UMDF connect

UNITED MITOCHONDRIAL DISEASE FOUNDATION®

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Quarterly publication

Volume 19, Issue 2, Spring 2015

# Mitochondrial Medicine 2015

Each year, the United Mitochondrial Disease Foundation holds what is described as "THE" scientific/family meeting for mitochondrial disease and dysfunction. Mitochondrial Medicine 2015, which is being held in Herndon, VA, features two sessions. Scientific/Clinical meetings will be held June 17-20, 2015. Family sessions will be held June 19-20, 2015. On June 18, the UMDF will hold its third "Day on the Hill." Both family and scientific attendees are encouraged to sign up and attend.

For the scientific and medical community, the UMDF Symposium is the major meeting that updates and educates on the latest advances in mitochondrial medicine. The meeting does offer CME credits. The meeting will bring together clinical and basic science researchers. Participants come from many fields, including biochemistry, genetics, neurosciences, cardiology, cancer, diabetes, nephrology, pediatrics and aging research.

At any major scientific meeting, a handful of presentations on mitochondrial disease will be found; but in order to stimulate research interactions in this ever-expanding cross-disciplinary field, the UMDF symposium focuses entirely on mitochondrial medicine. This year's scientific session is chaired by Marni Falk, MD, Children's Hospital of Philadelphia and Danuta Krotoski, PhD, National Institute of Child Health and Human Development, National Institutes of Health, Bethesda, MD.

For affected individuals and families, the UMDF Symposium provides a unique opportunity to interact with researchers and clinicians on the forefront of mitochondrial medicine. The meeting offers a two-day patient/family program with two tracks to meet a variety of needs – affected adults, parents, caregivers, teens, and an opening session targeted for all attendees to prep them for the entire conference. Patients and families can also participate in our "Ask the Mito Doc" panel and the very important "The Doctor is In," which offers patients and families the opportunity to meet with some of the top specialists in mitochondrial medicine one-on-one.

Scientific and Family registrations, hotel and transportation information can be found at www.umdf.org/symposium.

Since the symposium is being held in the Washington DC area, UMDF will coordinate our third "Day on the Hill" advocacy event. Day on the Hill will be held on Thursday, June 18. Scientific and family attendees who participate will have a meeting with the two U.S. Senators and their Congressmen. UMDF will help prepare attendees for these meetings with a special session on June 17. To sign up for the UMDF's Day on the Hill, please visit https://www.surveymonkey.com/s/Dayonthehill2015.

We hope to see you in Herndon, VA, for Mitochondrial Medicine 2015: Washington DC in mid-June!

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## Contents





# From the Chairman

In the last newsletter, I shared how I am constantly struck by the progress and rate of change that we are witnessing throughout the broader mitochondrial community and how this fuels my optimism for the arrival of effective treatments and cures in the coming years. I am also committed to use this space to share examples of the progress we are making, to spark a dialogue about the challenges we are facing and to highlight where we need your help.

One of the things that I have learned over the years is that achieving a truly meaningful goal in life is most often achieved as a result of lots of very small, yet deliberate actions performed consistently over a long period of time, and not the result of a singular definable event. In these types of situations, I have found that it is helpful to periodically take a step back and look at the total picture in order to fully appreciate the impact and degree of change. As part of our annual UMDF Board of Directors Strategic Planning retreat this past January, we took the opportunity to step back and reflect on UMDF's impact. If you are reading this newsletter, you are one of the thousands of patients, family members, clinicians, researchers, or elected officials who have contributed to UMDF's progress over the years. I trust you will enjoy reading just a few of the highlights that we summarized at our Board retreat regarding UMDF's impact over the years.

Since our founding in 1996, we have made significant progress in raising awareness of mitochondrial disease, empowering those affected and those providing treatment, resulting in quicker diagnoses, improved treatments and better coordinated research efforts.

- We are active in all 50 states and have built engagement in 152 countries around the world.
- We host Energy for Life Walk events in 28 cities and created the first-ever Congressional Caucus on Mitochondrial Disease focused on raising awareness leading to significant growth of federal research funding.
- UMDF has awarded nearly $13 million in scientific and clinical research grants, leading to current clinical testing trials of new drugs and other potential therapies.
- We have established UMDF as the central steward of the therapeutic development process by collaborating with government agencies, academic institutions and drug development companies.
- We recently launched the Mitochondrial Disease Community Registry, a patient-populated database of medical and genetic information used to develop better diagnoses and new treatments.
- Our Grand Rounds program has already educated over 4,000 medical professionals at hospitals in 64 cities nationwide on the latest developments in diagnostics and treatments.
- We host an international Annual Symposium, and regional meetings across the U.S., where scientists, doctors, and the affected community come together to share and exchange new trends in research, diagnosis, and potential treatments.

While UMDF's impact to date is significant and something for which we are rightfully proud, UMDF's role is growing more urgent every day with research linking mitochondrial dysfunction to numerous other diseases like Alzheimer's, Parkinson's, diabetes and autism.

Although the challenges are great, I am confident that working together and harnessing the power of our collective efforts, we can transform medicine for millions -- unlocking treatments and cures for those afflicted with mitochondrial disease, as well as these other conditions. Thank you for your continued efforts.

I look forward to seeing many of you at our annual Symposium and "Day on the Hill" in the Washington DC metropolitan area in mid-June. More information on the Scientific/Clinical meetings, the Family sessions and the Day on the Hill are included in this newsletter.

Patrick Kelley, UMDF Chairman

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# McGovern to Co-Chair Caucus

The United Mitochondrial Disease Foundation is pleased to announce that Representative Jim P. McGovern has agreed to serve as co-chair of the Congressional Mitochondrial Disease Caucus.

McGovern, who represents Massachusetts' second congressional district, is the democratic co-chair of the caucus. He will join Representative Tim Murphy of Pennsylvania's 18th district. Rep. Murphy serves as the republican co-chair of the caucus. Rep. McGovern replaces Rep. Anna Eshoo (D-CA-18) as democratic co-chair. Rep. Eshoo remains on the Congressional Mitochondrial Disease Caucus.

The caucus was formed by Rep. Eshoo and Rep. Murphy. It serves as a way to educate members of congress on issues that affect the entire mitochondrial disease community. Each year, the UMDF develops and presents briefings on mitochondrial medical issues. Some of the topics have included how mitochondrial dysfunction is linked to many other well-known diseases, and an update on research that is aimed towards better treatments and potential cures.

*Representative Jim P. McGovern*

Massachusetts residents should contact Rep. McGovern and thank him for agreeing to help our community in Congress. His office number is 202-225-6101. California residents should contact Rep. Eshoo and thank her for her help in creating the caucus and for remaining a champion in Congress for members of the mitochondrial disease community. Her phone number is 202-225-8104.

# UMDF Secures DoD Funding

For some organizations, it takes years to have a disease or condition listed in what is known as Congressionally Directed Medical Research Program (CDMRP). Beginning in 2008, the UMDF annually submitted information and language to key House and Senate members requesting that mitochondrial disease and dysfunction is added to the list of diseases that are eligible for research funding through the Department of Defense. With the help of Senator's Richard Durbin (D-IL) and Lamar Alexander (R-TN), mitochondrial disease made the list for fiscal year 2015!


The CDMRP was created by the Department of Defense in 1992. It was needed after a grassroots petition from the National Breast Cancer Coalition (NBCC). The petition secured more that 2.6 million signatures asking for more federal research dollars for breast cancer. At the same time, two U.S. Senators, Tom Harkin (D-IA) and Alphonse D'Amato (R-NY), introduced legislation that was designed to repurpose military funds. They believed that since the cold war was ending, those dollars could be put to better use. The legislation asked that the money be moved from the DoD to the National Institutes of Health (NIH) for breast cancer research. Both the petition and the legislation were not successful.

Senators Harkin and D'Amato did not give up. They introduced an amendment to the DoD Appropriations Act to transfer $210 million within the DoD budget to a peer reviewed cancer research program. The measure was overwhelmingly approved. Initially, the money would have gone to the NIH; but, when cancer researchers were asked how they would spend the money, they offered little change in research programming underway. Advocates decided they needed to go the DoD when they said they would "fight hard to win the war on breast cancer." Over the years, the program at the DoD has grown from breast cancer to 41 different diseases that are eligible for $247.5 million dollars. Mitochondrial disease is now one of them, and the CDMRP is charged with managing the projects and the dollars.

Since being listed and since it was through the effort of the UMDF, Defense Department officials reached out to us looking for help from the entire patient community. CDMRP seeks consumer reviewers for the research projects that may be considered for this funding. They are also looking for scientific reviewers for potential research projects. Since advertising these positions on social media and through UMDF eBlasts, we have had a number interested in signing up and participating.

