PATIENT REGISTRY THROUGH NAMDC TO BE AVAILABLE THIS FALL

The North American Mitochondrial Disease Consortium (NAMDC) is targeting this fall as the timeframe for receiving all of the required approvals to begin soliciting information from mitochondrial disease patients for a new Clinical Patient Registry. The Clinical Patient Registry will be open to all affected individuals. The UMDF serves as a collaborative partner with NAMDC and will fill the role of liaison between NAMDC and the affected community.

By participating in the NAMDC Clinical Patient Registry, patients will provide researchers with a large database of information that will be used for research at clinics around the nation and the world. “This wealth of information will help researchers in their development of potential treatments of mitochondrial diseases,” said Salvatore DiMauro, M.D., Columbia University Medical Center, one of the principal investigators of the project. Joining Dr. DiMauro as principal investigators are Michio Hirano, M.D., Columbia University Medical Center and Russell Saneto, D.O., PhD, Seattle Children’s Hospital and University of Washington School of Medicine. Dr. DiMauro says patients who participate will have the option of receiving periodic research updates about mitochondrial diseases, including personal notification of upcoming research projects for which they may be eligible.

The NAMDC Patient Registry is being created to inform parents, or the parents of patients, of clinical research studies. When patients participate, researchers can identify and recruit those who are eligible for participation in current and future clinical research studies. “It is critical that all members of the mitochondrial disease community participate because this helps researchers continue to seek new ways to improve the quality of life for all mitochondrial disease patients,” said Charles A. Mohan, Jr., CEO and Executive Director of the UMDF. “Patients who participate in this type of research make it possible to find new treatments and help us a little farther in our journey towards a cure,” Mohan said. “NAMDC tells us that if a patient submits specimens for evaluation, the medical experts there will do their best, based on the information they have, to provide a diagnosis for the patient. This is phenomenal for patients who wonder what type of mitochondrial disease they have and for those who suspect they have mitochondrial disease, but who have not received a diagnosis.”

At the present time, NAMDC has 10 clinical centers ready to participate. They are:
- Columbia University Medical Center – New York, NY
- Seattle Children’s Hospital and Regional Medical Center – Seattle, WA
- Mayo Clinic – Rochester, MN
- Cleveland Clinic, Rainbow Babies & Children’s Hospital, Case Western Reserve University Medical School – Cleveland, OH
- McMasters University – Hamilton, ON, Canada
- University of Florida College of Medicine – Gainesville, FL
- University of Texas Southwestern Medical School – Dallas, TX
- Baylor College of Medicine – Houston, TX
- University of Southern California – San Diego, CA
- Buffalo General Hospital – Buffalo, NY

The goal of the consortium is to register patients in all 50 states and in every country around the world. When patients register, their information will be kept confidential. No personal identifying information will be given without the permission of the individual registering. Watch for an Eblast and information posted on www.umdf.org indicating when the clinical patient registry will be accepting patients.
Fall is a tremendously busy time for all of us at the UMDF. Over the past month or so, eight “Energy for Life Walkathons” have kicked off with great success. At press time, we are still monitoring the progress of the September walks. Our first walkathon this fall was in Normandale, Minnesota, and the organizers, Kalynn Wendt and Stacey Pieper, set a goal of just under $61,000. This goal was a substantial increase over the $28,000 raised last year. Not only did the Minnesota walk meet its 2010 goal, but it exceeded it by more than $15,000! We are still collecting walk pledges as we go to print, but so far, the walkathon in Minnesota has raised nearly $75,000 towards a cure. Well done ladies and everyone else involved – I can’t wait to see what happens next year!

The UMDF also wishes to extend its gratitude and thanks to Andrew Nesseth and Lindsay Chapman, the parents of Leo James (The Lion) Chapman-Nesseth, their family, friends and supporters. Leo was born June 6, 2009, and passed away June 9, 2010. Leo had Alpers Syndrome, and his family and friends were so touched by this courageous child that they came together and used the Minnesota walk to help raise significant research dollars and awareness for mitochondrial diseases. Thank you for your dedication and for becoming part of the cure.

I also want to thank everyone who participated in “Awareness Week” this year. Hundreds of informational packets were sent from Pittsburgh to individuals who scheduled various events in schools, churches and synagogues, community centers and medical offices. For the first time, Awareness Week was celebrated across social media channels like Facebook and MySpace. Our Jack Black public service announcement was scheduled to air on television stations in 11 cities. In addition to the service announcement, we launched the ‘Jack Black Power Squad’ web page. The Power Squad web page has been getting a lot of hits and is helping to spread the word about mitochondrial disease.

Finally, I want to take this opportunity to ask for your participation in the North American Mitochondrial Disease Consortium (NAMDC), of which UMDF is a collaborator. By participating in the NAMDC Clinical Patient Registry, patients will provide researchers with a large database of information that will be used for research at clinics around the nation and the world. Participation may also identify patients for potential clinical trials. One of these trials could produce a cure or a treatment. Remember, TRIALS are the required next step to bring us close to cures for mitochondrial disease, and they are a critical part of our Mission.

Energy to all,

W. Dan Wright, UMDF Chairman
Living with mitochondrial disease presents many twists and turns and a maze of questions. UMDF is pleased to offer answers to some of those questions as taken from Ask the Mito DocSM at UMDF.org. Please note that information contained in Ask the Mito DocSM is for informational and educational purposes only. Such information is not intended to replace and should not be interpreted or relied upon as professional advice, whether medical or otherwise.

Responder for this issue: Sumit Parikh, MD, of The Cleveland Clinic, Cleveland, OH and Marni J. Falk, MD, of The Children’s Hospital of Philadelphia, PA.

THE QUESTION IS...
My 3 year old daughter, who has been diagnosed with a mitochondrial disorder (complex 1 and 3) has been prescribed methadone for chronic pain. What are your views on using methadone vs other pain medications? We are concerned about its toxicity towards mitochondria vs other medications.

RESPONSE FROM SUMIT PARIKH, MD:
I am sorry to hear that your daughter is having such pain, and a little surprised as well. Primary mitochondrial diseases infrequently lead to severe pain as their primary or only manifesting symptom, especially to the degree where methadone is needed. It is also atypical to hear of such severe symptoms at such a young age.

Since I do not have all the details about your child’s medical history, I would urge you to ensure that the symptoms are truly pain and not being automatically chalked up to mitochondrial disease. I would be sure that other causes of pain (occult fractures, dental caries, gastrointestinal problems, nerve disease) have been looked at - and treated prior to embarking on using Methadone.

Regardless of the cause of pain, there are other approaches to pain management outside of methadone that may have already been considered. These should include use of a chronic pain management program, where a team of physicians evaluates and treats your child in a rehabilitation setting for a 1-2 week period. There are only a few such pediatric programs available in the country, however, and you may have to leave your city to have your daughter attend one of these.

