateful."

Jenevieve loves her new space and she has even finished her own book, "Peach," which will be out later this year.

Matching Champions: Aiden's Red Wagon

2016 was the second year that the Koch Family participated in the Energy for Life Walkathon-Minnesota. Nick & Briana, who lost their son Aiden in 2015, volunteered in leadership roles for the walk, along with several other family members and friends.

In addition to an emphasis in walk involvement, the Koch Family also set a goal of maximizing donations to their team Aiden's Red Wagon. Nick gave a presentation to a group of approximately 25 co-workers at his employer, Ryan Companies. The employees were from across the country attending a training held in Minnesota. The presentation focused on his son Aiden, Aiden's battle with Mitochondrial Disease and the UMDF's mission.

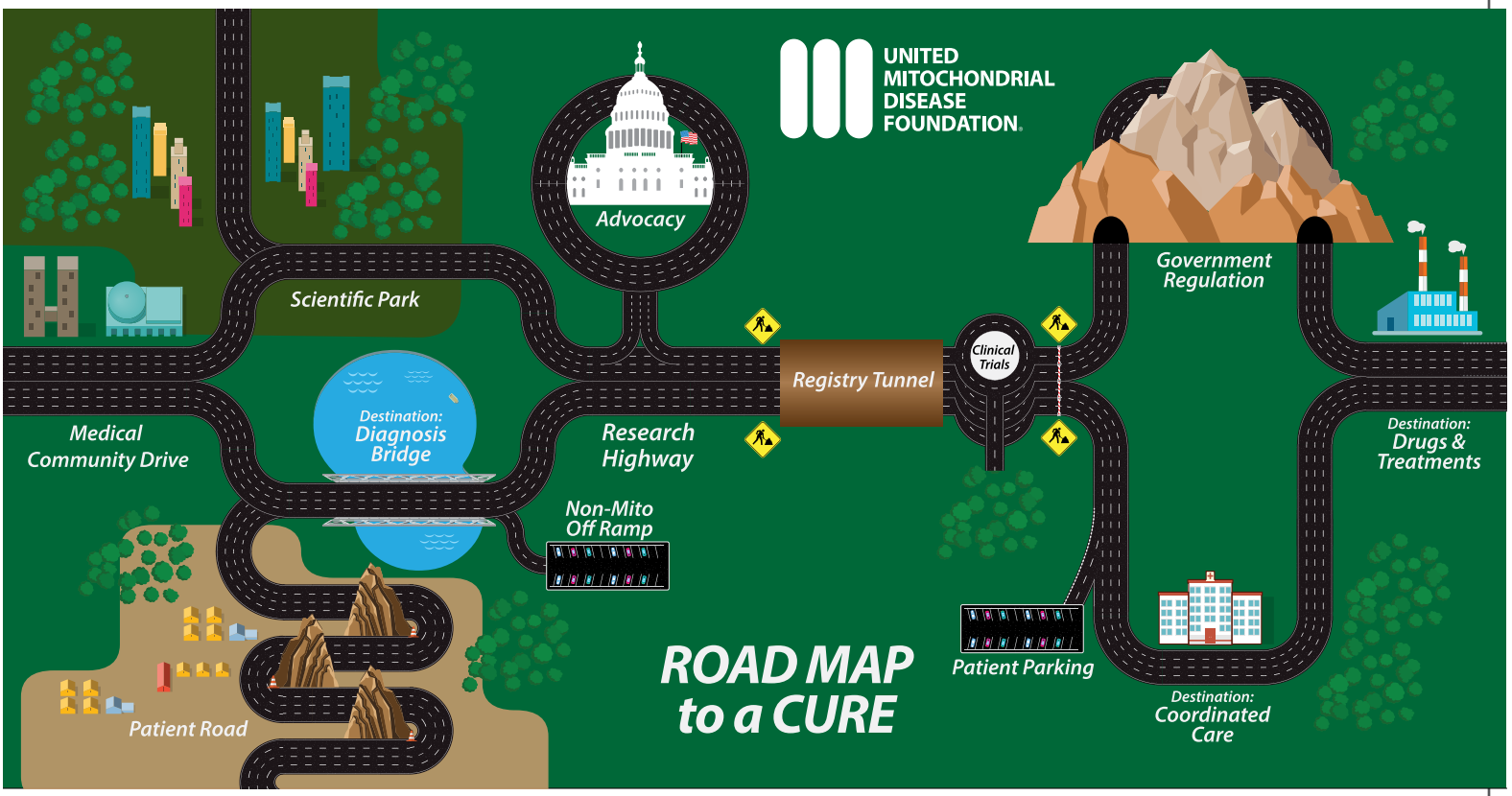
"Most of my Minneapolis co-workers knew about Aiden, but mitochondrial disease was not known to them or the employees from other regions. I made sure to share the linkage between mitochondrial dysfunction and other more well-known diseases, like Parkinson's and Alzheimer's, which was very interesting to many of them".

As a result of the presentation, the group of Ryan Company employees raised $5,240 for Aiden's Red Wagon. Ryan Company leadership supported their employees with a 100% match of contributions, bringing the company's overall walk donation total to $10,480! Aiden's Red Wagon was the top fundraising team for Minnesota!

Nick and Briana are so thankful for all of the support. "We could not be more proud of our family and our Ryan Family!"

BE A MATCHING CHAMPION! DOUBLE YOUR IMPACT WITH MATCHING FUNDS!

The UMDF makes it easy for our families and donors to access matching dollars from their employers. Simply visit www.doublethedonation.com/umdf to start the process. Requesting an employer matching gift is an easy process and can make a significant impact to your UMDF donations. We'd like introduce and share examples from two "Matching Champions" who have made a difference through coordinating, communicating and collaborating with their co-workers.



The Roadmap to a Cure

It's a phrase you will no doubt be hearing more of as we progress through the years. But it's more than a phrase or a clever graphic. The Roadmap to a Cure is a three pillar approach that will help UMDF and the mitochondrial disease community focus on faster diagnosis, therapeutic development and the coordination of care for our patient community.

DIAGNOSIS

We know that genetic testing provides a clear opportunity to achieve a specific diagnosis for patients. With genetic testing more widely available, less than half of current cases diagnosed were made through this important scientific advance. Many patients are diagnosed through muscle biopsies, swabs, brain imaging, and exercise physiology and lab measurements. While these too show promise, none of them have been standardized in providing a clear path to the diagnosis of patients. UMDF believes that it can bring together the resources that will create a better diagnostic plan for patients that would include genetic testing, bio samples and other important health related information.

THERAPIES

We know there are no licensed therapies for mitochondrial disease within the United States. Numerous trials by researchers have been conducted. Trials by members of the industrial community are rapidly increasing. What we believe is missing is well controlled studies within the field. The Roadmap to a Cure will bring everyone together. We want stakeholders who are members of academia, government and the drug development industry to address the important issues that are required to move all of us towards treatments and cures for mitochondrial disease efficiently and quickly.

PATIENT CARE

When you have mitochondrial disease, it is often difficult to find a physician who understands your condition, let alone make sure that you are treated by other physicians in other specialties. The many different types of mitochondrial disease and the many symptoms associated with each challenge even the most knowledgeable doctors. The result is clinical care that is often inconsistent. Additionally insurance reimbursement for rare disease care is an increasingly challenging situation.