UMDF will do its very best to keep mitochondrial disease on the list to be eligible for research funding within the Department of Defense. It must be renewed each year. If you would like to know how you can help us keep it there --- visit www.umdf.org/advocacy today or sign up for our 2015 Day on the Hill.

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# DAY ON THE HILL

It happens once every two years. UMDF invites and empowers the mitochondrial disease community to let their voices be heard throughout the halls of Congress. We are excited to report that on Thursday, June 18, 2015, UMDF will hold its third "Day on the Hill," and you are invited to participate!

The first UMDF "Day on the Hill" was held in June 2009. More than 230 affected individuals, their families and friends fanned out across Capitol Hill for meetings with their Congressman and two United States Senators. For some elected officials, it was the first time they heard about mitochondrial disease. Those early meetings produced two pieces of legislation that called on the National Institutes of Health (NIH) to expand its research into mitochondrial disease and dysfunction.

By the time UMDF members and supporters gathered for our second "Day on the Hill" in 2012, the affected community had the attention of the NIH and gained several key champions along the way. Senator Barbara Boxer, who retires at the end of the year, and Representatives Anna Eshoo (D-CA) and Tim Murphy (R-PA). With Sen. Boxer's help, the NIH continues to hold various medical meetings investigating mitochondrial disease and dysfunction. With the help of Congressmen Eshoo and Murphy, we have been able to launch a platform to educate additional members of the House and Senate with our Congressional Mitochondrial Disease Caucus.

In December of 2014, because of the efforts of the affected community and many meetings on Capitol Hill by the UMDF, for the first time ever, we were able to secure language in the Department of Defense Appropriations bill that lists mitochondrial disease as a fundable research project.

So where do we go from here? We need you to participate in Day on the Hill 2015. If you are planning to come to Mitochondrial Medicine 2015: Washington DC, sign up to participate in the UMDF's Third "Day on the Hill".

Visit www.surveymonkey.com/DayontheHill2015 to sign up and tell us that you will participate. Once you sign up, we will provide transportation for you to and from Capitol Hill. We will schedule your meetings with your House and Senate Members. And, we will educate you on how to conduct a meeting with elected officials and what you need to say. We make it incredibly easy.

If you can't participate in Day on the Hill in Washington DC this year, visit your Congressman and Senators in their offices near you. If you need help with conducting that meeting, call us at 888-317-8633, and we will be happy to help.

Without you making your voice heard, our community's progress comes to a halt!

*Rep Tim Murphy (above) and Rep Anna Eshoo (below).*

UMDF
# members

Uplifting stories about our members

## An Artist with a Vision

Many people have been asking the UMDF for more information about the artist for the 2014 Holiday Appeal card.

Meet our cover artist, **Matt Calhoun**. Matt lives in Georgia and has been painting since 2012. Matt also has mitochondrial disease, and it impacts his vision. UMDF Gifts Officer Cassie Franklin was honored to work with Matt on the holiday card project and on this interview:

***Did you take any art classes or learn to paint from someone?***
No, I didn't take any formal art classes. I attended a UMDF holiday party in December 2011 and met a local artist named Deb Weiser. She was interested in working with mito patients who had an interest in art. Although I had never attempted to paint before, she offered to come to my home and help me learn to paint using acrylic paints. She worked with me on several occasions.

***Tell us about your favorite painting.***
My favorite subject is lighthouses. I have painted many of the lighthouses on the East Coast.

***What are your biggest obstacles? Are there things that you do that help you overcome them?***
My biggest obstacle is being visually impaired. As a result of having RP [retinitis pigmentosa], my vision is very limited. My field of vision is about the size of a pinhole. With my visual situation, it's also hard for me to be able to differentiate colors. Although I know in my head what I want a scene to look like, it doesn't always end up this way. Another issue is that I tire easily, and therefore, I am not able to paint for long periods. In light of the obstacles, I recognize that I wouldn't be able to do this without God and the encouragement of others.

***Why do you paint? Who do you hope will see and enjoy your work?***
Because of my health issues, I'm at home 24/7. Painting gives me something to do which I enjoy. I've been surprised that so many people in my local community find my paintings inspiring. Then to be able to take my canvases and create note cards which I've been able to sell and donate the profits to UMDF and Phoenix Pass gives me even a greater satisfaction. It's a way of taking a hobby which I enjoy and using it to benefit others.

***How did you feel about being UMDF's 2014 holiday card artist? Why did you say yes?***
I was very humbled and honored to be chosen. I said YES because I hoped that the cards could assist UMDF in raising funds that would allow it to help others.

### UMDF SAYS THANKS

We are so thankful for Matt's contribution to the 2014 Holiday Appeal Card. Because of his help and the generosity of our holiday donors, over $100,000 was raised toward a cure for mitochondrial disease--more than any appeal in the last five years!

**THANK YOU!**


# UMDF Night with the New Jersey Devils

On Saturday, February 21st, over 75 people attended the New Jersey Devils NHL hockey game at the Prudential Center in Newark, NJ, to support the UMDF. Through the Devils Fundraising Program, a portion of each ticket sold was donated to the UMDF.

Perth Amboy, NJ, resident Susan Roque was one of the event organizers. She and her husband, Lloyd Roque, fundraise for the UMDF on a regular basis in memory of their daughter, Grace Roque, who passed away from mitochondrial disease in 2011 at the age of 13 months.

"I'd like to thank everyone who came to the game in support of this cause," Roque said. "It really means a lot to our family to remember Grace in this way as we work to help others who are affected by mitochondrial diseases."

As part of the festivities for the evening at the Devils game, the group supporting the UMDF took a picture on the ice after the game.

"We really had a great time at the game and I can't thank the Devils organization enough for supporting a charitable cause in this way," said Ryan Green, Grace's uncle and co-organizer of the event. "We definitely want to do it again next season with an even larger group of UMDF supporters."

For additional information, contact Ryan Green at (732) 614-5810.


*Rebecca Grace Green, named after Grace Roque, embraces the UMDF banner.*

# Through Mito Eyes: Making Education Work

*by Liz Kennerly*

Making Education Work" is the motto of Simmons College, my alma mater, from where I graduated in 2009. My majors were Society & Health and Sociology, with minors in Psychology and Music. Studying so many things simultaneously felt dizzying at times, but I somehow managed to get it all done in four years; you might say I made education work for me despite many mito stumbling blocks.

Many of my friends asked me why I chose to add Music as my second minor. Well, I grew up surrounded by it. My parents started taking me to the Philadelphia Orchestra performances when I was five years old, and I immediately fell in love with every note! Soon I began playing the violin, clarinet and piano, and the music I played and listened to seem to stimulate different parts of my brain providing challenges and diversions that my other classes could not do. This was my way of de-pressurizing and re-energizing. My interest in music, and my quest for diversion motivated me to join the concert choir during my senior year.

I can remember days sitting in class for 10 hours straight wondering if I would even get a chance to get to the cafeteria to grab lunch or dinner; I was living off of yogurt parfaits and fruit cups with as much coffee as needed. I remember taking short naps using a hard wood table as my pillow and texting my roommate to please bring me some sushi or pizza. Despite being exhausted, choir became another form of therapy; it was my reward at the end of a long day.

My Fridays, from 1:00 pm to 5:00 pm, were spent volunteering on the complex care unit at the local children's hospital. I cared for children of all ages with multi-system diseases of varying severity, including mitochondrial disease. I read to them, played toys and helped them fall asleep. I began to realize that chronic illnesses affects the entire family, especially when extended hospital stays are involved; the patient, siblings, parents and extended family were all equally important! I was able to give parents breaks so they could talk alone, with their doctors, or simply go to the cafeteria knowing their child was in good hands. I was an extra pair of hands for the nurses adjusting pillows, wires and tubes, and I wish I had a nickel for every time I pressed the call button or ran to get a nurse. No two patients were alike and every shift was different. It was the perfect ending to my hectic weeks and just as challenging as my classes, but far more rewarding. It was just what the doctor ordered - for both of us!

I never could have maintained my hectic schedule without support, understanding and many accommodations. I was allowed extra time on exams and permitted to miss classes without penalty. I was given deadline extensions and the ability to type essay questions instead of writing by hand. My energy levels really began to fluctuate during the day and there were many times that I didn't think I would make it to the end. During those days, I took my time getting from one class to the other and, once in class, found myself closing my eyes from time to time while keeping my ears open.

My roommate came to me one day asking if I had any Sudafed. Well of course I did! Sudafed came along with many other over the counter and prescribed medications that I had to take daily; after all I'm a mito patient. She actually had the nerve to tell me she didn't know how to swallow pills! I looked at her with one furrowed brow and the other raised, "Seriously," I said, as I motioned to all the pill bottles on my shelf. I took my daily dose in my hand, tossed them in my mouth and downed them with one gulp of water. This was my first time teaching someone how to swallow pills and instead of a "thank you" I got a "AAAhhhhEEEwww…. That's nasty!" Her one little Sudafed went down very easy after my demonstration.