If the pain is secondary to something else, and all other options of treatment have been looked at, methadone may be the only choice. While there are many medications with potential or even proven mitochondrial toxicity, there are times when we are forced to use them since we do not have a better option. However, Methadone is not a medication that is outright contraindicated in mitochondrial disease.

THE QUESTION IS...
My three boys (7, 5, and almost 3) are suspected of having a probable mitochondrial disorder, and my two youngest have had a muscle biopsy. On my 5-year old’s biopsy, there were only minimal findings for a congenital myopathy (this was done when he was 2). Recently, my almost 3-year old was biopsied to see if we could get any more answers, and although his respiratory complexes were normal, his pathology had several findings such as type 2 fiber atrophy & basophilic regenerating fibers. His electron microscopy showed increased amounts of mitochondria in subsarcolemma, dilated mitochondria, and abnormal “cristae” structure. Genetics is convinced that this is the expression of a definite mitochondrial disorder, but neuro still won’t give a mitochondrial diagnosis, because the respiratory complexes were normal. It was a frozen biopsy. Do you think these findings constitute a mitochondrial diagnosis? Also, although his respiratory complexes were normal, his cytochrome C oxidase was elevated. Does this mean anything for diagnosis?

RESPONSE FROM MARNI J. FALK, MD:
It is certainly important to know the clinical manifestations in the children that have warranted suspicion of mitochondrial disease, as well as the family history of whether there are similarly affected individuals, particularly in the maternal lineage. However, the findings of “increased subsarcolemma mitochondria” together with “increased cytochrome C oxidase activity” are suggestive of mitochondrial proliferation. In view of abnormal cristae structure and mitochondrial dilution, this would together suggest the mitochondria are not normal. However, it is not clear if this is a “primary” or “secondary” mitochondrial problem. A “primary” mitochondrial problem implies the underlying genetic defect is in a nuclear DNA gene or mitochondrial DNA gene that encodes a protein directly involved in the energy-generating respiratory chain. A “secondary” mitochondrial problem implies there is mitochondrial dysfunction, but the underlying genetic etiology lies elsewhere beside a gene directly encoding the respiratory chain. Discerning between these two options, therefore, lies in the genetic etiology.

Historically, the diagnosis of “definite” mitochondrial respiratory chain dysfunction required demonstration of enzyme activities less than 20% of controls. However, it is well known that measuring “enzyme activity” of individual respiratory chain enzymes in the laboratory on a frozen piece of muscle will miss at least 10-15% of cases that might be identified by a different method involving polarographic assessment of integrated mitochondrial respiratory capacity across all of the respiratory chain complexes. This latter testing must be done on a fresh muscle specimen and is only available at a few centers world-wide (including CIDEM in Cleveland, OH, and Medical NeuroGenomics in Atlanta, GA). It is now recognized that only a minority of individuals with suspected mitochondrial disease have identifiable respiratory chain deficiency on muscle biopsy specimen testing.

What might be most helpful in this situation is to complete genetic-based testing in the remaining muscle specimen. This should include whole mitochondrial DNA genome sequencing for point mutations, mitochondrial DNA content analysis, and mitochondrial DNA deletion analysis. This testing is now commercially available at many US diagnostic laboratories, including Baylor Molecular Laboratory in TX. If mitochondrial DNA depletion is identified, that would lead to at least 9 nuclear genes that might be tested on a clinical basis. The ultimate diagnostic goal is thus not only to recognize the part of the cell that is dysfunctional but to understand the specific genetic cause for their problems. Only this will clarify their prognosis, the recurrence risk for other family members, and whether there are potential targeted treatment options available or on the horizon.

Submitting questions to Ask the Mito DocSM is a benefit of the UMDF “Energy” membership. If you are a member and would like to submit a question, log in to the UMDF website using your user ID and password. If you would like more information on becoming a member of the UMDF, email info@umdf.org.
CHAPTER EVENTS

CALIFORNIA CHAPTER
• August 14, 2010. The 17th annual Gibson Pot Luck BBQ was held in Ukiah, CA, in memory of Heidi Daniels. The annual event raised close to $4,000 for the UMDF this year! Thank you to Norma Gibson for your hard work and dedication to the UMDF!

CENTRAL OHIO CHAPTER
• August 6, 2010. The third annual Baylee’s Ball Bash was held at the Cannelville Softball Field in Cannelville, OH. The event was held in honor of Baylee Thompson and raised a little over $1,000 for the UMDF. Thank you to the Thompson family for your support!

CHICAGO CHAPTER
• July 4, 2010. A group from the Chicago Chapter made a float for the Wheaton parade. They spread awareness of mitochondrial disease to approximately 100,000 people and passed out nearly 6,000 green lollipops with info on mitochondrial disease! It was amazing to be asked by so many, “What is mitochondrial disease?”.

DELWARE VALLEY CHAPTER
• June 8, 2010. Approximately 90 people attended a luncheon to raise funds for the UMDF in honor of Rina Goldberg, who has mitochondrial disease. This luncheon was sponsored by the Women’s Club of Four Seasons South Knolls in Jackson, NJ, where Rina’s grandmother resides. Laurel Smith and Beate Pohlig of the UMDF joined to explain the complexities of the disease. The luncheon raised $1,650 for research.

• August 23, 2010. The Delaware Valley Chapter held an Awareness Night at the Camden Riversharks game. Despite the rain and bad weather, the Chapter members raised awareness of mitochondrial disease and raised money for the UMDF. Thank you to the Riversharks and all of you who came out to support the UMDF!

INDIANA CHAPTER
• August 28, 2010. Cornhole for Mito was held at Boston’s Restaurant in Newburgh, IN, and was a huge success! A total of 25 teams participated in the tournament with around 75-100 people in attendance. About $1,600 was raised at the event that day with a total of $3,600 donated to the UMDF.

OHIO CHAPTER
• July 17, 2010. Deb Fleming held her third annual picnic to raise money for the UMDF. The event raised over $1,500 for the UMDF in her honor. Thank you to Deb and her friends and family for your hard work and support!

OTHER NOTABLE EVENTS
• June 5, 2010. Thank you to everyone who sponsored and participated in the 2nd annual Landon’s Hope walk held in Windsor, CO. The day could not have been more beautiful. This years 5k walk included a balloon launch and was held in memory of not only Landon Weatherby but also Marie Schlachter. This year, Landon’s Hope raised $5,300 for the UMDF.

• June 12, 2010. Mason’s Mountain Run was held in the beautiful mountains south of Red Lodge, MT, in memory of a very special boy, Mason Bailey Shuck. Mason passed away in August 2009 after living with mitochondrial disease for 11 years. Mason loved spending time in the mountains. His parents, Mike & Gretchen, wanted to have an event that would encourage others to enjoy the outdoors, even if it takes a little more effort with children of special needs. Over two hundred people and one moose participated. The event was a huge success with over $22,000 raised!