UMDF will make the Roadmap to a Cure a priority as we move forward into 2017 and beyond as we continue to collaborate, coordinate and communicate the needs of the patient community into accurate diagnosis, real treatments and therapies, and coordinate and enhanced patient care.

Community Registry Updates

by Philip Yeske, PhD - UMDF Science & Alliance Officer

In the spring 2016 issue of UMDF Connect we provided a snapshot of demographic data contained in the Mitochondrial Disease Community Registry (MDCR) as well a high level description of our plans for continuing to grow MDCR. Over the last six months we have made tremendous progress on those plans.

The first major milestone achieved over the summer and into this fall was the creation of a multi-stakeholder Advisory Board for MDCR. Our aim was to form a small but representative group that would put in place the processes by which the registry would be utilized as well as clarify the near-term objectives of MDCR. I am pleased to have Dr. Amy Goldstein (University of Pittsburgh Medical Center), Dr. Michio Hirano (Columbia University Medical Center), Jodie Vento (Genetic Counselor, University of Pittsburgh Medical Center) and Jodi Wolff (Patient Advocate & Medical Science Liaison, Santhera Pharmaceuticals) join me on the initial Advisory Board. Additional perspectives will be gathered as we move forward, but this is the group charged with putting the foundation in place. Based on the work of this group over the last several months I am confident MDCR is in good hands.

The Advisory Board drafted and adopted version 1.0 of the MDCR Charter, which describes the over-arching goals of MDCR and lays out the processes for appropriate data collection and utilization. These guidelines will never supersede the privacy directives of any individual registrant, but instead establish how a researcher or clinician active in the mitochondrial disease space can request to either engage the registrants of MDCR via a survey or access (mine) the data already collected.

The charter also reinforces the need for regular communication of insights gleaned from patient-provided data back to the community. A data mining project is planned, the results of which will be shared early in the New Year here and via other communication channels. We are also planning a revamped landing webpage for MDCR that will be much more informative about the how's and why's of patient registries.

Besides the data mining project, there are several other exciting near-term projects in various stages of development. With an Advisory Board in place, MDCR is now prepared to accept research study requests and two are currently in the pipeline. As soon as approvals are in place we can share the details, but in general the pace of new survey activity inside MDCR should pick up quickly in 2017.

Beyond surveys we also want to utilize MDCR as a central resource for registrants to provide "informed consent" on the use of their data residing outside of MDCR. A first planned example of this would be genetic testing results, the goal being for MDCR registrants to consent to the upload and use (per customized privacy directives) of health and genomic data within the Mitochondrial Disease Sequence Data Consortium (MSeqDR)- a set of online tools for researchers trying to develop better diagnoses and novel therapeutics for mitochondrial disease. There is significant global interest in this capability that will assure that the patient's wishes are respected as to how their own data are used.

Finally, please consider registering for MDCR today from the UMDF website (*www.umdf.org/registry*) if you haven't already done so. If you have registered or perhaps did not complete the initial survey, now would be a good time to update your answers on completed questions and push forward with new ones. Remember- only do as much as you can at any one time. The system automatically saves in real time. Try it out today!

It All Adds Up

The Cederburg Family and Recurring Giving

Since 2012 when Scott Cederburg found UMDF as a charity option on PricewaterhouseCoopers employee giving, he and his family have given over $5,000 in monthly gifts. The Cederburgs want to make a difference. For their busy family, recurring giving allows them to do just that.

Scott and Melissa Cederburg have two daughters, twelve-year-old Addi and ten-year-old Lauren. Their oldest daughter, Addi, was diagnosed with mitochondrial disease when she was two years old. At that time, Melissa asked their doctor where they could find trusted information about Addi's new diagnosis. Their doctor recommended UMDF. Since then, UMDF has been the family's go-to resource. When friends have questions about Addi's diagnosis, the Cederburgs send them to umdf.org.

Melissa encourages others to check into employee giving with their Human Resources department and find out if monthly, recurring giving is an option. If you are considering giving on any level, you could break up that amount into smaller, more manageable monthly gifts. In that way, she said, you might even find that you could give more. Melissa also recommends using Amazon Smile, so that a percentage of Amazon purchases benefit UMDF. For their family, giving is one less thing for them to think about, because it is automatic.

They hope that one day their giving will result in a benefit for Addi, and if not, they know that it will one day do another family a lot of good. The Cederburgs want to fund mitochondrial research to find answers or ideas about next steps. Whether the research results in new information, new therapies or even, one day, cures, they believe new discoveries will help Addi and others.

We appreciate the Cederburgs and their long-time dedication to helping others and funding research through recurring gifts. They know and understand that smaller monthly gifts add up, and, over time, make a big impact that is certainly inspirational!

UMDF
education
Bringing the experts to your community

Symposium 2016: LHON Recap

Are you aware of Leber's Hereditary Optic Neuropathy (LHON)? LHON was the first mitochondrial mutation ever identified, by Doug Wallace in 1988. Unlike most mitochondrial disorders, which usually have multi-system involvement, people affected by LHON usually have just one symptom - sudden-onset legal blindness. It happens to about 100 people each year in the U.S. This sudden vision loss can occur at any age, in both males and females. While the most common situation is a male in his late teens/early twenties, about half are diagnosed younger or older, and many women are also affected.

Since 2013, the annual UMDF Symposium has included a special LHON program prior to the patient program. This year in Seattle, the LHON program took place on the Friday of the Patient Program so that attending LHON sessions was an option for all attending the full Symposium.

About 100 people attended the 2016 LHON Conference. Here's a recap of the content with links to each of the session videos. To see the complete list of video from the 2016 LHON Conference visit *www.umdf.org/types/lhon*

RESEARCH PROCESS

LHON provides unique opportunities for research and treatments. It's relatively easy to get a confirmed genetic diagnosis, as about 95% of those carrying a LHON mutation will get genetic confirmation of one of the three primary mutations (11778, 14484, 3460) with just a specialized blood test. Since each eye can be treated individually and both eyes almost always lose about the same amount of vision when someone becomes affected, therapies in drop form or gene therapy injections can be delivered to one eye and a placebo to the other, so each patient can be both the treated and the placebo control and all participants in those clinical trials have the possibility of benefitting from the treatment. Since there's generally a two month delay between onset of vision loss in one eye and onset in the second eye, there's even an opportunity to treat the second eye before it loses vision.

Until very recently, there were no clinical trials for therapeutic options for LHON in the U.S. Now is an exciting time in the LHON community, as currently there are several clinical trials underway. To provide the LHON community an understanding of the overall clinical trial process, Dr. Rustum Karanjia, The Ottawa Hospital, provided an overview.

LHON NEW TREATMENTS AND TRIALS

Dr. Alfredo Sadun, UCLA Doheny Eye Center, presented the treatment options that have been explored until now, including products that have also been studied in other mitochondrial disorders such as EPI-743. He described several exciting new research directions, including several gene therapy trials taking place at several locations in the US and Europe. In addition, he described a trial in LHON patients of elamipretide, the same investigational drug being studied in patients with genetically confirmed mitochondrial myopathy. Dr. Patrick Yu-Wai-Man, Newcastle University, and Dr. Valerio Carelli and Dr. Chiara LaMorgia, University of Bologna, then joined their colleagues on a panel to address the audience's questions about the science of LHON.