During my senior year, I was not only "Making Education Work" for me but also giving my doctors an education of their own! I made certain each and every doctor and nurse knew about Mitochondrial Disease, inside and out. To hear firsthand what I went through and felt daily was an added benefit to what they could read in the medical literature. At this time, I was being followed by five different specialists and made sure each and everyone knew what Mitochondrial Disease was and what it was doing to me. Fortunately, the hospital that had the biggest claim on me was directly across the street which provided me the shortest commute, because I was at the health center nearly every week for one reason or another; I was riding the typical mito roller coaster.

I ended up with three hospital stays during my senior year, resulting in me being four credits shy of graduating with my class. I was, however, allowed to walk with them during graduation. I remember as I walked down the steps being intercepted by my registrar with a big hug. It meant the world to me that she recognized the dedication it took for me to complete the work I was able to do; education was working for me!

Even though mitochondrial disease put the brakes on my energy levels, I made sure that, with the help and support of others, I continued to step on the gas. Mitochondrial disease and education can go together. You can make education work for you!

---

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

*VCU School of Engineering Dean Barbara D. Boyan, Ph.D. and VCU School of Arts Dean Joe Seipel with Bioenergetics Project team.*

# VCU Exhibit Raises Awareness

An exciting new exhibit opens March 17, 2015 at the Science Museum of Virginia. It's called the BIOENERGETIC Exhibit. The exhibit is designed to increase awareness of mitochondrial diseases.

The exhibit, which will be displayed until June 17, 2015, was created through the collaboration of a team of hybrid faculty and sixteen students from Schools of Engineering and Arts. Experts from the Science Museum of Virginia, a patient advocate from the UMDF's Virginia Chapter, and clinical consultants from the VA Medical Center also participated in the creation of the exhibit. The exhibit uses science, technology, engineering, arts, mathematics and health (STEAM-H) in its approach to communicate concern and awareness for mitochondrial disease. The exhibit was funded by VCU Quest Innovation Fund and is under the direction of Shilpa Iyer, PhD, Assistant professor, Department of Chemical and Life Science Engineering and Director of the Dean's Undergraduate Research Initiative (DURI) at Virginia Commonwealth University (VCU)

Dr. Iyer says the exhibit uses multiple multimedia outlets to talk about how energy is made and sustained in the body. It shows the connection between energy, metabolism and health, and how we can make good decisions to maximize our wellness. The exhibit is also designed to increase awareness of mitochondrial diseases.


"The exhibition showcases the importance of mitochondria, and the flow of energy within this powerhouse of the cell. We will be showcasing teaching modules, art illustrations, sculptures, movies, computer games and personal reflections to explain the meaning of bioenergetics and the importance of maintaining mitochondrial health through knowledge, fitness and nutrition," Dr. Iyer said. "The outcomes for the exhibit will be a better understanding of the central role of mitochondrial health in healthy lifestyle and how problems in mitochondrial genome and function can impact bioenergetics levels in our bodies."

Dr. Iyer has researched many aspects of mitochondrial physiology and bioenergetics and its relevance to energy failure in several diseases since 2006. Given the recent exponential rise in mitochondrial and energy-deficiency diseases in children and adults, she felt that the best way to address this problem was to target young minds, as seeds sown at an early age would reap bountiful harvests later.

"The idea behind the bioenergetics and mitochondrial education program stemmed from a study that indicated that close to 40% of children suffer from disorders that affect their energy levels. It was thus critical to educate the public on the importance of this health and lifestyle issue. Equally important is the fact that mitochondrial dysfunction is at the core of numerous diseases that affect energy production. An urgent cell-to-society integrative approach is needed to address this problem, to increase awareness for improving nutrition and bioenergetics of young children and their families, and ultimately improve the quality of life. This wake-up call presents an urgent need to educate the public about the importance of "bioenergetics" and mitochondria in our daily lives," Dr. Iyer said.

For more information, visit *http://wp.vcu.edu/bioenergetics*


# Regional Symposium: Great Lakes

Can't make it to Washington DC in June for the National Symposium, but still want to hear from the mitochondrial disease experts?

MICHIGAN STATE UNIVERSITY

Join us May 1-2, 2015, for the Great Lakes Regional Symposium at Michigan State University, Kellogg Conference Center, in East Lansing, Michigan.

Share with your physicians, nurses, and therapists – learn to navigate the mitochondrial disease maze and earn CME credits on May 1st. Saturday morning, May 2, is dedicated to the patients and families.

For more details and to register online today, visit the Great Lakes website at www.umdf.org/symposium/greatlakes.

Faculty include Laurie S. Kaguni, PhD; Marni Falk, MD; Bruce Cohen, MD; Sumit Parikh, MD; Lawrence Grossman, PhD, and Gerald Feldman, MD, PhD, FACMG.

# Double Your Gift to the UMDF!

Donating to an Energy for Life walk? Sending a gift to the UMDF? Supporting a research fund for a family member or friend? You gift may be eligible for a dollar to dollar match from your employer. UMDF has made it very easy for you to check to see if your employer participates in a matching gift program enabling you, in most cases, to double your donation!

Simply visit https://doublethedonation.com/umdf.


Employee matching gift programs are corporate giving programs in which the company matches donations made by employees to eligible nonprofit organizations. Requesting a matching gift or volunteer grant is normally a five minute process which must be initiated by the donor / volunteer.
You can do this by filling out and submitting a paper match form provided by your employer or through an electronic submission process. Many corporations match employee donations to the UMDF. If you volunteer with us, your employer may also provide us with a grant as a way to recognize your ongoing support. Please visit https://doublethedonation.com/umdf and start the process today!

# Planning for the Future

As the new Director of Development for UMDF, and as a parent of an adult with special needs, I know firsthand how scary and overwhelming planning for my child's future is. What will happen to my child when I'm gone? Who will take care of them the way I/we do? Where will they live? Will there be enough money to care for them? In the next few issues of our newsletter, we will share some simple but vitally important steps that you can take now to prepare for the future.

It's very important to start the estate planning process, and one of the simplest steps is starting with a will. Don't have a will? Don't know what a will is? Do you already have a will but haven't updated it in a while? The folks at **The Monteverde Group** offered more information - excerpts follow below, the full article is available on *www.umdf.org*.

***- Beth Whitehouse***

## Wills: The Cornerstone of Your Estate Plan

If you care about what happens to your money, home, and other property after you die, you need to do some estate planning. There are many tools you can use to achieve your estate planning goals, but a will is probably the most vital. Even if you're young or your estate is modest, you should always have a legally valid and up-to-date will. This is especially important if you have minor children because, in many states, your will is the only legal way you can name a guardian for them. Although a will doesn't have to be drafted by an attorney to be valid, seeking an attorney's help can ensure that your will accomplishes what you intend.

### *Wills avoid intestacy*

Probably the greatest advantage of a will is that it allows you to avoid intestacy. That is, with a will you get to choose who will get your property, rather than leave it up to state law. State intestate succession laws, in effect, provide a will for you if you die without one. This "intestate's will" distributes your property, in general terms, to your closest blood relatives in proportions dictated by law.

However, the state's distribution may not be what you would have wanted. Intestacy also has other disadvantages, which include the possibility that your estate will owe more taxes than it would if you had created a valid will.

### *Wills distribute property according to your wishes*

Wills allow you to leave bequests (gifts) to anyone you want. You can leave your property to a surviving spouse, a child, other relatives, friends, a trust, a charity, or anyone you choose. There are some limits, however, on how you can distribute property using a will. For instance, your spouse may have certain rights with respect to your property, regardless of the provisions of your will.

Gifts through your will take the form of specific bequests (e.g., an heirloom, jewelry, furniture, or cash), general bequests (e.g., a percentage of your property), or a residuary bequest of what's left after your other gifts.

### *Wills allow you to nominate a guardian for your minor children*

In many states, a will is your only means of stating who you want to act as legal guardian for your minor children if you die. You can name a personal guardian, who takes personal custody of the children, and a property guardian, who manages the children's assets. This can be the same person or different people. The probate court has final approval, but courts will usually approve your choice of guardian unless there are compelling reasons not to.

### *Wills allow you to nominate an executor*

A will allows you to designate a person as your executor to act as your legal representative after your death. An executor carries out many estate settlement tasks, including locating your will, collecting your assets, paying legitimate creditor claims, paying any taxes owed by your estate, and distributing any remaining assets to your beneficiaries. Like naming a guardian, the probate court has final approval but will usually approve whomever you nominate.