• June 12, 2010. The Iowa Mito Group hosted the first annual Energy for Life walk in Cedar Falls, IA. Formerly Myles for a Cure, the event raised over $3,000 to help find a cure for mitochondrial disease.

• July 4, 2010. For the very first time, the Cowlitz Valley Runners hosted the 4th of July Fun Run in Kelso, WA, in honor of Joshua Chilson. A total of $1,000 was raised for the UMDF. A big thank you to volunteers and participants. The event will occur next year; hopefully, with an even bigger turnout!

• July 31, 2010. The Cincinnati Mito Group held the 2nd annual MitoMania benefit at The Farm in Cincinnati, OH. Over 400 people attended the gala and raised over $11,000 for the UMDF in honor of Ayden and Faith Hingsbergen! Thank you to the Hingslergen family and friends for your hard work and support!
**OTHER NOTABLE EVENTS (CON’T)**

- **August 7, 2010.** With close to 300 participants for the 3rd year in a row, Run4Raley has continued to be a success! Over $14,000 was donated to the UMDF, bringing the three year total to over $45,000!! Thanks to all the returning families and new members for supporting this cause!

- **August 8, 2010.** Aubrey’s Cut-a-Thon was held at the Harmony Salon in Pittsburgh, PA. The annual event is held in honor of Aubrey Neeley and raised over $3,500 for the UMDF. Thank you to all who participated and made the event possible.

- **August 16, 2010.** The Bobby Rahal Mercedes Golf Outing was held in honor of Aubrey Neeley in Pittsburgh, PA. A special thanks to Trent Neeley for nominating the UMDF to be the beneficiary of the donations. Thanks to everyone’s support, $9,000 was donated to the UMDF.

- **August 21, 2010.** The 4th annual Brew at the Zoo was held at the Pittsburgh Zoo & PPG Aquarium in Pittsburgh, PA. The event sold out with over 2,000 participants and raised nearly $130,000 for the UMDF. Thank you to all of the volunteers who made the event a smashing success!

- **August 21, 2010.** A roller derby fundraiser was held at Dads Broadway Skating Rink in Mesquite, TX. A special thanks to the Dallas Assassination City Roller Derby and Brandi Arnold for getting the ball rolling. Over $850 was donated to the UMDF for the Grace Brewer Research Fund.

**GIFTS FROM THE HEART**

- **Lizzie Palmer of Floyds Knobs, IN, was an essay finalist in the 2010 Disabilities Awareness Essay contest held by Rauch, Inc. Lizzie is a 4th grader at the New Albany County School District. As one of the winners, Lizzie was able to donate a cash prize to her designated charity, and she chose the UMDF. Thank you Lizzie for your support and congratulations on your winning essay!**

- **The “Brayden Turns 3” event was held in Barboursville, WV. Brayden has a mitochondrial defect of Complexes 1, 2 and 5 including OXPHOS. In lieu of gifts for his birthday, everyone made a donation to the UMDF. Friends and family were very generous and donated almost $700. Brayden had a great day playing with his water table, and the kids had fun with the inflatable slides.**

- **Happy 3rd Birthday Brayden; we cherish every year!**

- **A Casual Day was held at the Great River Medical Center in West Burlington, IA, in honor of Kristen McGuire. The employees raised a total of $437 for the UMDF. Thank you to all those who participated in the Casual Day!**

- **The 7th annual Kate’s Fun Walk was held in Pittsburgh, PA, in loving memory of Kaitlin Vasilich. The event raises funds for a scholarship in Kate’s name and a portion of the proceeds are donation to the UMDF. This year, the walk generated $310 for the UMDF in Kate’s name. Thank you to the Vasilich Family for your support!**

- **Lemonade stands were set up in honor of Katie Probert in Lyndhurst, OH. The Lemonade stands were conducted by Katie’s siblings, Becky and Jessie, and best friends, Jordan, Danny and Dominic Morlani. The little philanthropists were able to raise $111 for the UMDF in honor of Katie! Thank you for all of your hard work!**

- **Beth Mansmann held a jewelry party fundraiser in honor of her daughter Katlyn Mansmann. The Mansmann Family of Pittsburgh, PA, donated a total of $160 to the UMDF in honor of Katlyn! Thank you for your support!**

- **SandyMount Elementary School in Finksburg, MD, held a Jump-a-Thon Fundraiser at the school in honor of classmate Kayla Newman. The fundraiser raised a total of $1,600 for the UMDF in Kayla’s honor! Thank you to all of the teachers, students and parents for your support!**

- **Andrew Radney passed away on May 11, 2010. His teachers at Walnut Creek Elementary (Shay Prince, Michelle Neese, Elizabeth McCoy, and Diane Sales) set up “The Andrew Caleb Radney Research Fund” in his honor. The first fundraiser was spearheaded by Higgy’s Pizzeria. A buffet luncheon was provided and Higgy’s Restaurant donated 100% of the proceeds to Andrew’s Research Fund. Proceeds and donations from this event totaled $2,800.**

- **The annual Save Barnegat Bay 8k walk/run event was held in Lavallette, NJ, on June 26, 2010. The event benefited several charities, including the UMDF.**

- **Vicki Sendelbach participated in a 50k in honor of her nephew Alex who suffers from mitochondrial disease. Through donations, a total of $1,240 was raised for the UMDF. Thanks to everyone for their support!**

- **A Family Fun Day Event was held in Reisterstown, MD, with the primary focus being mitochondrial disease awareness. Mix 106.5 made an appearance at the event and approximately 100 people were in attendance. The event included a face painter, magician, and a guest appearance by Batman. A total of $250 was donated to the UMDF!**

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- **August 29, 2010.** Bowling for Mito was held at the Colonial Lanes in Orlando, FL. About 65 bowlers came out and raised $800 for the UMDF!
CHAPTERS, MITO GROUPS AND AMBASSADORS

ALABAMA
North Alabama Mito Group
Contact: Margie Silerp
E-mail: NorthALMito@aol.com

ARIZONA
Arizona Mito Group
Contact: Gina Blair, Susan Lake or Kelly LaFlamme
E-mail: aзо_аз@yahoo.com

CALIFORNIA
★California Chapter
President: Norma Gibson
E-mail: CalChapter@umdf.org
Chapter Ambassador – Sacramento Valley
Contact: Valina Combs
E-mail: valinajewel@comcast.net

COLORADO
Colorado Mito Group
Contact: Tami Weatherby
E-mail: tannieweatherby@msn.com

DELWARE
Delaware Mito Group
Contact: Judy Weeks
E-mail: jimmyjudyweeks@verizon.net