NAMDC; MRT ATTITUDES STUDY RESULTS

Kris Engelstadt, MS GCG, provided an overview of NAMDC, and explained why LHON patients should consider participating in the NAMDC registry and biorepository. She described the NAMDC study of Attitudes Regarding Prevention of mtDNA-Related Diseases Through Oocyte Mitochondrial Replacement Therapy, a study which included many LHON participants.

LHON EMOTIONAL ADJUSTMENT

Sudden-onset legal blindness has a very powerful emotional impact. The LHON Project at UMDF awarded a grant to the LHON team at UCLA Doheny to conduct research on the psychological impact of losing vision to LHON, and Dr. Rustum Karanjia presented the research findings. Jeremy Poincenot, who was affected by LHON at age 19 in 2008 and has become a professional Inspirational Speaker and World Blind Golf Champion, and Maria Johnson who was affected at age 49 in 2013 and is a fitness instructor and GirlGoneBlind blogger, described their LHON emotional journeys. Jeffrey Gerhardstein, a Social Worker at Seattle's Sight Connection organization, and his colleagues shared the techniques they recommend to clients for managing the challenging emotions in the transition from a fully-sighted to a legally-blind life.

LHON ADULTS PANEL

One of the most valuable aspects of the annual LHON Conference involves the sharing of stories about living with LHON legal blindness. This panel included four people who shared their experiences with work, dating, parenting, guide dogs and much more.

LHON GENEALOGY PROJECT

LHON patients often wish to know if any of their maternal ancestors had vision loss, and would like to inform living maternal relatives about LHON. However, they lack the knowledge of how to conduct a genealogical search, as well as how to communicate this sensitive genetic information. The LHON Genealogy Project was created and undertaken thanks to the generous support of Global Genes. A professional Genetic Genealogist worked with three LHON families to build their mitochondrial tree, first going back in time, then forward to identify and locate their living maternal relatives. Each family received a consultation with the genealogist and a LHON patient advocate, and was offered a consultation with an LHON-trained genetic counselor. In this session, the genetic genealogist explained some genealogy skills, provided tips on how to find living relatives, and shared ideas for reaching out to unknown cousins.

LHON TEEN/YOUNG ADULTS PANEL

The challenges faced by teens affected by LHON can be very different from those of adults. Coping with the educational process, dealing with the reactions of friends and fellow students, and maintaining participation in sports, band and other activities are just a few of those challenges. Three teens affected by LHON shared their experiences. One young adult spoke of the impact of his mom's vision loss, both in terms of adapting to being the son of a legally-blind mom, and suddenly learning that he also is at risk of LHON vision loss.

ASSISTIVE TECHNOLOGY OVERVIEW

Before people affected by LHON lose vision, they usually have no experience with the many assistive technology tools available that can help those who are legally blind. Laura Rodriguez of Seattle's Sight Connection provided an overview of the range of equipment available. She and colleague Joyce Shoemaker brought some of the more popular items, and had them on display for all in attendance to try out.

GLOBAL LHON COMMUNITY

Opportunities for connection among those whose lives have been impacted by LHON continue to expand. In addition to the annual LHON Conference, there are several active LHON Facebook groups, a monthly Conference Call, a LHON Report podcast, and networking events. Fundraising efforts support research and raise awareness of LHON. A subset of those carrying an LHON mutation have symptoms more typical of other mitochondrial disorders such as tremors, muscle weakness and pain, and those with these "LHON Plus" or "LHON-MS" symptoms are also developing connections. Anyone interested in connecting with the LHON community and/or supporting its development is encouraged to contact Lissa Poincenot at *LHONpoince@aol.com.*

Planned Giving

by Beth Whitehouse, UMDF Director of Development

Our last few issues of the newsletter provided some informative articles on the importance of planning for your future through the creation of a will, an introduction to estate planning, the launching of our Legacy of Hope, Energy and Life Society in conjunction with our 20th anniversary, and different avenues to make a Planned Gift. In this issue, we've asked our contributing partner, Ryan Duchak, Senior VP of Financial Planning from The Monteverde Group to provide us with some guidance on the required minimum deduction for someone over 70 ½ and donating the proceeds to avoid the taxation. If you are someone you know is at this stage in life and interested in establishing a planned gift, please be sure to contact us.

CHARITABLE CONTRIBUTIONS FROM IRAs

The Pension Protection Act of 2006 first allowed taxpayers age 70½ and older to make tax-free charitable donations directly from their IRAs. By making a qualified charitable distribution (QCD) from an IRA directly to a qualified charitable organization, older IRA owners were allowed to exclude up to $100,000 annually from gross income. These gifts, also known as "charitable IRA rollovers," would otherwise be taxable IRA distributions. The law was originally scheduled to expire in 2007, but was extended periodically through 2014 by subsequent legislation and finally made permanent by the Protecting Americans from Tax Hikes (PATH) Act of 2015.

HOW QCDS WORK

You must be 70½ or older in order to be eligible to make QCDs. You simply instruct your IRA trustee to make a distribution directly from your IRA (other than SEP and SIMPLE IRAs) to a qualified charity. The distribution must be one that would otherwise be taxable to you. You can exclude up to $100,000 of QCDs from your gross income each year. And if you file a joint return, your spouse (if 70½ or older) can exclude an additional $100,000 of QCDs. Note: You don't get to deduct QCDs as a charitable contribution on your federal income tax return--that would be double-dipping.

QCDs count toward satisfying any required minimum distributions (RMDs) that you would otherwise have to receive from your IRA, just as if you had received an actual distribution from the plan. However, distributions that you actually receive from your IRA (including RMDs) and subsequently transfer to a charity cannot qualify as QCDs.

Assume that your RMD for 2016, which you're required to take no later than December 31, 2016, is $25,000. You receive a $5,000 cash distribution from your IRA in February 2016, which you then contribute to Charity A. In June 2016, you also make a $15,000 QCD to Charity A. You must include the $5,000 cash distribution in your 2016 gross income (but you may be entitled to a charitable deduction if you itemize your deductions). You exclude the $15,000 of QCDs from your 2016 gross income. Your $5,000 cash distribution plus your $15,000 QCD satisfy $20,000 of your $25,000 RMD for 2016. You'll need to withdraw another $5,000 no later than December 31, 2016, to avoid a penalty.

Assume you turned 70½ in 2015. You must take your first RMD (for 2015) no later than April 1, 2016. You must take your second RMD (for 2016) no later than December 31, 2016. Assume each RMD is $25,000. You don't take any cash distributions from your IRA in 2015 or 2016. On March 31, 2016, you make a $25,000 QCD to Charity B. Because the QCD is made prior to April 1, it satisfies your $25,000 RMD for 2015. On December 31, 2016, you make a $75,000 QCD to Charity C. Because the QCD is made by December 31, it satisfies your $25,000 RMD for 2016. You can exclude the $100,000 of QCDs from your 2016 gross income.

As indicated earlier, a QCD must be an otherwise taxable distribution from your IRA. If you've made nondeductible contributions, then normally each distribution carries with it a pro-rata amount of taxable and nontaxable dollars. However, a special rule applies to QCDs--the pro-rata rule is ignored and your taxable dollars are treated as distributed first.

Assume you have a single traditional IRA with a current value of $100,000, which includes $10,000 of nondeductible

contributions. Therefore, you have a taxable balance of $90,000 and a nontaxable balance of $10,000. If you were to make a $5,000 withdrawal from your IRA, nine-tenths ($10,000/100,000) of your distribution, or $4,500, would be taxable and one-tenth ($10,000/100,000), or $500, would be nontaxable. However, if you make a $5,000 QCD, the entire $5,000 amount will be considered to come from your $90,000 taxable balance.