### *Wills can create a testamentary trust*

You can create a trust in your will, known as a testamentary trust, that comes into being when your will is probated. Your will sets out the terms of the trust, such as who the trustee is, who the beneficiaries are, how the trust is funded, how the distributions should be made, and when the trust terminates. This can be especially important if you have a spouse or minor children who are unable to manage assets or property themselves.

### *Wills can fund a living trust*

A living trust is a trust that you create during your lifetime. If you have a living trust, your will can transfer any assets that were not transferred to the trust while you were alive. This is known as a pourover will because the will "pours over" your estate to your living trust.

# ABLE ACT

In the waning days of 2014, President Barack Obama signed a piece of legislation that may benefit families affected by mitochondrial disease and dysfunction.

The measure, called Achieving a Better Life Experience Act is also known as the ABLE Act. The law now allows people with disabilities to open a tax free savings account where they can save up to $100,000 without losing government benefits.

Under the ABLE Act, individuals will be able to keep Medicaid coverage no matter the amount of money saved in the ABLE Account.

The program is modeled after the 529 accounts that many parents have established to save for the college education of their children. Interest earned on the ABLE account is tax free and can be used for education, health care, transportation, housing and other expenses. To be eligible, an individual must have an illness that occurred before the age of 26 and they only open one ABLE account.

The program is expected to be up and running this year, but each state must put regulations in place so that institutions can begin offering these types of accounts. If you are interested, you should check with your financial planner or local lending institution.

# FHFC Seeking Parents for Project

The **Franciscan Helps Families Connect** parent project is looking for parents of children with complex medical conditions to help communicate the challenges and successes they encounter in obtaining their child's medical services.

Jointly developed by dedicated parents and Franciscan Hospital for Children and Kennedy Day School staff, the goal of the project is to:

- Identify the issues and barriers parents face in caring for their child with a complex medical condition.
- Engage enrolled parents to share their wisdom, insights and coping strategies.
- Combine parent responses to educate relevant healthcare providers about the challenges these parents face.
- Direct future efforts to fix the parent-identified problems through research or advocacy.

As a parent of a child with medical complexity, you have a unique perspective on healthcare delivery and the systems of care available for your child. As your child's most important care provider and advocate, your voice must be heard.

To enroll in this survey, visit http://franciscanhospital.org/parent-project/

# 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:** Are sulfonylureas safe to use with complex I and complex III deficiency mito? My hgb A1c is 5.8 and my average blood sugar level is 99. I still get hypoglycemic. I have a new doctor in the mix and she wants me to take one of these and I feel uncomfortable about this as I feel my sugar is controlled.

**A:** In general sulfonylureas are not contraindicated in mitochondrial disease. Some mitochondrial patients have had trouble tolerating Metformin, which is in a different class of diabetes drugs. In regards to whether or not you need this medicine for your diabetes, I would have to defer to an endocrinologist. You may want to ask her to explain her reasoning as to why she wants you to try this medicine if your numbers are as good as you noted. - *Sumit Parikh, M.D.*

**Q:** Are there any laboratories in the united states that can do pre-implantation genetic diagnosis for maternally inherited Leigh's syndrome if I do invitro fertilization??? If so, how do I contact them??? I've already lost my baby to this disease. Please help me.

**A:** Pre-implantation diagnosis is available for known autosomal recessive and autosomal dominant genetic mutations. However, because of problems with heteroplasmy in maternally inherited mutations, evaluating laboratories are unable to determine with a high degree of accuracy whether or not the cells tested for the presence of a maternally inherited mutation are reflective of the overall status of mutation load in the fetus. More simply stated, the laboratories are not sure if the cells of the fetus evaluated accurately reflect the status of the new baby meaning is it affected or not? As such, I am unaware of any pre-implantation diagnostic centers that will screen for maternally inherited mtDNA mutations.- *Fran D. Kendall, MD*

**Q:** My maternal 1st cousin (Complex IV Mito with Limb Girdle Dystrophy per exome sequencing) and I were just diagnosed in March 2013 after a lifetime of symptoms. What do you think are the chances of gene or stem cell therapy for me in my lifetime?

**A:** I think the chances of seeing gene or stem cell therapy in our lifetime is extremely high. There are already several clinical trials dealing with gene therapy, including targeting diseased mitochondrial DNA by several researchers at the U of Miami *http://med.miami.edu/news/clinical-trial-uses-gene-therapy-to-target-mutations-in-mitochon* . And work by Carlos Moraes, Univ of Miami *http://biomed.miami.edu/?p=493&pid=309&m=facultyph&mid=2&item=128* . Also, there are active trials in the UK with mitochondrial replacement in embryos, termed three parent babies. Of course, all gene therapy techniques are going to be met with skepticism and must pass various ethical hurdles to be fully engaged. One of the more promising and wide spectrum gene therapies involves a newly discovered/invented technique called CRISPR, which was first described only two years ago. This involves a highly efficient and rapid inactivation and replacement of a target disease gene with a functional one. For more information, please see Wikipedia or read its potential use in gene therapy in the December 2014 issue of *Scientific American*, pp 42-46. *William Copeland, PhD*

**Q:** My daughter was diagnosed with multi-complex mitochondrial disease. They called it multi-complex because all of her super complexes in her muscle biopsy were abnormal as well as complex 1,3, and 5. She has been having constipation issues. She is prone to dehydration even while being on a 16 hour continuous feed. My question is: Her GI doctor has placed her on mineral oil and on Senna because of constipation. Is it safe to use this with her history of dehydration? If she starts having complications of diarrhea from these meds I am afraid she will get dehydrated. I don't want to go against the GI doctor but I want to get an opinion.

**A:** In general, mineral oil and Senna are relatively mild treatments. Because constipation can be so difficult to treat, it seems reasonable to try these laxatives, and taper back if there is any indication of diarrhea. Of course, monitoring your daughter closely for dehydration sounds like a good idea too given her history. - *Greg Enns, MD, ChB*

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


Dr. Anna Kaisa Niemi is not only a doctor at Stanford Children's Hospital, but also an ***ACTIVE-ATE your Mitochondria*** participant. She received a UMDF Clinical Fellowship Award in 2011 and is now working to raise awareness and pay it forward to those in the community by doing what she loves - running. I interviewed her about her goals and experience. We at the UMDF are looking forward to following her progress and sharing it with all of our members.

***What previous schools did you attend and what degrees do you hold?***
I did my medical school (MD) at University of Oulu, Finland. I did my PhD on the role of mitochondrial DNA in longevity and elite athletic performance in University of Oulu, Finland. I did Pediatric Residency, Medical Genetics Residency, Medical Biochemical Genetics Fellowship and Clinical Mitochondrial Fellowship at Stanford Children's Hospital, Stanford, CA.

***Are you an MD or a PHD?***
I am both an MD and a PhD. I am a physician scientist but do mostly clinical work now - I love taking care of and treating patients - so, you may just say, "physician at Stanford Children's".

I work also at the new Complex Primary Care Clinic (CPCC) at Stanford Children's, which is a primary care clinic for children with complex medical needs, such as those with mitochondrial diseases. Most of the patients that are seen have a genetic or a metabolic syndrome, including those with mitochondrial disease. The goal is to improve primary care for children with complex medical needs and improve transition from hospital to home as well as communication and collaboration between sub-specialties to make the medical world friendlier and easier to navigate for families.

Officially, my title at Stanford is Clinical Instructor in Neonatology and Developmental Medicine (primary), General Pediatrics and Medical Genetics.

***What is your specialty (fellowship) in?***
I specialized first in Pediatrics, then Clinical Genetics and after that Medical Biochemical Genetics (so the so-called metabolic i.e. biochemical disorders are my specialty).

***What made you decide to pick that specialty?***
I was always fascinated by metabolic pathways and how amazingly our body coordinates everything that needs to be coordinated. I was interested in sports physiology, neurology and pediatrics and once I discovered medical biochemical genetics I realized that it is a field that combines all my interests, and there is a potential for treatments in metabolic pathways which always interests me.

***Why did you become interested in mitochondrial health?***
Mitochondrial health and mitochondrial diseases is part of biochemical genetics and combines a lot of my interests: neurology/brain, biochemical genetics, genetics, muscle physiology, potential for treatment (e.g. novel molecules, vitamins, supplements, diet). Mitochondria are the power plants of our cells that are important from birth to old age, and related to many disease processes and also general ageing. Mitochondrial health is important throughout life. I also did my PhD in mitochondrial genetics.