FLORIDA
Central Florida Mito Group
Contact: Amber Ferrell - Gainesville
E-mail: amberferrell@gmail.com
Contact: Jennifer Sauter - Orlando
E-mail: jsauter@yahoo.com
Contact: Kimberly Gray - Tampa Bay Area
E-mail: mitomom91@yaho.com

HAWAII
Ambassador – North East Florida
Contact: Sophie Sillag
E-mail: sillagy44us@yahoo.com

GEORGIA
★Atlanta Area Chapter
President: Chris Swinn
E-mail: ATLchapter@umdf.org
Southern Georgia/Northern Florida Mito Group
President: Ina Swinn
E-mail: dcbaltimore@umdf.org

IDAHO
Ambassador – West Central Georgia
Contact: Gail LaRamaiboise
E-mail: qgbirdie@aol.com

ILLINOIS
★Chicago Area Chapter
President: Cherie Lawson
E-mail: ChicagoChapter@umdf.org
Central Illinois Mito Group
Contact: Crystal Smith
E-mail: bandsmith@verizon.net

AMBASSADOR – Phlo
Contact: Luke or Leslie Kirby
E-mail: lkirby35@comcast.net
or lesliekirby@gmail.com

AMBASSADOR – Springfield
Contact: Patti Bauer
E-mail: pattibauer.aspen@yahoo.com

IOWA
Iowa Mito Group
Contact: Kim Novy or Darla Klein
E-mail: Knovy4@mcnsci.com
or honeybear50317@msn.com

AMBASSADOR – Northern Iowa
Contact: Ronda Eck
E-mail: mitoioa@yahoo.com

LOUISIANA
AMBASSADOR – Baton Rouge
Contact: Mandy Poche
E-mail: mpoch1@cox.net
AMBASSADOR – Bossier City
Contact: Anna Stewart
E-mail: philippanna@bellsouth.net

MARYLAND
★DC/Baltimore/Northern Virginia Chapter
President: Sharon Goldin
E-mail: dcbaltimore@umdf.org

MASSACHUSETTS/CONNECTICUT
★New England Chapter
President: Stefani Bush
E-mail: NENgChapter@umdf.org

AMBASSADOR – Jamaica Plain
Contact: Lindsay Knops
E-mail: lindsayknops@hotmail.com

MICHIGAN
Western Michigan Mito Group
Contact: Michelle DeWitt
E-mail: mldewitt729@yahoo.com

AMBASSADOR – Michigan
Contact: Carrie Gervaseone
E-mail: mxgervaseone@yahoo.com

MINNESOTA
★Minneapolis/St. Paul Chapter
President: Kaylyn Wendt
E-mail: MNCChapter@umdf.org

MISSISSIPPI
Greater Jackson Mito Group
Contact: Julie Manley
E-mail: manley_family@comcast.net

MISSOURI/KANSAS
Kansas City Mito Group
Contact: Theresa Edwards
E-mail: KZChapter@umdf.org
St. Louis Area Mito Group
Contact: Hope Grover
E-mail: hopey@charter.net

NEW YORK
★New York Metro Chapter
President: Kim Zuccollo
E-mail: NVYMetroChapter@umdf.org

AMBASSADOR – Albany
Contact: Jacqueline Perrotta
E-mail: caj1313@hotmail.com
AMBASSADOR – Ulica
Contact: Kimberly Dedrick
E-mail: bknedrick@yahoo.com

NORTH CAROLINA
Tar Heel Mito Group
Contact: Adriana Smith or Heather Baudet
E-mail: adriana.lisa.soiloff@gmail.com or hbaudet@mnc.org

AMBASSADOR – Fayetteville
Contact: Terry Holeman
E-mail: Terryt.shall@yahoo.com

OHIO
★Ohio Chapter – North East
President: Darcy Zehe
E-mail: OILChapter@umdf.org
★Central Ohio Chapter
President: CentralOhio@umdf.org

AMBASSADOR – Southeast Ohio
Contact: Jody Thompson
E-mail: gthompson@columbus.rr.com
AMBASSADOR – Toledo
Contact: Chris & Alisa Rawski
E-mail: arawski@aim.com

OKLAHOMA
AMBASSADOR – Oklahoma
President: Kyle & Katie Serfoss
E-mail: helphalley@yahoo.com

OREGON
Pacific Northwest Mito Group/Oregon
Contact: Gretta Cole or David Doyle
E-mail: Glo66@aol.com
or ddoyle@nanometrics.com

Pennsylvania
★Delaware Valley Chapter
President: Beate Pohlig
E-mail: DelValChapter@umdf.org

Pittsburgh Mito Group
Contact: Karen Wilson or Heather Pallas
E-mail: bwilson@cvzoom.net, hhcr2@comcast.net
AMBASSADOR – Central Pennsylvania
Contact: Kim Oleniski
E-mail: gabby244@deja2.com

SOUTHWEST CAROLINA
★Carolina foothills Chapter
President: Allison Rogers
E-mail: carolinafoothills@umdf.org

SOUTHERN CALIFORNIA
AMBASSADOR – Chapin
Contact: Karis Mott
E-mail: karismott@yahoo.com
AMBASSADOR – Warrenville
Contact: Brandi Polarity
E-mail: mitomovers@aol.com

TENNESSEE
★Middle Tennessee Chapter
President: Courtney Fellers
E-mail: midtennchapter@umdf.org

Memphis Area Mito Group
Contact: Emily Colley or Karrie LaCroix
E-mail: mitojack@gmail.com
or lacroixj@bellsouth.net
East Tennessee Mito Group
Contact: Kristie Goodwin
E-mail: mitomom@charter.net

TEXAS
★Houston Chapter
President: Deb Schindler - Boutinghouse
E-mail: HoustonChapter@umdf.org

Dallas Mito Group
Contact: Tova Sido
E-mail: tsido@hotmail.com
North Texas Mito Group
Contact: Joshua Brewer
E-mail: Joshuabibrewer@gmail.com

AMBASSADOR – Austin
Contact: Manuel Castro
E-mail: mitoustateun@gmail.com
AMBASSADOR – McAllen
Contact: Maya Rivera
E-mail: cutiesis696@aol.com

AMBASSADOR – Wichita Falls
Contact: Shamyin Kennedy
E-mail: mayn@kxando.com

VERMONT
AMBASSADOR – Vermont
Contact: MaryBeth LeFevre
E-mail: athynmyb@aol.com

WASHINGTON
Ambassador – NW Washington
Contact: Joy Krumdiack
E-mail: jekrumdiack@ihinet.com

WEST VIRGINIA
Ambassador – West Virginia
Contact: Stacy Spurlock
E-mail: shanesntacy@msn.com