If you have multiple IRAs, they are aggregated when calculating the taxable and nontaxable portion of a distribution from any one IRA.

Assume you have two traditional IRAs. IRA One has a value of $50,000 and does not include any nondeductible contributions. IRA Two also has a $50,000 value but includes $10,000 of nondeductible contributions. For tax purposes you are treated as owning a single traditional IRA with a value of $100,000 and a nontaxable balance of $10,000. If you were to make a withdrawal of $50,000 from IRA Two, nine-tenths ($10,000/100,000) of your distribution, or $45,000, would be taxable and one-tenth ($10,000/100,000), or $5,000, would be nontaxable. However, if you make a $5,000 QCD from IRA Two, the entire $50,000 amount will be considered to come from your $90,000 taxable balance.

RMDs are calculated separately for each traditional IRA you own, but may be taken from any of your IRAs.

Your QCD cannot be made to a private foundation, donor-advised fund, or supporting organization (as described in IRC Section 509(a)(3)). Further, the gift cannot be made in exchange for a charitable gift annuity or to a charitable remainder trust.

WHY ARE QCDS IMPORTANT?

Without this special rule, taking a distribution from your IRA and donating the proceeds to a charity would be a bit more cumbersome and possibly more expensive. You would request a distribution from the IRA and then make the contribution to the charity yourself. You'd include the distribution in gross income and then take a corresponding income tax deduction for the charitable contribution. But due to IRS limits, the additional tax from the distribution may be more than the charitable deduction.

QCDs avoid all this by providing an exclusion from income for the amount paid directly from your IRA to the charity--you don't report the IRA distribution in your gross income, and you don't take a deduction for the QCD. The exclusion from gross income for QCDs also provides a tax-effective way for taxpayers who don't itemize deductions to make charitable contributions.

CAN I NAME A CHARITY AS BENEFICIARY OF MY IRA?

Yes, you can name a charity as beneficiary of your IRA, but be sure to understand the advantages and disadvantages. Generally, a spouse, child, or other individual you designate as beneficiary of a traditional IRA must pay federal income tax on any distribution received from the IRA after your death. By contrast, if you name a charity as beneficiary, the charity will not have to pay any income tax on distributions from the IRA after your death (provided that the charity qualifies as a tax-exempt charitable organization under federal law), a significant tax advantage.

After your death, distributions of your assets to a charity generally qualify for an estate tax charitable deduction. In other words, if a charity is your sole IRA beneficiary, the full value of your IRA will be deducted from your taxable estate for purposes of determining the federal estate tax (if any) that may be due. This can also be a significant advantage if you expect the value of your taxable estate to be at or above the federal estate tax exclusion amount ($5,450,000 for 2016).

Of course, there are also nontax implications. If you name a charity as sole beneficiary of your IRA, your family members and other loved ones will obviously not receive any benefit from those IRA assets when you die. If you would like to leave some of your assets to your loved ones and some assets to charity, consider leaving your taxable retirement funds to charity and other assets to your loved ones. This may offer the most tax-efficient solution, because the charity will not have to pay any tax on the retirement funds.

If retirement funds are a major portion of your assets, another option to consider is a charitable remainder trust (CRT). A CRT can be structured to receive the funds free of income tax at your death and then pay a (taxable) lifetime income to individuals of your choice. When those individuals die, the remaining trust assets pass to the charity. Finally, another option is to name the charity and one or more individuals as co-beneficiaries. (Note: There are fees and expenses associated with the creation of trusts.)

The legal and tax issues discussed here can be complex. Be sure to consult an estate planning attorney for further guidance.

The Pension Protection Act of 2006 first allowed taxpayers age 70½ and older to make tax-free charitable donations directly from their IRAs. The law was originally scheduled to expire in 2007, but was extended periodically through 2014 by subsequent legislation and finally made permanent by the Protecting Americans from Tax Hikes (PATH) Act of 2015.

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Family Research Funds

UMDF Family Research Funds are established by families as a way to honor or memorialize a loved one affected by mitochondrial disease. Donations to these funds ensures that the world's top mitochondrial scientists are receiving the support they need to perform breakthrough research.

Check out our ACTIVE list of family research funds below. Have a Research Fund but don't see yours listed? We may need an updated agreement from you, please be sure to contact Beth Whitehouse for details.

Rachael Albertson
T.J. Amber
Rylee and Xavier Andersen
Logan Sloane Aronson/Sydney Breslow
Carter Buffum
Kyndel Craig
Samuel Cutliff
Emma Frances Dalton
Jack Edwards
John Garrett Evans
Chloe Fields
Luca Florio
John Geraci
Olivia Paige Goldberg
Unstoppable Nina Hall
Bennett Hanneman
Brandon David Harris
Olivia Hesse
Ayden & Faith Hingsbergen
Kaden Jarret Huddleston
Lincoln Huff
Team Hunt - Hunt Hollis
Caleb Jacobs
Dawnta & Levi J. Kendall
Melissa Kieffer
Rachel Kindbom
Carter Lackey
Brandon Leach
Hayley Leib
Michael Angelo LoPresti
Isabella Magee
Jude Manley
Brionna Myers
Lindsey Norris
Andrew Radney
Jonah Ritterbush
Alexander Schumacher
Ty Seldes
Breylon Senn
Jaxon Sharma
Kaidon Stamper
Brady Sterchi
Corynna Strawser
Nicholas James Torpey
Cooper and Isla Watson
Brittany Wilkinson
Leslie Whitt-Williams
Will Woleben

We are happy to work with you to establish a research fund in honor/memory of your loved one. Here's how it works:

1. UMDF will draft a Memorandum of Understanding stating that a Family Research Fund will be established in the name of your loved one
2. UMDF will create and provide you with a brochure, personalized with your loved one's photo and biography. The brochure will also contain information about mitochondrial disease and UMDF, as well as a link to the Research Fund page on the UMDF website
3. Your Family Research Fund will be included on the Research Fund page, enabling supporters to learn more about your loved one, view photos and make an online credit card donation
4. UMDF will provide acknowledgements and tax receipts for all donors to your Family Research Fund
5. Our Development Team will work with you on ways to fundraise – you're encouraged to fundraise by hosting a special event and/or on-line with Activate Your Mitochondria

Once a Family Research Fund is established, UMDF will provide you with progress reports on a quarterly basis. We will also recommend a UMDF, SMAB peer-approved and board approved research project for funding that aligns with your particular Family Research Fund. Once a Family Research Fund reaches $10,000, it can be designated for disbursement to our grant funding cycle.

To learn more about how you can establish a Family Research Fund to honor or memorialize your loved one, please call Beth Whitehouse at (888) 317-8633.