***How important is activity and Mitochondrial health?***
Moderate physical activity and mitochondrial health are both important. And related as moderate aerobic activity may also improve mitochondrial health. Studies have suggested that progressive

endurance activity improves exercise capacity and mitochondrial enzyme activity, and is generally well tolerated by individuals with mitochondrial disease. Of course we are all different and "moderate" activity level depends on that. And while some enjoy running others may not and may prefer biking, swimming, walking or hiking. There is something for everyone to choose from. Current recommendations of physical activity (30 minutes of moderate-intensity aerobic activity 5 times per week) is likely a good recommendation for anyone. There is a good article on exercise and mitochondrial health on the UMDF website (under Mito 101) for those interested.

***How long have you been a runner?***

I was a runner years ago in high school until early med school (track & cross country). After that, I did not run for years but hiked, did yoga, etc., until recent years when I rediscovered running again and love it. Running for me makes a tough day good and a good day better.

***What was the first organized run you completed and what year?***

I don't remember exactly when my first race was. As an exchange student in Irvine (CA) High School, I competed in the school's cross country team, and in Finland (where I am from) in our city's track team. But the first race I ran after I rediscovered running was The Relay (2011). The Relay is a fun 12-people team relay of 191 miles from California Wine Country to Santa Cruz and it benefits organ donation.

***Why did you decide to participate in Active-Ate?***

I am a past recipient of the UMDF Clinical Fellowship Award on Mitochondrial diseases. The idea for this fellowship initially came from families. During that year I met a lot of families and, most importantly for me, learned about their daily life. While research can benefit a patient years later, I wanted to do something for the families now. And as I love running, and running is a great way to raise awareness, I partnered with UMDF to establish ATP Synthase Fund that benefits children, adults and families with mitochondrial disorders: http://bit.ly/ATPsynthaseFund

***How many races have you participated in since signing up?***

I signed up late Nov 2014 and have participated in two races so far: Silicon Valley Turkey Trot 10k on Thanksgiving Day and a 10k at a beautiful Coyote Hills park. I post updates about my races on my Facebook and Twitter page as well as on my Active-Ate page:

***What's your race schedule looking like for the rest of the year?***

My next race will be right before St. Patrick's Day, a green-themed Badger Cove 10k (March 14). After that I plan to walk the UMDF Energy for Life Walkathon (5k) in San Francisco. In May, I will run a Zombie Runner race in San Francisco. At all these races I will be wearing a T-shirt to raise awareness of mitochondrial diseases. I plan to also run in other states to raise more awareness of mitochondrial diseases.

***Anything else you would like to add?***

I am excited to raise awareness of mitochondrial diseases with my runs (and on social media). I can't wait to see the ATP Synthase Fund grow and help children, adolescents and families with mitochondrial disease by supporting their trips to the UMDF annual meeting to meet others with mitochondrial disease and feel connected.

Facebook:
www.facebook.com/drannakaisa.
Twitter: DrAnnaKaisa

# AACT Update

On behalf of the UMDF Adult Advisory Council Team, we wish you good health, happiness, and all the best in 2015.

We want to highlight a number of UMDF events you may be interested in. Mark your calendars and hope you can join us!

- **UMDF Mitochondrial Medicine 2015: Washington, DC:** Family Sessions June 19-20 & Day on the Hill June 18
  *www.umdf.org/symposium*

- **UMDF Great Lakes Regional Symposium: East Lansing, MI:** Patient/Family Program May 2
  *www.umdf.org/symposium/greatlakes*

If you are not able to attend the National Symposium in Washington, DC, the Regional Symposiums are a wonderful opportunity to attend a one-day program, exchange information, time to network with some of the top mito doctors in the field, and meet others battling this disease as well.

•UMDF Energy for Life Walkathons: Over two dozen EFL Walkathons take place across the country to help fund vital research grants to find treatments and cures for mitochondrial diseases and disorders. If you cannot walk a good distance, don't let this discourage you from forming a team, joining a team, or attending. The venues are fantastic, and it's a great day to join together with energy, resilience, and hope.
*www.energyforlifewalk.org*

To find and view listings of other upcoming events and meetings in your area, visit www.umdf.org and click on Find Support - lots happening!

AACT is honored and proud to represent, serve, and support you.

Yours toward a cure,
Jennifer & Gail
AACT Co-Chairs

## IN MEMORIAM

***Robert "Bob" Brieff***
***1944 - 2015***

Bob was a proud New Yorker and Wisconsin Badger. He had a great mind, sense of humor and many interests. He was also very kind, giving and generous. With tireless dedication, Bob was one of the vital original UMDF AACT Council Members who was instrumental with its development, mission and purpose; and, he was deeply committed to carrying out UMDF's mission - even until the time of his passing. He loved life and fought valiantly with courage and dignity.

We will miss him greatly. Thank you, Bob. Shalom.

## *Adult Advisory Council Team (AACT)*

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

**Medical Advisors:**
Bruce H. Cohen, MD
Amy Goldstein, MD

## *Purpose of AACT*

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

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

# A Message from Devin...

Hi, my name is Devin, and I'm 22 with mito. I became a Youth Ambassador for the UMDF in 2010 after attending my first symposium because meeting other young adults with mito quite actually changed my life. I'm also the Young Adult Coordinator for AACT and run a Facebook page for youths with mito co-run with Renees Ruth.

If you are a teen or young adult with mito or if you know one, I highly encourage you to contact me by e-mail at devin-shuman@comcast.net or the Facebook page "Mito Friends (Teens and Young Adults)." There is no reason anyone should have to go through this journey alone. I look forward to hearing from you.

*- Devin Shuman, AACT Young Adult Coordinator*

*To read Devin's bio, visit www.umdf.org, click on the Find Support tab then click on Adult Advisory Council Team.*

*Andrew and Makenzie presented a check for $40,000 from Butterflies of Hope to the UMDF on their mission to raise one million dollars!*

*Katie Parsons and family from Marietta, GA, visited the UMDF office in Pittsburgh and brought along some great crafts and gifts for the staff!*

# The Past and Future of the UMDF

*by Phil Yeske, PhD, UMDF Science & Alliance Officer*

Did you know that the UMDF is the single largest non-governmental funder of primary mitochondrial disease research? Over the past 15 years, the foundation has invested over $13 million in basic, translational and clinical research - research that has launched the careers of many preeminent scientists, created enabling technologies and ultimately is paving the way for the development of treatments and cures for mitochondrial disease. In a few weeks, the UMDF grant review committee, composed of thought leaders from the mitochondrial scientific community, will help the foundation select for the 16th straight year another set of research grant awardees. Proposals from around the world have been submitted and are being reviewed for merit, potential impact and alignment with the UMDF mission. We will share more details about the selected proposals in the next newsletter; but, today we'll take a look back at some of the highlights from the first 15 years of the UMDF Research Grant Program and provide a glimpse of exciting changes to come.

When Chuck Mohan founded the UMDF in 1996, he knew that research would hold the key to eventually finding a cure for mitochondrial disease. After a couple years of fundraising, the foundation was ready to make first awards in the spring of 1998. "I am very proud that in that first cycle of grants we funded two clinicians and researchers in John Shoffner and Richard Boles that almost two decades later remain active contributing members of the mitochondrial disease community," said Mr. Mohan. The first 5 years of grant awards included many other now well-recognized scientists and physicians such as Drs. Manfredi, Enns, Mootha, Chan, Haas and Chinnery. Through their awards, we learned about the genetic nature and prevalence of mitochondrial disease and even how to diagnose this mysterious malady. All of these scientists have given back to the foundation many times over the relatively small investments made in their research by volunteering their time to serve on numerous advisory boards, assist with advocacy efforts, and help plan world-class symposia, and for that we are most appreciative.

Following on the heels of those initial 5 years came a group of awards to investigators now in the prime of their professional careers, when major breakthroughs typically occur in science. Awards to now-established names such as Palladino, Wenz, Saada, Khrapko, Pallanck and Tein extended the impact of the research grant program from early basic research to more translational (e.g., fruit fly models) and even clinical studies (e.g., use of L-arginine to alleviate the impact of strokes in patients with MELAS). These researchers were able to leverage the grant awards made by UMDF into dozens of publications and millions of dollars of follow-on NIH funding - critical hallmarks of a successful grant program.

In more recent years new scientists have emerged at the cutting edge of research on mitochondrial disease, with names like Garcia-Diaz, Kaufman, Raimundo, Sinclair, and Torres-Torronteras. A greater emphasis is being placed on therapeutic development within the grant program based on the tremendous progress made in recent years in understanding the complex basic biology of mitochondria, and these researchers are leading the way toward future treatments and cures. We are also collaborating on a global level, co-funding a pair of projects together with our patient advocacy counterparts in Italy (Mitocon).