WISCONSIN
Ambassador – Kimberly
Contact: Mindy Welhouse
E-mail: mwwelhouse63@ionix.org

AMBASSADOR – Milwaukee
Contact: Karen Loftus
E-mail: karen.loftus13@yahoo.com

INTERNATIONAL
Ambassador – Australia
Contact: Rob Ryan
E-mail: gma1@bigpond.com

Ambassador – Hungary
Contact: Andrew Alexander
E-mail: andrewvangold@yahoo.co.uk

AMBASSADOR – India
Contact: Nilam Argawal
E-mail: neelamshroff@gmail.com

Ambassador – Norway
Contact: Anne Hansen or Vidar Hunstad Vik
E-mail: anne.h@mitokondrieforeningen.no or
vidar.v@mitokondrieforeningen.no

Ambassador – United Kingdom
Contact: Rowland Dicker
E-mail: Rowland@dicke.org.uk

Ambassador – Winnipeg
Contact: Keely Schellenberg
E-mail: kschellenberg@mts.net

UMDF YOUTH AMBASSADORS
California
Contact: Joe Wise
E-mail: jbwise@gmail.com

Georgia
Contact: Emily Swinn
E-mail: ATLchapter@umdf.org

New York
Contact: Alexandra Simonian
E-mail: ahsimonian@msn.com

Pennsylvania
Contact: Tyler Liebegott or Colleen Powell
E-mail: Tliebegott@yahoo.com or justlive67@aim.com
UPCOMING EVENTS

ARIZONA CHAPTER
• December 19, 2010. The Energy for Life Walkathon: Arizona will be held at Kiwanis Park in Tempe, AZ. Please visit www.energyforlifewalk.org/arizona for more information.

ATLANTA CHAPTER
• October 30, 2010. Sandy Riggin, a 46 year old woman with a mitochondrial disease, is running in the Silver Comet Half Marathon in Atlanta, GA. Sandy hopes to raise $5,000 to help fund research and welcomes your support. For more information visit www.umdf.org/sandy.

CAROLINA FOOTHILLS CHAPTER
• October 9, 2010. Greg Wellman of the Carolina Foothills Chapter will participate in the Swim for Them 10K swim. Greg will be swimming in honor of Adam and Braeden Rogers. For more information or to make a pledge, visit www.firstgiving.com/wellman10kswim.

CENTRAL OHIO CHAPTER
• October 3, 2010. The Olivia Steele Memorial Golf Outing will take place at The Players Club at Foxfire in Lockbourne, OH. The outing will begin at 9:00am. To register, please email JR Steele at jr-steele@hotmail.com.

• October 17, 2010. Scott Hammond is running in the Columbus Marathon in memory of his son, Teddy Hammond. For more information, or to make a pledge visit www.umdf.org.

DC/BALTIMORE/NORTHERN VIRGINIA CHAPTER
• October 23, 2010. The 2nd annual Fall into a Cure gala will be held at Belle Haven Country Club in Alexandria, VA. Tickets are $75 per person. Visit www.umdf.org/dcgala for more information and to purchase your tickets.

HOUSTON CHAPTER
• October 28, 2010. Gleannloch Farms Holiday Market Show will be held at Gleannloch Pines Golf Club in Spring, TX. The event will benefit the UMDF in honor of Curtis Jackson. Show will begin at 10:00 am and run until 8:00 pm.

NEW ENGLAND CHAPTER
• October 2, 2010. The Annual LEGO Walk and Masquerade Parade will be held at the LEGO Campus in Enfield, CT. Get in the Halloween spirit early while raising funds and awareness for mitochondrial disease! There will be LEGO building activities, raffles, and prizes for the best costumes! FUN for the whole family! Costumes encouraged but not required.

• October 23, 2010. The Mito Masquerade will be held at Harrington Elementary School in N. Chelmsford, MA, starting at 6:00 pm. Admission is $5 at the door and you will enjoy music, raffle prizes, food, and a costume contest!

• November 15, 2010. The Publick House Cooks for UMDF will be held at the Publick House on Main Street in Sturbridge, MA. An All-You-Can-Eat Buffet of a Traditional Thanksgiving Meal, including lemonade, soft drinks, and cupcakes, will be served from 5:00-7:30 pm.

NEW YORK CHAPTER
• October 16, 2010. Helping on the Hudson dinner and auction will be held at the Sunset Cove Restaurant in Tarrytown, NY. Tickets can be purchased for $100 each. Please call Kim Zuzzolo at 914-332-0490 or email kimzuz@optonline.net to purchase your tickets! For more information, please visit www.umdf.org/helpingonthehudson.

AROUND THE COUNTRY
• October 8, 2010. A Trivia Night with live auction will be held at the Knights of Columbus Council #384 in Springfield, IL. The event will include beer, wine and soda for only $25. Save $5 by registering online at www.umdf.org/trivianight.

• October 9, 2010. Held at South Lakes Park in Denton, TX, the 4th annual Kure for Kat offers all participants a fun-filled experience with entertainment, refreshments, mitochondrial disease resources, and much more! Please visit www.umdf.org/kureforkat for more information.

• October 10, 2010. The Double Wide Grill in Pittsburgh, PA, will be holding a Pancake Breakfast to benefit the UMDF. For just $12, you can get all-you-can-eat pancakes, potatoes, juice or coffee. For more information contact the UMDF at 888-317-UMDF.

• October 16, 2010. Macy’s will host the 5th annual Shop for a Cause to benefit charities nationwide. UMDF will be participating and selling $5.00 tickets through the national office. This ticket entitles you to 25% off Macy’s merchandise on October 16th. Go to www.umdf.org/shopforacause to purchase a ticket.

• October 23, 2010. The 2nd Bruster’s Fundraiser & Costume Contest will be held at the Bruster’s Ice Cream in Ingomar, PA.

• November 6, 2010. The 2nd annual Photo’s for Mito is being held in Gainesville, FL. Come out and have a photography session in exchange for donations to the UMDF. Visit www.umdf.org for more information.

If you are having or have held a fundraising event, or are in need of assistance, we want to talk to you!
Email events@umdf.org or call 888-317-UMDF.
WHAT IS THE MOST IMPORTANT QUESTION SOMEONE HAS WHO IS CONSIDERING A GIFT TO THE UMDF?

Before a person donates, they want to know how much of their gift will be used to promote education about mitochondrial disease, support affected individuals, or provide researchers with grants for use towards finding a cure. “We are very proud of the fact that 84 cents of every dollar donated to the UMDF is spent on our programs, research and awareness,” said Marian Weil, Director of Development. “Our donors are very pleased with the fact that only 06 cents on every dollar is spent on administrative costs, which is well below the national average, and 10 cents is spent on the effort to support our fundraising.” Weil says that donors have come to expect a high level of trust from the UMDF when gifts are made in support of the UMDF and its research projects.