Donor Spotlight

July 1 - September 30, 2016

The United Mitochondrial Disease Foundation thanks our many individuals, organizations, foundations and companies who so generously support our mission. We've updated our Donor Honor Roll Giving Society to now include cumulative giving throughout our fiscal year versus what was previously reported on a quarterly basis in our newsletters and have also included the number of years of support to UMDF next to each donor's name. We strive for accuracy and completeness. Please send any questions or suggestions to info@umdf.org

Life Investors
$25,000 - $49,999

Mr. and Mrs. Richard Forman (2)

Energy Investors
$10,000 - $24,999

Charlotte Pipe & Foundry Company (5)

Gensight Biologics*

The George W. Bauer Family Foundation (1)

Mr. David Heikkinen and Dr. Ann Heikkinen (2)

Kelley Management Consulting (7)

RA Kirby Foundation (1)

Reata Pharmaceuticals, Inc. (1)

Stealth BioTherapeutics (3)

William S. Kallaos Family Foundation (2)

Hope Investors
$5,000 - $9,999

Mr. John Duffey*

JDM Fund (7)

NIEHS (3)

Raptor Pharmaceuticals (3)

Mr. and Mrs. Marc Shirley (7)

Dr. Annette St. Pierre-MacKoul MD (2)

Mr. and Mrs. Brent Staples (6)

Friends
$1,000 - $4,999

Akron Childrens Hospital (4)
Arena Sports, Inc. (1)
Auction Masters (1)
Mr. and Mrs. Tim Babiarz (2)
Mr. Anthony Baldi (5)
Anthony Baldi & Associates (3)
Ball Corporation (6)
The Bell Family*
Bill & Melinda Gates Foundation*
Mr. Fred Berlinsky*
Mr. Gerald Biller*
Mr. and Mrs. Richard Biller (6)
Bradley Arant Boult Cummings (2)
Mr. and Mrs. George Breslow (12)
Mr. and Mrs. Lyle Caddell*
CBRE Charlottesville*
Mr. and Mrs. Ronald Christenson (5)
Dr. and Mrs. Bruce Cohen MD (16)
Commercial Furniture Transport, Inc.*
Mr. and Mrs. Scott Connell (11)
Corporate Office Properties Trust (8)
Mr. and Mrs. David Dobke (7)
Mr. James Dooley (2)
Dooley Gasket and Seal, Inc.*
Mr. and Mrs. Justin Ebert (2)
Electrical Associates (3)
Mr. and Mrs. Chris Florio*
Ms. Angelina Foglia (2)
Nathalie Garner*
Mr. and Mrs. Elliott Goldberg*
GraceWorks Unlimited (1)
Mr. and Mrs. David Gray (13)
Mr. Brian Greene*
Mr. Louis Hazel (9)
Mr. and Ms. Thomas Hefferon (18)
Henrico Fraternal Order of Police - Lodge #4*
The Hessler Family (1)
Mr. and Ms. Tom Hodge (4)
Horwitz*
The Hunt Michael Hollis Fund (4)
Illinois Tool Works Foundation (10)
Mr. and Mrs. Darren Jackson*
Mr. and Mrs. Glenn Jorden (2)
Kendra Scott Design (1)
Mr. and Mrs. Nicholas Koch (1)
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Lalilab, Inc. (6)
Mr. John Lore (1)
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Mechanical, Inc. (7)
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Scharff Charitable Foundation (2)
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Mr. and Mrs. Eric Sklut (2)
Mr. David Smith (2)
Star Fuel Centers, Inc. (12)
Mr. and Mrs. Peter Stathakis (3)
Mr. Robert Stevick (9)
Mr. and Mrs. Douglas Szopo*
TD Bank (4)
United Incentives Incorporated*
Mrs. Janeen Waddell*

( ) Number denotes years of support to UMDF *(*) indicates new donor* To become a UMDF donor, please visit us online at *www.umdf.org/donate*

Corporate Partnership Spotlight

Reata Pharmaceuticals, Inc. is a clinical-stage biopharmaceutical company that develops novel therapeutics for patients with serious or life-threatening diseases by targeting molecular pathways involved in how cells produce energy and regulate inflammation. Reata's two most advanced clinical candidates (bardoxolone methyl and omaveloxolone) target important transcription factors, called Nrf2 and NF-κB, to restore mitochondrial function, reduce oxidative stress, and resolve inflammation.

Beyond their lead product candidates, Reata has several promising preclinical development programs employing both antioxidant inflammation modulators (AIMs) and other small molecules with different mechanisms of action. Reata believes that their product candidates and preclinical programs have the potential to improve clinical outcomes in numerous underserved patient populations.

Reata has initiated Phase 2 studies in two rare disorders related to mitochondrial dysfunction and muscle weakness, Friedreich's ataxia (MOXIe) and mitochondrial myopathies (MOTOR), which generally have very limited therapeutic options. If beneficial bioenergetic effects are demonstrated in Reata's ongoing trials, this could indicate that the AIMs may offer benefit in other neurological and neuromuscular disorders involving mitochondrial dysfunction and impaired bioenergetics.

Beyond Reata's platform technologies and in-licensed compounds, they are constantly working on novel science and have active internal discovery and preclinical programs in a number of significant diseases. In addition to internal discovery, Reata continues to seek additional opportunities to in-license and collaboratively develop novel technologies from premier academic institutions. This operating model of combined internal discovery, in-licensing, and collaborative development guided the founding of Reata, and they continue this strategy today in order to keep their pipeline strong.

HOW DID WE MEET?

In early 2015, Kara Eichelkraut at Reata Pharmaceuticals contacted UMDF expressing interest in sponsoring the Energy for Life walkathon in Dallas, TX and supporting the 2015 International Symposium.

WHAT DO THEY DO FOR UMDF?

Perhaps we should ask the question, what don't they do for UMDF?! Reata Pharmaceuticals, like so many of our other wonderful sponsors, is one of our newest and most generous corporate partners focused on the best interests of our patients and families. Reata directs their sponsorship opportunities on those events and areas that focus on our families and individuals. They have supported Energy for Life Walkathons in Akron, Central TX, Chicago, Dallas, Delaware Valley, Houston and New England; our Regional Symposia; National Symposia; LHON Program; Grand Rounds; Day on the Hill and so much more. In fact, they even showed their support during Mitochondrial Awareness Week by sporting our mitochondrial socks.

REATA SAYS....

"The United Mitochondrial Disease Foundation has been a collaborative and helpful organization to partner with as we conduct our MOTOR trial in patients with mitochondrial disease. We appreciate all of their support and are proud to continue our partnership with them."

Colin Meyer, MD – Chief Medical Officer, Reata Pharmaceuticals

UMDF STAFF SAYS...

Jennifer Davis, Kara Eichelkraut and Ed Doherty, have been fantastic to work with. They understand the urgency to finding effective treatments for individuals with mitochondrial disease and are committed to making that happen while keeping the patient at the center of the process. They are professional, easy to approach and have a great sense of humor. Our staff looks forward to seeing the Reata team at our events.

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, complete our contact form at *http://secure.umdf.org/RegionalContact* or call us toll-free at 1-888-317-8633.

WHAT UMDF REGION DO YOU LIVE IN?