UMDF was also proud to launch a Clinical Fellowship Program in conjunction with the North American Mitochondrial Disease Consortium (NAMDC), helping to ensure the next generation of clinicians receive the training necessary to deal with the complexities of mitochondrial disease. Perhaps some of you are patients or caregivers of someone receiving care from the Fellows: Drs. Niemi, Emrick and Kaara. They are a tremendous asset to our affected community.

So what does the future hold for UMDF-funded research? Look for increased collaboration, extending to other patient groups and even including other disease states with known connections to mitochondrial dysfunction such as Alzheimer's, Parkinson's and diabetes. By combining efforts, we can accelerate the pace of drug discovery for all patients, but know that the UMDF focus will always remain on those affected by mitochondrial disease. Also look for direct funding of orphan drug clinical trials by UMDF in the very near future. A handful of promising therapeutic leads have been identified where access to early seed funding could make the difference between treatments advancing to clinical testing or languishing in the lab.

Because of the abundance of high quality funding opportunities, we have an aggressive strategy to grow the current Research Grant Program over the next several years, doubling the number of projects funded and increasing the total dollar amount invested per year by a factor 5! Clinical trial funding, separate from the research grant program, will require creative partnerships and even higher levels of philanthropy. The groundwork and infrastructure are being put into place that will ensure the long-term success of these programs. Your donations do play a critical role in this strategy, and we hope you will continue to support our efforts to bring treatments and cures to those affected by mitochondrial disease.

UMDF
# national

News from the national office.

## Welcome Beth and Julie!

The United Mitochondrial Disease Foundation is pleased to welcome two new additions to our staff.

Beth Whitehouse joined the UMDF in January 2015 as Director of Development. In this role, she is responsible for developing and implementing the organization's annual fundraising plan to maximize revenue in support of the UMDF mission. Beth comes to UMDF with 15 years of experience in non-profit fundraising.

Prior to joining UMDF, Beth held several positions with Autism Speaks. Most recently as National Walk Director, responsible for driving revenue growth of 80+ events through the development, enhancement and dissemination of tools, processes, systems, and marketing materials for Autism Speaks' signature event, Walk Now for Autism Speaks. Beth has a bachelor's degree in Finance from La Roche College. She is a member of the Association of Fundraising Professionals and Association for Talent Development. She resides in Pittsburgh, PA, with her husband Bob, and two sons, Benjamin and Nicholas.

Julie Hughes rejoined the UMDF in November of 2014. Upon leaving UMDF in 2003, researchers were just beginning to understand the link between mitochondrial dysfunction and other more common diseases. She says seeing the progress and advancement on so many levels is more than promising that the UMDF is on its path toward a cure.

Since her time away from the foundation working in the home healthcare private nursing field in the Pittsburgh region. She is delighted to be back on board with UMDF and its mission and is happy to be a part of the development team.

## United Mitochondrial Disease Foundation Staff

***Executive Staff***

**Charles A. Mohan Jr.**
*CEO/Executive Director*
**Janet Owens**
*Executive Administrative Assistant*
**Philip Yeske, PhD**
*Science & Alliance Officer*

***Finance***

**Mark Campbell**
*Chief Financial Officer*
**Donna Nameth**
*Data Entry Manager*
**Barbara Podowski**
*Administrative Assistant*

**Communications**

**Clifford Gorski**
*Director of Communications*
**Jeff Gamza**
*Multimedia Coordinator*

**Member Services**

**Kara Strittmatter**
*Meeting Event Director*
**Liz Weiss**
*Special Events & Member Services Associate*

**Development**

**Beth Whitehouse**
*Director of Development*
**Leslie Heilman, JD**
*Associate Director of Development*
**Julie Hughes**
*Development Associate*
**Tania Hanscom**
*Special Events Coordinator*
**Tara Maziarz**
*Special Events Associate*
**Cassie Franklin**
*Gift Officer*

**Regional**

**Crissy Harris**
*Regional Coordinator - Central*
**Margaret Moore**
*Regional Coordinator - Southeast*
**Nicole Shanter**
*Regional Coordinator - Northeast*
**Anne Simonsen**
*Regional Coordinator - Great Lakes*

## 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.

UMDF
# events

The energy providing education, support and research.

# Fundraisers Benefitting the UMDF

*Carter's Christmas raised over $1900 for the Carter James Lackey Research fund*

**September 5, 2014** Shane Stewart hosted the 3rd annual 'Birdies for the Blind' Golf Tournament at the Gardener Municipal Golf Course in Gardner, MA *(right)*. The event included golf, a barbecue, and raffle prizes! 88 golfers participated and the event raised $7000 for the UMDF's LHON project fund.

**December 2014** Matt Calhoun displayed his talents by creating beautiful Holiday artwork on cards and canvases for the UMDF and sold his original pieces to fundraise at the UMDF Atlanta holiday party.

**December 6, 2014** Carter's Christmas was held in Sayre, PA, at the Sayre Elks Club *(above)*. It was a unique event that showcased local vendor's and raised over $1900 for the Carter James Lackey Research fund!

**January 9, 2015** The Appalachia intermediate Unit 8 hosted a Jeans for charity day and selected the UMDF as their charity of choice.

**January 9, 2015** The law office of Ackerman, Link, and Sartory hosted a casual day for charity and selected the UMDF as their Charity of Choice.

**January 16, 2015** The Moorestown Friend's School held a Dress Down day for the UMDF and raised over $300!

**January 23, 2015** Westmoreland Intermediate Unit's Clairview School held a faculty jeans day and chose the UMDF as their charity of choice.

**February 7, 2015** The First Energy for Life Walk of 2015 took place at Sam Houston Park in Houston, TX, and raised over $33,000!

**February 14, 2015** Dance Your Cares Away for a Mito Cure was held at the Brookston Area Elementary School in Brookston Indiana. The family semi-formal raised over $1300!

**February 21, 2015** The UMDF partnered with the New Jersey Devils of the National Hockey League as a charity partner for their home game against the Carolina Hurricanes *(page 9)*. Representatives from the Delaware Valley Region walked out onto the ice before the fame to accept their check from the team.


*Shane Stewart and his team for "Birdies for the Blind"*

*EFL: Atlanta*

# Upcoming Events & Fundraisers

**March 21, 2015** – The 6th annual Jackson Culley Mito What? 5k will be held at the USA stadium in Millington, TN. For more information please contact Angie Nunn: angienunn73@gmail.com.

**March 28, 2015** – Energy for Life Walkathon: Atlanta will be held at Piedmont Park's Promenade Lawn. 1342 Worchester Drive, Atlanta, GA 30306. Contact Cheryl Porter for information: energyforlifewalkatlanta@gmail.com

**March 28, 2015** – Energy for Life Walkathon: Dallas-Fort Worth will be held at Downtown Garland Square. Main Street and N 6th Street, Garland, TX 75040. Contact Shawna McElveen and Sara Puckett for more information: efldallastx@gmail.com

**March 28, 2015** – Energy for Life Walkathon: Nashville will be held at Centennial Park. 2500 West End Avenue Nashville, TN 37203. Contact UMDF Southeast regional coordinator Margaret Moore for more information: Margaret.moore@umdf.org

**March 29, 2015** – Energy for Life Walkathon: Tampa Bay will be held at Al Lopez Park. 4810 N. Himes Avenue, Tampa Bay, FL 33614. Contact Cecilia Coloret for more information: ccoloret@aol.com.

**April 11, 2015** – Energy for Life Walkathon: Shreveport / Bossier City will be held at Airline High School. 2801 Airline Drive, Bossier City, LA 71111. Contact Tammy Reyna for more information: tammy_veit@yahoo.com.

**April 18, 2015** – The 12th annual Bet on Baylee event in honor of Baylee Thompson will be held at the Perry County Fairgrounds in New Lexington, OH. For more information please contact Jody Thompson: buff2506@hotmail.com.

**April 18, 2015** - Energy for Life Walkathon: San Francisco Bay Area will be held at Bishop Ranch Business Park BR8. 5000 Executive Parkway, San Ramon, CA 94583. Contact Norma Gibson for more information: mn_gibson@yahoo.com.

**April 25, 2015** – Energy for Life Walkathon: Cincinnati will be held at Eden Park Mirror Lake Gazebo. 950 Eden Park Drive, Cincinnati, OH 45202. Contact Kristi Strawser and Alissa Whitt for more information: cincyenergyforlifewalk@gmail.com.

**April 25, 2015** – Energy for Life Walkathon: Pittsburgh will be held at the North Shore Heinz Field Lawn. 100 Art Rooney Avenue, Pittsburgh, PA 15212. Contact Northeast Regional Coordinator Nicole Shanter for more information: efl.pittsburgh@gmail.com.