It is no secret that the UMDF is the nation’s largest non-governmental funder of mitochondrial specific research projects. To date, more than $7 million has been donated by individuals and used for some of the world’s most promising research. Securing a UMDF research grant is not an easy task for a researcher or clinician. In the last grant cycle, the UMDF received 175 letters from researchers from around the world. The applicant must briefly describe their proposed project. Each letter received is then reviewed by the UMDF’s Grant Review Committee. Projects that present an opportunity to fund promising research are advanced to the next stage.

Last year, only 35 researchers were asked to submit a full proposal to the Grant Review Committee for consideration. Each proposal can contain 20-30 pages of information. The UMDF was able to make available $315,000 to fund four projects. Unfortunately, there were seven more projects with competitive scores within 2% of these winning grants that would have been funded if the UMDF had the available dollars. Scientists refer to these grants as “fundable”. The committee must prioritize projects that provide the “most bang for the buck” in moving us one step closer to a cure.

The stringent guidelines for grant awards assure that projects receiving a grant are only for mitochondrial disease and dysfunction research. Many times, funding requests received by the Grant Review Committee may highlight the ‘mitochondrial’ angle of a particular project, but in reality, mitochondrial disease and dysfunction are the secondary or even tertiary focus of the proposed project. The UMDF focus on the diagnosis, treatment and potential cures for mitochondrial diseases assures a donor that their gift is financially supporting the research for which it was intended.

Since 1998, the UMDF Research Grant Program has provided awards to 76 projects. Many of them are works still in progress. None of them are the singular work of one individual, institution or university. Several have already provided amazing findings.

In 2006, the UMDF funded a project proposed by Michael Palladino, PhD, a researcher at the University of Pittsburgh. Dr. Palladino and his lab received a $98,000 grant for research that used fruit flies to assess the effectiveness of potential treatments for mitochondrial disease patients. Based on the data that Dr. Palladino and his team were able to collect with the grant award from the UMDF, they secured a $750,000 grant from the National Institutes of Health (NIH). As he continues his work, Dr. Palladino may be able to help determine which treatments for mitochondrial diseases are effective and which are not.

In 2005, Dr. Patrick Chinnery, Professor of Neurogenetics at University of Newcastle on Tyne in the United Kingdom, was awarded a $162,000 UMDF grant to determine the prevalence of mutations in the mtDNA in the general population. Dr. Chinnery wanted to test his theory that these mutations were more common than currently understood. In 2008, Dr. Chinnery made worldwide news when his findings were published indicating that 1 in 200 people carry a mutation in the mtDNA that could develop into a mitochondrial disease at some point in their lives. This finding is important because it tells us that mitochondrial diseases are not as rare as many may think.

In 2004, Vamsi Mootha, MD, Associate Professor of Systems Biology at Harvard Medical School, Associate Professor of Medicine in the Center for Human Genetic Research at Massachusetts General Hospital, and Associate Member of the Broad Institute of MIT and Harvard, received a $90,200 UMDF research grant. The grant enabled Dr. Mootha and his team to use powerful new research tools to identify 1,100 genes in our nuclear DNA that make proteins found in mitochondria. Dr. Mootha and his team are now able to search for the mutations in these genes in patients who have mitochondrial disease. As Dr. Mootha and his team continue their work, they hope the molecular underpinnings of mitochondrial disorders may offer clues for new treatment strategies.

The peer review process used by the UMDF to award grants is modeled after a process used by the NIH. Not all organizations follow this model or a similar process. Many donors choose to provide a gift to a hospital or university. What they are unaware of is the fact that hospitals and universities may use a portion of that gift as an ‘overhead’ charge. That charge can amount to as much as 50% in some cases and significantly reduce the overall effectiveness of the gift. In some cases, the money can be diverted to support well meaning but unintended efforts.

Some donors have decided that they would like to support the work of a particular physician or researcher directly and steer their contributions to that individual. When donations

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Devin Davis with her iPOP! Award

Devin Davis with her iPOP! award

Devin during one of her auditions

**LIGHTS...CAMERA...ACTION**

**A Day in the Life of Devin Davis**

The stage is set and Devin Davis is ready to be in the spotlight. Since she was a young girl, Devin has been interested in the performance arts. She started with a love of music and has since discovered her passion for acting. This past July, Devin had the opportunity to participate in the iPOP! (International Presentation of Performers) in Las Vegas, NV, and network with some of the top agencies in the industry.

Devin was born on May 26, 1992, and was a healthy baby girl. At about 6 months of age, she began to have difficulties lifting her head up from the floor when she was crawling. When she progressed to walking, she took care to keep herself from falling; a simple sneeze or giggle would knock her off balance and she would fall. Just 6 months later, at the age of 1, Devin was diagnosed with mitochondrial myopathy. Despite her diagnosis, Devin has been living her life to the fullest. This 18 year old is at the beginning of an exciting career.

In September 2009, Devin enrolled in the John Robert Powers Acting & Modeling School in Chicago, IL. The performing arts school works with children and adults to help better their modeling and acting skills. “The great part of this school is we have the opportunity to audition for all types of agencies,” says Devin. “These agencies are interested in up and coming talent, like me.” While attending the school, Devin learned about the iPOP! Convention that was being held in Las Vegas. “In order to attend iPOP!, you must first audition to be on the team,” Devin explains. “Only the top 12% are accepted; I was one of those lucky top 12%.”

Devin and her family joined 1,500 other contestants from four countries in Las Vegas on July 6, 2010. The convention spanned four days ending on July 9th with an awards ceremony and special showcase for top contestants. On Tuesday, Devin and her fellow contestants had their first round of auditions and did their first ‘impression walk’ on the runway. “On either side of the runway were all the agencies, managers, casting directors and producers that were looking for new talent,” says Devin.

Wednesday, Devin continued with auditions all day and had the opportunity to interview Jeremy and Jourdan Steel, two up and coming television hosts. “Throughout the course of the week, we were able to watch other auditions in our free time, such as the runway model competition, and dancing and singing competitions,” says Devin. “It was amazing!”

On Thursday, Devin was able to network with all of the agencies and producers who were in attendance. This was Devin’s chance to put a personality with her beautiful face. “It was our last chance to talk to them before call backs on Friday.” At the first awards ceremony on Thursday night, Devin received two honorable mentions (18-21 TV Commercial and Comp Card), and she took first place for the TV Beauty Commercial. “I was so excited for these awards,” said Devin. “I was especially proud because out of the 1,500 contestants, I was the only disabled one!”