Northeast Region
Nicole McCaslin
Nicole@umdf.org
www.umdf.org/regions/northeast

Southeast Region
Margaret Moore
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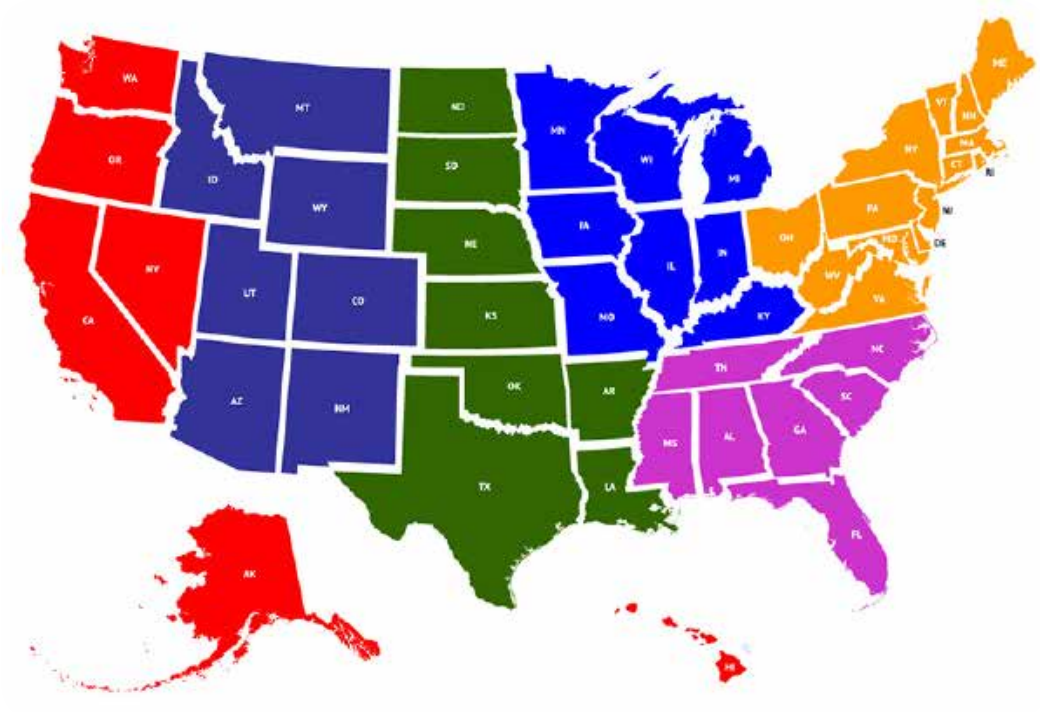
www.umdf.org/regions/southeast

Great Lakes Region
Anne Simonsen
anne.simonsen@umdf.org
Stephanie Perron
stephanie.perron@umdf.org
www.umdf.org/regions/greatlakes

Great Lakes Region 5
Jessica Rios
jessica.rios@umdf.org
www.umdf.org/regions/central



United Mitochondrial Disease Foundation Staff

Executive Staff

Charles A. Mohan Jr.
CEO/Executive Director

Janet Owens
Executive Administrative Asst.

Philip Yeske, PhD
Science and Alliance Officer

UMDF Symposia

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Chief Financial Officer

Donna Nameth
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Jeff Gamza
Multimedia Coordinator

Development & Member Services

Beth Whitehouse
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Margaret Moore
Regional Coordinator - Southeast

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Regional Coordinator - Great Lakes

Stephanie Perron
Regional Associate - Great Lakes

Jessica Rios
Regional Coordinator - Central

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.

Test Your Mito IQ

Test your mito IQ! Good Luck! Answers kindly provided by Amy Goldstein, MD. Dr. Goldstein is based at Children's Hospital in Pittsburgh and an AACT Medical Advisor.

Q In general, should all adults and children diagnosed with mitochondrial disease take CoEnzyme Q10 supplements? And, if so, which types and forms are the best and most effective (i.e. Ubiquinol; capsules; liquids; etc.)?

Dr. Goldstein: In general, we believe that every mito patient deserves a trial of coenzymeQ10, as we discussed in our Consensus on Treatment paper (Genetics in Medicine, Dec 2014). There have been debates about whether getting and following a level helps, and we think that a level in white blood cells is better than a level in serum. We also believe that ubiquinol is more bioavailable (i.e. better able to enter the cell and mitochondria) than ubiquinone. There are some rare forms of mitochondrial disease that are due to coQ10 synthesis defects and these are especially responsive to coQ10.

Q What are the connections between aging, age related diseases/illnesses, and mitochondrial disease?

Dr. Goldstein: Aging causes changes in our mtDNA, mitophagy (destruction of the mitochondria) and autophagy (programmed cell death, as didacted by the mito). Some would say that aging is a mito disease! For most of the progressive neurodegenerative diseases (Huntington, Alzheimer, Parkinson, etc.) the mito have a primary or secondary (sometimes referred to as mito dysfunction) role in the pathology of these disorders."

Q What is Oxidative Stress? Does it help or harm the body? Is it possible to prevent, if so how?

Dr. Goldstein: Oxidative stress is the result of metabolism: the mito are taking our oxygen and other chemicals derived from the food we eat, and putting them through a "factory" or "assembly line" of making energy (ATP) through the electron transport or respiratory chain. Think of oxidative stress (also called oxygen free radicals) as the black smoke pouring out of a factory; it causes damage to cell membranes and leads to cell death. We believe the role of taking antioxidants is to help contain the amount of oxidative stress and reduce the damage.

Q Please explain primary vs. secondary mitochondrial dysfunction.

Dr. Goldstein: Primary mitochondrial disease is caused by a mutation/s in a gene that codes for a protein directly involved in the mitochondria, which then

causes the mito to not function properly, leading to disease. Secondary mito dysfunction is due to another primary genetic problem (or environmental, etc.) where the mito are affected. We see good example of this not only in the diseases discussed in #2, but also in Down syndrome, Rett/Angelman, Dravet disease, etc. The muscle/skin biopsy which indicates a complex deficiency (a unit of the electron transport/respiratory chain) could be primary (i.e. the gene encoding for that subunit is mutated causing the deficiency) or secondary (some of the disorders listed above cause a secondary deficiency).

Q Which types of prescription drugs and over-the counter products can harm or damage the mitochondria?*

Dr. Goldstein: There are many medications/drugs that we think could interfere with mito function. After all, they are derived from bacteria, so medications like antibiotics and others could be damaging. By far, the medication most concerning for children/ adults with epilepsy or delay and POLG mutations is valproic acid or Depakote, which can cause fulminant hepatic failure, affecting the liver. Otherwise, the list of potentially harmful medications is long and every medication should have a thoughtful risk: benefit ratio and individually discussed with your physician.

* For more information, we would refer you to the UMDF website and Mito 101. Please see the topic *"A Modern Approach to treatment of Mitochondrial Disease."*

Q What are the biggest challenges with treating mitochondrial disease patients? Is there any differences between treating mito adults and children?

Dr. Goldstein's answer:
The biggest challenges are:
1) Obtaining a definite/molecular diagnosis
2) Deciding which components of the mito cocktail are most beneficial
3) Referring to other specialists needed for multisystemic disease, who may or may not be familiar with mito; especially within Adult Medicine
4) Offering clinical trials, which should grow and grow in the future!

AACT WEBINAR RECORDED

Earlier this fall, AACT conducted a webinar entitled "New Treatment and Research Updates". The webinar was presented by Marni Falk, MD., of the Children's Hospital of Philadelphia. Dr. Falk presented the latest information from Mitochondrial Medicine 2016: Seattle. If you would like to see the webinar, simply visit ww.umdf.org/aact and click on the link from the page. We are always looking for webinar topics. If you have any thoughts or suggestions, email us at news@umdf.org and type "AACT Webinar Suggestion" in the subject line.