**April 25, 2015** – Energy for Life Walkathon: St. Louis will be held at Tower Grove Park. 4256 Magnolia Avenue, St. Louis, MO 63110. Contact Victoria Helms for more information cbsblasmom@gmail.com.

**May 9, 2015** – Energy for Life Walkathon: Evansville will be held at Burdette Park. 5301 Nurrenbern Road, Evansville, IN 47712. Contact Jill Jansen, Amanda Sharma, and Jamie Sterchi for more information: evansvilleefl@gmail.com.

**May 30, 2015** – A Bike Run will be held in memory of Conner Hadden and benefit the UMDF at the Ford City Eagles Club in Ford City, PA. The event will include a motorcycle poker ride, dinner, and a Chinese auction! For more information contact Rachele Hadden at all4conner@yahoo.com.

**June 6, 2015** – Muddin in the Pines, a video game tournament, will be held in Flagstaff, Arizona, to benefit those with mitochondrial disease. For more information please contact Phantom Gamers Society via Facebook: www.facebook.com/pages/phantom-gamers-society.

**June 13, 2015** - Energy for Life Walkathon: Iowa will be held at Zsavooz . 206 Brandilynn Blvd. Cedar Falls, IA, 50613. Contact Ronda Eick and Ashley Dawn Arnold for more information: mitoiowa@yahoo.com.

# Awards

*Jade Thompson (center) accepts the 2014 Heartstrings Award from Dan Wright and Chuck Mohan at the 2014 UMDF Symposium*

Every year, the UMDF honors the accomplishments of our constituency. A number of awards are invited for nominations from the public. The UMDF invites you to nominate candidates for the three awards listed below. The deadline for nominations is April 30, 2015.

The awards will be presented at the UMDF's annual symposium on June 19, 2015. The winners will be honored with a plaque and will be featured in the UMDF Newsletter.

## Energy Award

The purpose of the UMDF Energy Award is to recognize an individual who embodies the spirit of the UMDF and its Mission of "promoting research and education for the diagnosis, treatment, and cure of mitochondrial disorders and providing support to affected individuals."

There is no age restriction for the nominee. You may nominate an individual for the UMDF's Energy Award by filling out the form online with a 100 word explanation as to how this individual has exemplified the UMDF Mission.

You may also mail or e-mail supportive documents of your nomination to info@umdf.org (please put Energy Award Nominee and their name in the subject line) -- listing projects, activities, or other information that highlights their efforts in supporting the UMDF mission.

*Submit your nominations online at https://www.surveymonkey.com/s/2015Energy*

## Heartstrings Award

The Heartstrings Award recognizes a child or teen that has donated or raised funds for the UMDF, enabling the UMDF to continue its mission. The individual recognized must be under 18 years of age at the time of the donation or fundraising activity.

As part of the criteria for the award, the nominee must implement a fund raising project, demonstrate how the project was communicated to the community for awareness, and show the time invested in the project. The amount raised in comparison to the age of the individual will be considered. For nominees who donate funds, the judges will consider the generous spirit shown, communication, and amount donated in relation to the age of the individual.

You may nominate an individual for the Heartstrings Award by filling out the form online with a 100 word explanation as to how this individual has "tugged at your heartstrings" through fund raising for or donation to the UMDF. Identify important features of the nominee's activity, such as the time invested, creativity, communication skills, determination, effectiveness, and generosity.

*Submit your nominations online at https://www.surveymonkey.com/s/2015Heartstrings*

## LEAP Award

The LEAP Award recognizes an individual who is living positively with mitochondrial disease (Living, Encouraging, Achieving, & Persisting).

In order to be nominated, the nominee must be at least 14 years of age or older. The nominee must have a confirmed or suspected mitochondrial disease and has demonstrated how they overcome the daily challenges to achieve their goals in career, family or volunteer service. The nominee must demonstrate a positive attitude, hope for a brighter future, and have enthusiasm that inspires others.

You may nominate an individual for the LEAP Award by filling out the form online with a 100 word explanation as to how the nominee demonstrates a positive attitude, hope for a bright future, and inspires others. If you wish, please provide copies of articles about the nominee, lists of projects, activities, or clubs to which the nominee belongs.

*Submit your nominations online at https://www.surveymonkey.com/s/2015LEAP*

# MITOCHONDRIAL MEDICINE: 2015 WASHINGTON DC

## HYATT DULLES, HERNDON, VIRGINIA

### Scientific Program
June 17-20, 2015

**Experts from around the world will be harnessing the power of BIG DATA to understand mitochondrial disease and deliver the following learning objectives:**

- Describe the ways in which "Big Data" can be used to find new gene disorders, understand mitochondrial disease mechanisms, and develop new therapies for mitochondrial disease.
- Recognize how cellular signaling is altered by mitochondrial disease, and can be targeted to devise new mitochondrial disease therapeutic approaches.
- Explain the current knowledge of how mitochondria interacts with the rest of the cell, both through physical connections and diverse import mechanisms.
- Identify the role of proteostatic stress and nuclear response to mitochondrial disease in contributing to disease pathology.
- Describe the ways in which cellular nutrients and nutritional interventions influence mitochondrial function.
- Associate the ways in which genetic counseling can best be applied in mitochondrial disease.
- Indicate how patient priorities, new drugs, and personalized clinical trials are being aligned to bring effective treatments to mitochondrial disease patients.

### Patient/Family Program
June 17-20, 2015

***Wednesday*** - LHON Sessions

***Thursday*** - Day on the Hill

***Friday and Saturday***

Topics include:

- Basics of Mitochondrial Disease
- Pulmonary Care for Patients with Mito
- Exercise and the Mitochondrial Disease Patient
- Gastrointestinal Issues and the Mitochondrial Disease Patient
- Palliative Care Sessions
- Feeding Issues: Optimal Nutrition for Gastrointestinal Dysmotility
- Special Young Adult Session
- Adult and Parent Sharing Workshops
- Immunizations and the Mitochondrial Disease Patient
- Marijuana: Myth, Legend, or Just Madness – Implications for Epilepsy and Mitochondrial Disorders
- Neurological Manifestations in the Adult Mitochondrial Patient

## NEW - Genetic Counseling and the Mitochondrial Community

A special track targeted to both the Clinical and Patient/Family attendees.
This special track will provide continuing education for genetic counselors and CME credits.

# PROGRAM REGISTRATION FORM
## Mitochondrial Medicine 2015: Washington DC
## Hyatt Dulles - Herndon, Virginia
## June 17 - 20, 2015

**REGISTER NOW TO GUARANTEE YOUR ATTENDANCE!**

**To Register:**
1. Complete the registration form below and mail it back to the UMDF.
2. Complete the registration form below and fax it to UMDF at 412-793-6477.
3. Register online at www.umdf.org/symposium/registration. Use the registration code FAM1505 or SCI1505.

**Registration Code: SCI1505**

**SCIENTIFIC PROGRAM FEES (Full four-day registration)**

- ☐ $800 Physician/Researcher
- ☐ $750 UMDF/MMS/MRS/MIP Members (discount rate)
- ☐ $450 RN's/Allied Health Professionals/Residents/GCs/Fellows*/Students
- ☐ $10 Transportation Fee *(Bus travel to Capitol Hill on Thursday)*

*(*Letter from program director must be received in our office before May 29, 2015, in order to receive this fee.)*

*Full registration entitles you to a hard copy syllabus, daily continental breakfast, refreshment breaks, lunch and the Friday night UMDF banquet. Daily Rate Fee includes all of the above except for the banquet. Payment must be received prior to attendance at symposium.*

**Registration Code: FAM1505**

**FAMILY PROGRAM REGISTRATION FEES**

- ☐ $225 Individual Registration
- ☐ $400 Family Registration *(2 adults/same household)*
- ☐ $50 LHON Program **Only**
- ☐ $65 Additional Friday Night Banquet tickets *(per ticket)*

Registration fees includes hard copy of syllabus, daily continental breakfast, lunch, refreshment breaks, Wednesday LHON session and the Friday Night Banquet.

**TEEN REGISTRATION** *(Sessions are free but registration is required!)*

- ☐ FREE Teen Registration *(Lunches and banquet not included)*
- ☐ $5.00 Friday Lunch *(per teen)*
- ☐ $10.00 Friday Night Banquet *(Special pricing for teens)*
- ☐ $5.00 Saturday Lunch *(per teen)*

Please make all checks payable to: **The United Mitochondrial Disease Foundation**

Please charge this registration to the following: Visa MasterCard Discover American Express

Card Number _____ Expiration Date _____

Name as listed on card (please print) _____

Signature _____ (invalid without signature)

PLEASE PRINT CLEARLY

Last Name _____ First Name _____ MI _____

Degree/Suffix _____ Specialty _____

Address _____

City _____ State/Province _____

Country _____ Zip/Postal _____

Email: _____

Phone: _____ Fax _____

Mail to UMDF, 8085 Saltsburg Road, Suite 201, Pittsburgh, PA 15239 or fax to 412-793-6477

### Genetic Counselors
A special genetic counseling session will be offered on Saturday, June 20, 2015. Visit www.umdf.org/symposium for registration information.