On the Friday call backs, Devin was contacted by three separate agencies. “I was hoping to get one call back,” said Devin. “I was thrilled to receive three!” Out of the three agencies, one has a specific plan in mind for Devin. “I am unable to release the name of the company; however, if I land the job, I will let you know!” Devin promised us that the UMDF would be one of the first to know! Devin just learned that she has again been selected to attend the iPOP! Convention that will take place in January 2011 in Los Angeles, CA. “This was one of the best opportunities of my life!”

Devin is a true inspiration and example to what can be accomplished if you follow your dreams and shoot for the stars! We look forward to seeing Devin on the silver screen in the future. Lights...Camera...ACTION!
Living with mitochondrial disease presents many life challenges that extend far beyond the doctors, medical equipment, medications and constant explanations to individuals who ask us “Mito What.” It affects every aspect of daily life, and every “normal” transition that our children make is far more complicated than their non-affected peers. As a parent of a child with a mitochondrial disease, as well as a special educator, handling the public school system was not nearly as challenging as handling the transition to college. That being said, this transition makes me more proud of Jamie every day.

Jamie announced to my husband and me when he was ending his first year in high school that he was going to go to college in Philadelphia and that his goal was to attend Saint Joseph’s University. Those who know Jamie and his personality will not be surprised at that statement in the least, as he is a young man determined to meet his goals. So, not only did he make that announcement, but he made it while hospitalized for his IVIG therapy in the front of one of his doctors! His immunologist immediately supported his decision as Jamie explained his rationale for his choice and location. I will never forget one of his doctors’ statements during this “ambush.” He looked straight at me and said, “We have not worked this hard to keep him alive to not let him continue to strive for his goals.” With that, I entered the long and crazy journey of finding a college that would accommodate and welcome him and the unique challenges that mitochondrial disease brings.

Lessons Learned

College Students Have Different Legal Rights Than School Age Students

Throughout your child’s education, he or she receives a variety of rights under the Individuals with Disabilities Act. Once the student graduates, those rights end. College students who need any type of accommodations need to apply in their College’s Disability Office for a 504 Plan. This plan falls under the Civil Rights legislation, unlike the IDEA, which falls under Education Legislation. The process is different for every college as are the supports available at each college.

Another law, which is important for parents to be aware of, is the Family Educational Rights and Privacy Act. This is a federal law, which requires that parents provide consent for sharing of records when the student is in elementary and high school. Once a child turns 18 years of age, he or she is responsible for his or her own records. That means that without your child’s permission, you do not have access to records or even conversations with those at the college involved with your child.

Many colleges have a waiver that the student signs granting permission to his/her parents. In searching for a college, ask if they have such a waiver and then have your child sign it immediately.

It will be important for your child and you to understand how the college’s process works for accommodations. The accommodations are different in the following ways:

- Students have to ask for accommodations each semester.
- Students have to notify their professor and provide them with proof of the 504 plan.
- The student also must ask the professor to arrange for each accommodation, not just show them the form.
- If the accommodations are not meeting the students needs, the student must be the one to bring it to the attention of the professor and disability coordinator.

Some accommodations that the student received in high school, may not be available at the college.

Overcoming The Challenges Of Transition Requires Creativity, Flexibility and Letting Go

These are challenges; however, there are ways of working around them. Visit each college and meet with the disability coordinator. Take notes and then visit again after you have visited all the colleges, as you will have more questions.

Before the second visit, identify the supports that your child will need and ask your campus liaison to help you get them answered. Here is an example of supports that we have in place for our son.

- Cafeteria/Food Services: Dietary needs, meal plans
- Residence Life: Housing issues, accessibility, room maintained
- Learning Center: academic supports, test accommodations, tutoring
- Disability Coordinator: 504 Accommodations, testing issues, issues if the plan isn’t working
- Student Health Director: Medical needs, emergency plan, lab work, arranging medical visits, medications, etc.
- Counseling Center: Transition to college is difficult for all students, especially with mitochondrial disease.
- Student Success/Advocacy: Does the college have someone who serves as a student advocate?
- Security: Accessible transportation, emergency plans, transportation to lab, hospital, doctor’s appointments, what to do when the elevator does not work, your card does not swipe, etc.
- Financial Aide: Paying the bills, scholarship and other funding information.

The Decision, Setting it up and Trying it out

As you visit schools and ask for more specific information about their ability to accommodate the needs of your child, you will naturally find yourself weeding out schools. When they tell you upfront that certain things are or are not possible, immediately cross them off the list. If they are honest enough to tell you that they cannot do the things your child needs, you have found another school to visit.

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to keep those lines of communication open.

be happy that you asked.

with you about the feasibility of that option and

overnight for a visit, ask about having your
decision. If they have the opportunity to stay
and sitting in classes before you make that

is key that they feel comfortable on campus

ahead of time for your child's participation. It

needs, then there is no need to move forward.

Most colleges have accepted students days
where your child can spend the day on campus.

the day on campus. Arrange with the disability or admissions office
ahead of time for your child’s participation. It

is key that they feel comfortable on campus

and sitting in classes before you make that
decision. If they have the opportunity to stay
overnight for a visit, ask about having your
child participate. Most colleges will be upfront
with you about the feasibility of that option and
be happy that you asked.

Once the decision is made, you will need
to keep those lines of communication open.

The summer before, ask your contact if you
can meet to plan for a smooth transition. That
will be a valuable meeting; and if you have not
signed the FERPA waiver, sign it immediately
if possible. Decide how you will communicate
with those on the team. In our case, our son
has an advocate who works with the disability
coordinator to make sure that he is getting
what he needs to be successful.

The hardest part was letting go and seeing
if the plan worked. The difficult challenge
was sorting through struggles that our son
had and trying to determine if they were
“normal freshman struggles or “mitochondrial

struggles.” This will help you determine the
period for letting go depending on how your
child deals with the change. As with everything
in our mito world, there is no recipe that
works for all of us and identifying when you
need to reassess the situation. In our case,
we had several different changes in our plan
over the year and learned that it takes time,
patience and communication to make it work.
Our son has had many difficulties and now
heading into his sophomore year a confident
and active student at Saint Joseph's University
in Philadelphia. The college community has
learned about mitochondrial disease, and we
are a little bit grayer.

On June 17, 2010, the Board of Trustees for the United Mitochondrial
Disease Foundation approved an ambitious strategic plan for the
foundation. The plan, which took effect July 1, 2010, was created with
the help of Kelley Management and included the input of UMDF trustees,
staff, the scientific and medical community, and most importantly,
representatives of our chapters, groups and ambassadors.

The three year plan is ambitious and will help guide the foundation
to continue to fulfill our mission of promoting research and education
for the diagnosis, treatment and cure of mitochondrial disorders and to
provide support to affected families and individuals. Outlined below are our
strategic ambitions over the next three years.

MEMBER SERVICES

• Identify, establish and retain membership relationships with a
  significant percentage of total affected individuals, families and
  affiliated non-affected supported by a contact management
database/system that allows UMDF to capture all relevant data
relationships.