Ask the Mito Doc℠

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℠ at www.umdf.org. Please note that information contained in Ask the Mito Doc℠ 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 6 year old son has been diagnosed with respiratory chain enzyme complex IV deficiency. We are in Dublin, Ireland and we are going to attend a neurologist soon. Is this particularly rare and if so should I push to be seen abroad (US/UK) where bigger numbers are treated. I am a cancer nurse and can find very little info on this particular deficiency. Thank you.

A: I am sorry to hear about your son. It is somewhat difficult to answer your question just based on complex IV deficiency. As an isolated electron transport chain complex, complex IV is not the most common defect we see. However, if the genetic etiology of the complex IV defect is known, then it might be very helpful. For instance, if the deficiency is due to mutations in the SURF1 gene (this gene helps the assembly of complex IV), then this is one of the most common nuclear mutations causing Leigh syndrome. However, there are multiple other genes, both genes from the nucleus and mitochondrial DNA that can alter complex IV activity and give rise to disease. As a group, complex IV disorders are very heterogeneous in their clinical presentation and possible course. Knowing the possible genetic etiology of your son's complex IV might be helpful in knowing the next best steps. There are large mitochondrial centers in the UK, Newcastle and Cambridge come to mind. These larger Institutions may know of possible clinical trials that might benefit your son in your region, so I would keep a look out for possible treatment trials. In the US there is an internet site, https://clinicaltrials.gov that list the current trials in the US. Although many genes that are involved in complex IV are known, there are likely genes that remain unknown. I do hope for the best for your son..

Russell Saneto, DO, PhD

Russell Saneto, DO, PhD

Q: My 33 year old daughter abruptly lost most of her vision simultaneously in both eyes 5 years ago. MS was ruled out, NMO was feasible, and then she was found to have the LHON 11778 mutation, heteroplasmy. However, her neurologist suggested NMO was the root cause because of small spinal lesions and neuro-symptoms though blood NMO antibody was negative. Three years ago she suddenly started having severe headaches and a year ago abruptly presented with episodic muscle knots and severe pain, urinary retention, muscle weakness, exercise intolerance, unexplained weight loss, tachycardia, neuropathy, and worsening vision. MS and NMO have been discarded and MRIs actually show fewer lesions. LHON plus is thought to be the cause. Pain level and incapacity can be severe, especially during 'episodes'. Tizanidine and Lyrica help some but she needs better management. Is it worth testing for other mito disorders? What should she be tested for in order to determine an appropriate mito cocktail? She's taking idebenone and Ubiquinol but hasn't seen a marked improvement. She's seen two mito docs but this is so rare both have not seen a case and are uncertain.

A: The core neurological features are extremely likely to be due to the LHON mutation. MS-like features are more common in women likely because women have a higher propensity for auto-immunity. In fact, we have seen several people with true proven mitochondrial mutations (such as this case) with positive NMO antibodies and oligoclonal bands; consequently, it is likely that the mitochondrial disorder predisposes to auto-immunity (We know that mitochondrial damage can activate the inflammasome). I would not be looking for other genetic disorders for the LHON is the likely culprit and explains most of this. Pain medications are many and need to be carefully managed by a neurologist with expertise in pain or another pain specialist.
Mitochondrial medications for LHON are coeqnyme Q10 + alpha lipoic acid + vitamin E + creatine monohydrate - we also add VITALUX for LHON patients. (See sheets).
I would also consider acute MS/LHON if there are sudden acute flare ups of the neurological deficits (not pain but urinary retention, stroke-like episodes, etc.) and imaging abnormalities that change..

Mark Tarnopolsky

Mark Tarnopolsky, MD, PhD, FRCP(C)

Q: My niece (sister's daughter) was diagnosed by muscle biopsy with Mitochondrial Disease, she was 18 months at diagnosis and over a year behind developmentally. Since then she has improved remarkably and caught up to all milestones for her age. Other than being quite petite and less athletic than her sister, she has no symptoms. Her neurologist believes it is a mild to moderate case and my sister has decided not to pursue any more genetic testing which would reveal what specific type of Mito she has. I am 39 and after repeated miscarriages am pursuing IVF in the hopes of starting a family. My doctor feels strongly I should be tested for Mito before IVF. I went to see a genetic counselor, but they had little to offer since I do not know what type my niece has. I scheduled an appointment at Stanford some time ago to investigate Mito, but unfortunately the wait is quite long and my appointment is not until the end of the year. I do not want to hold up IVF any longer due to my advancing age (it took 4 months just to get the IVF process started), but I am at a loss for what to do next. My questions are 1) What are the chances that I am a carrier? 2) What type of testing would you recommend I do, and can my fertility doctor order these labs? 3) If I do turn out to be a carrier, what are my options during IVF to minimize risk?

A: Based on the information you provided, it is possible that your niece does not have a mitochondrial disorder or has a reversible form that can sometimes occur. Without knowing what caused her issues at a genetic level - there is no testing that would be recommended for you - especially if you are otherwise well and asymptomatic. Without knowing the genetic cause of her disorder - we cannot offer specific information as to whether you are a carrier. Meeting with a genetic counselor could help go over some of this information in more detail and they may be able to offer you a little more.

Sumit Parikh, MD

Sumit Parikh, MD

Q: Here is the link from Michael J. Fox Foundation. Is there a link between CVS with Mito? Mito problems…all together? My daughter has CVS with possible Mito. (Our ins. wouldn't pay for test). My youngest daughter has Hypothyroidism, and I have Parkinson with CVS characteristic. My mom (still living) has Parkinson with the same characteristic. Are they all connected?

A: At one time it was felt that CVS was a definite mitochondrial disease; however, in most cases there is at most a higher risk for CVS amongst certain types of mitochondrial DNA variants. Given the strong family history it would be worth getting the mom with PD and CVS tested with a muscle biopsy and mtDNA sequencing just to make sure that there is no rare mtDNA variant counting for this cluster of medical issues.

Mark Tarnopolsky, MD, PhD, FRCP(C)

Q: It is suspected that I have Mitochondrial Disease and was looking into the mtSEEK and nucSEEK testing, however, I was told that these tests are 50% likely to find something that will change management and improve care. Are there tests besides the mtSEEK and nucSEEK that provide more definitive answers for Mitochondrial Disease?

A: For suspected mitochondrial disease, most of the commercially available genetic tests have at best a 50% yield (likely to find something). It is much less likely that a positive gene test will also change management and improve care. We do not have specific therapies based on gene mutation for the majority of the mitochondrial disorders; gene therapy is just now in clinical trials for disorders such as LHON

Sumit Parikh, MD

Q: I have a levo carnitine deficiency along with B12 and CoQ10 deficiency since Christmas of 2015 I have had spontaneous compartment syndrome in both arms 5 times to the point I almost lost my arms.is there a correlation between the two?

A: Carnitine deficiency, if secondary to a fatty acid oxidation disorder, could lead to increased muscle breakdown and sometimes compartment syndrome. Carnitine deficiency can also occur due to nutritional issues. In that case it is less likely to be a cause of your symptoms. It would be worth determining why you have carnitine deficiency. Vitamin B12 deficiency and CoQ10 deficiencies, if not dietary, can also be due to select metabolic diseases, though they are less likely to cause muscle breakdown or compartment syndrome.

Sumit Parikh, MD

UMDF

events

The energy providing education, support and research.