### Daily Rates
Registration for single days of symposium is available online.

### Banquet Tickets
Additional tickets for the Friday night banquet are available online.

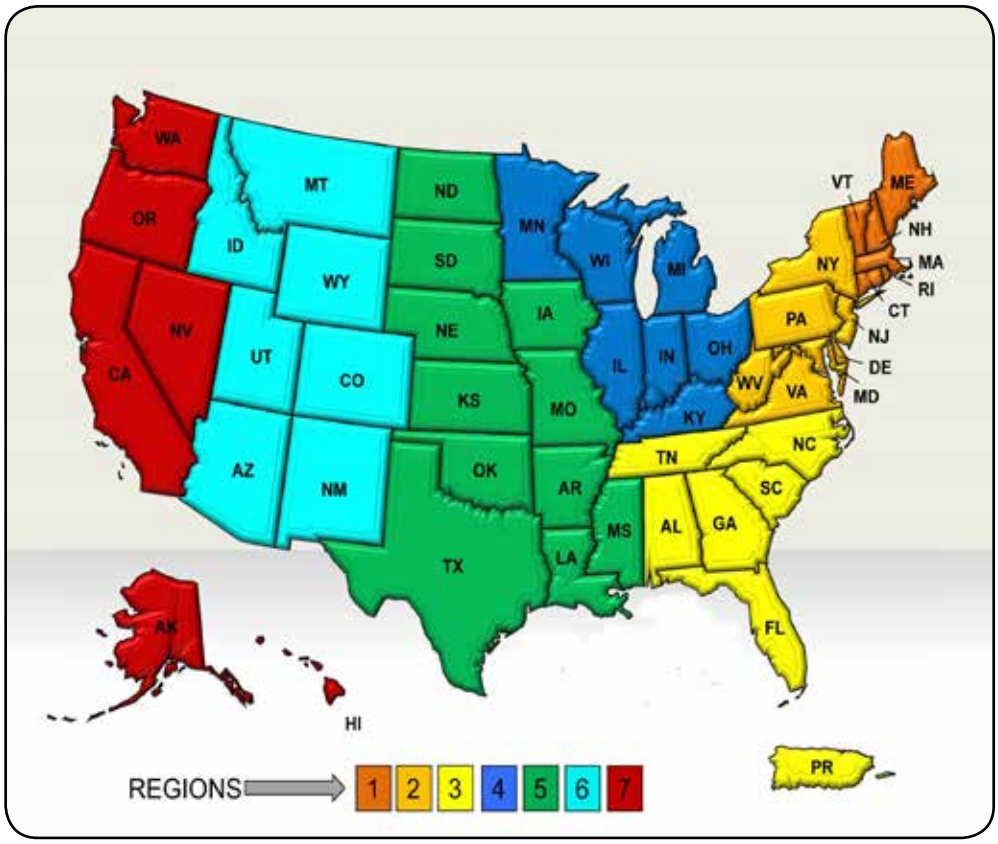
### Scooters
UMDF has arranged for scooters for those in need of this type of assistance. In order to ensure that we can meet your needs, please be sure to request a scooter on your registration form.

### Cancellation Policy
Because attendees or family members may face unforeseen illness, the UMDF will refund the registration fee, less $25 cancellation fee, for cancellations received by May 29, 2015. All refunds will be made after the symposium is over.

UMDF connect
Resources for help & support.

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.
Are you interested in volunteering? If yes, please visit www.umdf.org/volunteeropps!

# WHAT UMDF REGION DO YOU LIVE IN?




## NETWORK WITH OTHERS

Inspire™ together we're better℠

Inspire is a free online patient/caregiver community organized by discussion topics.
Visit us at:
*www.inspire.com/groups/united-mitochondrial-disease-foundation*

## Follow us on:

The UMDF Facebook Group is intended for networking with affected individuals and families. Join us at *https://www.facebook.com/#!/groupsumdfgroup.*

"Like" our page to stay updated! Simply type United Mitochondrial Disease Foundation in the search box on Facebook to find our page.

# UMDF REGIONAL COORDINATORS

Below are the UMDF's current regional coordinators and their email addresses.
We also encourage you to stay up to date in your region by visiting the regional webpages listed below

*Northeast Region 2*
**Nicole Shanter**
Nicole@umdf.org
www.umdf.org/northeast

*Southeast Region 3*
**Margaret Moore**
Margaret.Moore@umdf.org
www.umdf.org/southeast

*Great Lakes Region 4*
**Anne Simonsen**
anne.simonsen@umdf.org
www.umdf.org/greatlakes

*Central Region 5*
**Crissy Harris**
crissy.harris@umdf.org
www.umdf.org/central

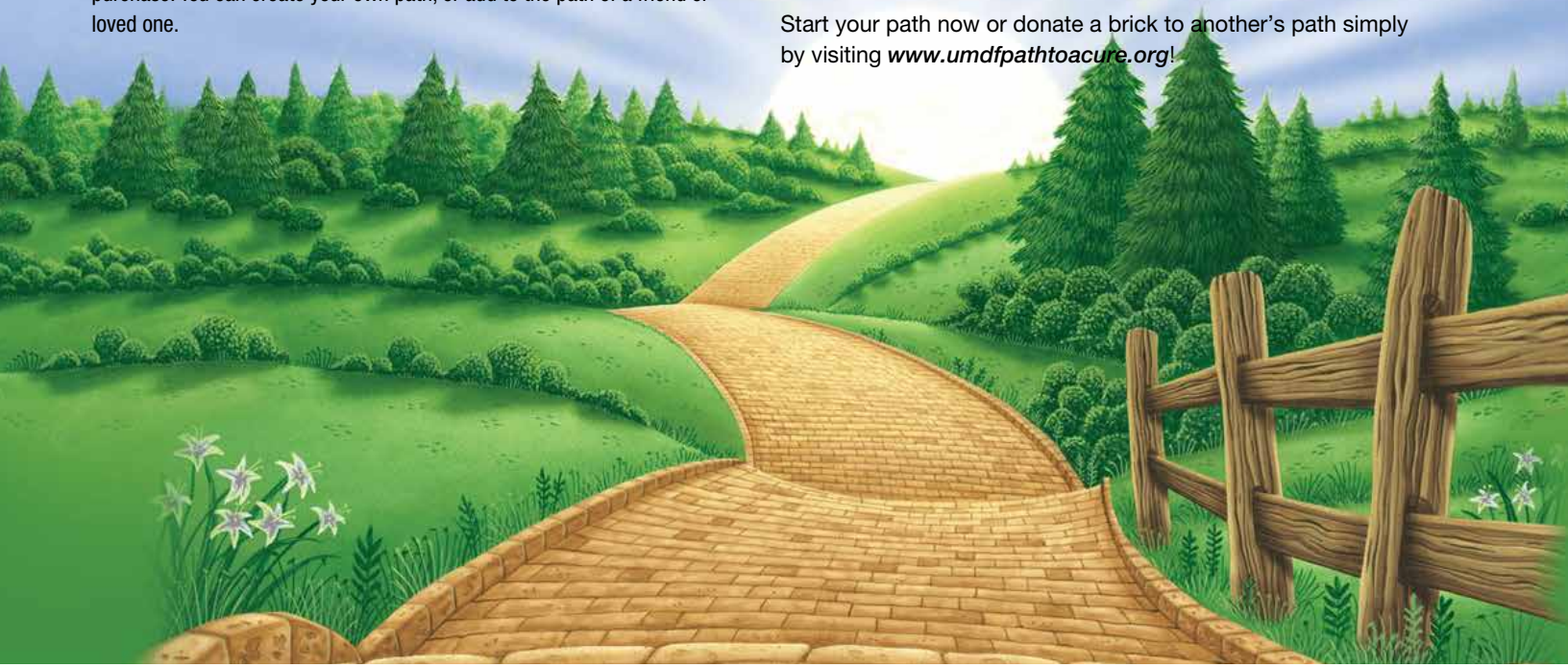
# Join the UMDF on the Path to a Cure!

Looking for a unique way to honor your loved one? Consider purchasing a brick on UMDF's Path to a Cure and help us fund crucial research at the same time. The donation of a virtual brick on UMDF's Path to a Cure is a perfect way to honor a loved one or celebrate the memory of a mitochondrial disease patient.

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

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

Start your path now or donate a brick to another's path simply by visiting ***www.umdfpathtoacure.org***!



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