Fundraisers Benefitting the UMDF

August 5, 2016 The annual Run 4 Raley was once again run, but with one key difference - a new course: the Streets of Philo, IL! It was a beautiful evening and the event raised over $14,000.

August 6, 2016 The first Carter Lackey Memorial Family Fun Day was held in Athens, PA. The event had a dunk tank, petting zoo, cotton candy, snow cones, and delicious treats from Wild Bloom Bakery. The event raised over $2,000 for the Carter Lackey Family Research Fund.

August 13, 2016 The annual Strike Out Mito with the New York Mets took place in partnership with the JDM fund. The event raised over $6,000 for UMDF.

August 24, 2016 Shane Muldowney of Brasselton, GA held a golf fundraiser in conjunction with the American Junior Golf Association in honor of his friend Blake who has LHON. He raised $3,000!

September 1, 2016 Kyndel Craig held various fundraisers including an Azzip's Pizza fundraiser, a Panera Bread fundraiser, an Origami Owl fundraiser, and held a local support meeting. She has raised $853 for her research fund through the UMDF.

September 2, 2016 The first annual Luca's Legacy Golf event was held in Crozetville, VA, and raised over $15,000 to benefit the Luca Florio Family Research Fund.

September 17, 2016 The annual Jaxon's Warriors 5k and Little Warrior Fun Run was held in Robinson, IL, and benefitted the Jaxon Sharma Family Research Fund through the UMDF. The event raised over $10,000!

September 18, 2016 The UMDF home office in Pittsburgh hosted a brunch to kick off awareness week at The Summit in Pittsburgh's Mount Washington. Food, drinks, and fun! The event raised $300.

September 24, 2016 The Pfefferle family hosted their 10th annual Mito Bowl in Meridian, ID. The event has raised $11,000 for the UMDF over the past 10 years.

September 24, 2016 The Lee Brothers Sidekick Foundation held a Mito Dash in memory of Aiden Lee. The event raised $20,000!

October 2, 2016 UMDF was happy to welcome back the Olivia Lauren Steele golf outing this year! The outing, held in Columbus, OH, is crucial to our mission to raise awareness.

October 2, 2016 A Dinner in the Dark was held by Jessica Loomer in Inglewood, AZ. Donations are still pouring in, to date the event has raised over $6,000!

Upcoming Events

December 3, 2016 The annual Carter's Christmas will be held in Athens, PA at the Athens Area High School. The event will be filled with artisan vendors as well as pictures with Santa!

April 1, 2017 The annual Jackson Culley Mito What?! 5k will be held in Millington, TN.

May 7, 2017 The UMDF is a contributing charity for the Pittsburgh Marathon. For more information on how to participate or fundraise please email events@umdf.org

June 17, 2017 The annual Luca's Legacy Golf Outing will be held in Crozetville, VA

October 8, 2017 The UMDF is helping the Bank of America Chicago Marathon celebrate their 40th anniversary by participating as an affiliate Charity!

EFL: Atlanta

Upcoming EFL Walkathons

Our Fall 2016 EFL Walk season is coming to a close! A special thank you to each and every one of our teams, walkers, volunteers, donors, committee members and sponsors who supported an EFL Walk this year!!!

THANK YOU TO:

Energy for Life Minnesota
www.energyforlifewalk.org/minnesota
Energy for Life Indianapolis
www.energyforlifewalk.org/indianapolis
Energy for Life Western New York
www.energyforlifewalk.org/westernnewyork
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Energy for Life Charlotte
www.energyforlifewalk.org/charlotte
Energy for Life Southwest Florida
www.energyforlifewalk.org/southwestflorida

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

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

Saturday, April 8 – San Francisco Bay Area
www.energyforlifewalk.org/sanfrancisco
Saturday, April 11 – Houston
www.energyforlifewalk.org/houston
Saturday, April 16 – Atlanta
www.energyforlifewalk.org/atlanta
Saturday, April 22 - Tampa Bay
www.energyforlifewalk.org/tampabay
Saturday, April 29 - Dallas/Fort Worth
www.energyforlifewalk.org/dallasforthworth
Saturday, April 29 – Nashville
www.energyforlifewalk.org/nashville
Sunday, April 30 – New England
www.energyforlifewalk.org/newengland
Saturday, May 20 – St. Louis
www.energyforlifewalk.org/stlouis
Saturday, May 20 – Cincinnati
www.energyforlifewalk.org/cincinnati
Saturday, June 10 – Pittsburgh
www.energyforlifewalk.org/pittsburgh

Upcoming Symposia

The UMDF is proud to enhance our educational programming through regional symposia and below is a list of the locations for 2017 within the United States. The regional program will offer a full day CME activity on a Friday and a half day of sessions for patients/families on the following Saturday.

UMDF Mitochondrial Medicine
Great Lakes Regional Symposium
Washington University School of Medicine
St. Louis, MO
Course Chairs: Christina A Gurnett, MD PhD and Marwan Shinawi, MD
Friday, March 10 &
Saturday, March 11, 2017

UMDF Mitochondrial Medicine
Southeast Regional Symposium
University of Alabama
Birmingham, AL
Course Chair: Bruce H. Cohen, MD
Friday, April 7 &
Saturday, April 8, 2017

UMDF Mitochondrial Medicine
Central Regional Symposium
University of Texas Health Science Center
San Antonio, TX
Course Chair: Sidney W. Atkinson, MD
Friday, November 3 &
Saturday, November 4, 2017

UMDF Mitochondrial Medicine
Northeast Regional Symposium
Location: TBD
Course Chair: TBD
Fall of 2017

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

SAVE THE DATE!

Mitochondrial Medicine 2017: Washington DC

Scientific Program: June 28 - July 1, 2017
Family Program: June 30 - July 1, 2017
UMDF "Day on the Hill": Thursday, June 29, 2017

Hilton Alexandria Mark Center

5000 Seminary Road,
Alexandria, VA 22311

Scientific Course Co-Chair:
William Copeland, PhD
NIEHS

Scientific Course Co-Chair:
Michio Hirano, MD
Columbia University

CME Chair:
Bruce H. Cohen, MD
Akron Children's Hospital

Remember the UMDF this Holiday Season

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

Share your story with us and others

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

New Year's Resolution

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

Holiday Gifts from the UMDF Store

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

Online Shopping and Search Options

AmazonSmile

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

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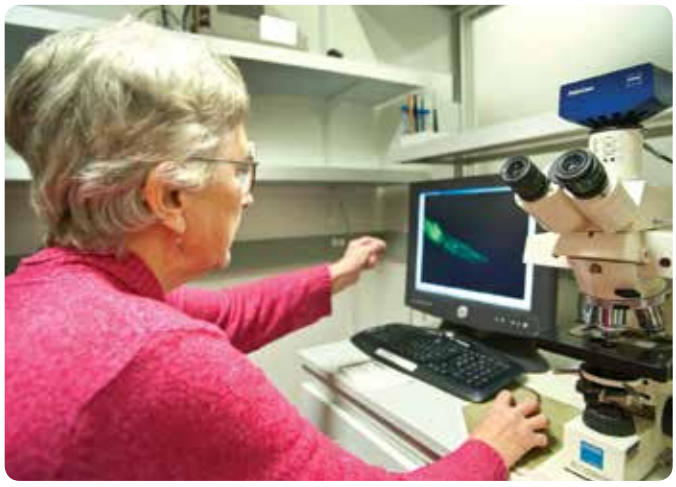

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