• Develop, pilot and implement a plan to restructure the chapter model
to support the future growth of the UMDF.

DEVELOPMENT

• Define/implement the development process for defining targets,
cultivating those targets, asking for gifts (specific projects/programs)
and the stewardship of targeted individuals, corporations and
foundations.

EVENTS

• Define and implement a UMDF Event strategy including an event audit
  process, categorization and standardization of events, the successful
  adoption of pledge based fundraising methods and the section/
adoption of a signature event by all chapters. Increase Energy for Life
Walkathon revenue by 2-3 times over 2009 levels by 2013.

AWARENESS AND EDUCATION

• The UMDF and mitochondrial diseases are recognized by the general
  population through the innovative use of emerging networking and
communication technologies (e.g., social media) and expanding
National media exposure and campaigns.

• UMDF is recognized as the “go to” resource on mitochondrial
  information for patient/family, pharmaceutical, nutriceutical, medical
and allied health communities.

• UMDF establishes a sustainable level of physician awareness in
the 50 largest populated area’s including a clinical and/or research
mitochondrial champion actively involved in the UMDF.

• Significantly increase U.S. Government support and coordination
across agencies for primary mitochondrial research and related
activities including the establishment of an NIH Office of
Mitochondrial Medicine.

INFORMATION TECHNOLOGY (IT)

• UMDF’s information technology (IT) solutions and investments are
  guided by a robust IT strategy and roadmap aligned to the UMDF
strategic plan by priorities. These IT solutions are recognized by
all who interface with it as meeting or exceeding needs in both
functionality and responsiveness to our strategy.

The UMDF will keep you updated on our progress as we continue in our
mission to provide research, education and support for affected individuals
and families.

Judy with her daughter Kate Rachau of Georgia

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needs, then there is no need to move forward.

Most colleges have accepted students days
where your child can spend the day on campus.

The summer before, ask your contact if you
can meet to plan for a smooth transition. That
will be a valuable meeting; and if you have not
signed the FERPA waiver, sign it immediately
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has an advocate who works with the disability
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we had several different changes in our plan
over the year and learned that it takes time,
patience and communication to make it work.
Our son has had many difficulties and now
heading into his sophomore year a confident
and active student at Saint Joseph's University
in Philadelphia. The college community has
learned about mitochondrial disease, and we
are a little bit grayer.

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At the international UMDF symposia, scientists, clinicians, and patients gather annually to share new scientific breakthroughs in the pursuit of improved diagnosis and treatment of Mitochondrial Disease. Such meetings serve to educate and build strong collaborations between scientists, physicians, and patients alike for the advocacy of mitochondrial research. In this year’s symposium, much of the scientific excitement surrounded PGC-1α, which serves to regulate the generation of new mitochondria, and Sirtuins, genes that regulate metabolism along with mitochondria function and aging, as new drug targets to treat mitochondrial diseases. Other meeting highlights included the development of reliable animal models to study human mitochondrial diseases and to test promising therapeutic treatments and the power of physical exercise to erase mitochondrial DNA mutations. Dr. DiMauro of Columbia University announced the North American Mitochondrial Disease Consortium, which will generate an infrastructure for patient groups, clinicians, and researchers. The last day of the meeting was dedicated to brainstorming about a potential connection between autism and Mitochondrial Disease.

Dr. Zolt Arany of Beth Israel Deaconess Medical Center and Harvard Medical School presented data on PGC-1α. Mice expressing PGC α run faster while mice which lack this gene are lazy and do not run at all in laboratory tests. Dr. Arany and his team further found that exercise increases PGC1α and the generation of new mitochondria, which leads to the formation of new blood vessels. Interestingly, the effect of PGC1α on increasing blood vessel formation depends on an estrogen receptor. Dr. Carlos Moraes of Miami University also discussed the benefits of PGC-1α in combating myopathies and delay muscle loss during aging.

A wide range of so-called mutator mouse models were conferred at the 2010 summer symposium. Such genetically engineered mice carry a mutation in the polymerase gamma gene, which causes the accumulation of mitochondrial DNA mutations, similar to those observed in some children suffering from mitochondrial diseases. These mice exhibit bone and muscle loss, neurodegeneration, weight loss, accelerated aging, and have a reduced life span. In addition, Dr. Richard Palmiter of Howard Hughes Medical Institute, Department of Biochemistry, presented data from a mouse model of human Leigh’s Syndrome, in which mitochondrial respiratory Complex I is defective. These models may serve as powerful tools for the pursuit of cures for such rare and debilitating mitochondrial diseases and to investigate potential pharmacological intervention.

Lydia Finaly, a graduate student in Dr. Haigi’s laboratory at Harvard University, presented recent data on the Sirtuin gene family, which are known to expand lifespan. Several members of the Sirtuin family, including SIRT3, are found in mitochondria. Sirtuins modify protein function by deacetylation. Mice which lack the SIRT3 gene have increased glycolysis. The metabolic switch for glycolysis seems to be dependent on HIF1, a factor which regulates gene expression when oxygen is lacking. Ms. Finaly also discussed the role of Sirtuins in preventing tumor formation and obesity.

Finally, Dr. Mark Tarnopolsky of the Neuromuscular and Neurometabolic Disease Clinic at McMaster University presented impressive data on the impact of exercise on mitochondrial health. Endurance exercise has been proven to boost mitochondrial volume density in muscle. Not only does exercise cause a substantial decrease in oxidative stress and free radicals, which result from dysfunctional mitochondria and age-related illnesses, but it also increases mitochondrial energy capacity. Most striking, however, is the discovery that exercise has the ability to shift entire mitochondrial DNA mutations, potentially saving subjects from numerous lethal diseases. Future research will focus on creating pharmaceuticals that mimic exercise; which will allow physically impaired patients, like those suffering with Mitochondrial Disease, to reap the extensive benefits of exercise.

While all of these exciting scientific advancements are currently underway, physicians and researchers have already teamed up to design and prescribe what is now known to be the energy-boosting ‘mito cocktail.’ Containing a variety of supplements such as L-Carnitine and Co-enzyme Q10, this oral treatment has been proven to increase mitochondrial function. Simply put, the use of these supplements can help the bodies of Mitochondrial Disease patients produce better functioning mitochondria—the powerhouse organelles responsible for energy metabolism. Having spent a few exciting and stimulating days in the desert of Arizona and learning about most recent advances in Mitochondrial Medicine has moreover left us with new hope that a cure is just around the corner.
A year of being completely bedridden is not the best formula for accomplishing great tasks. But that is exactly what sparked the inspiration for Elisabeth Tova Bailey’s new book, The Sound of a Wild Snail Eating, published by Algonquin Books.

Always a very active person, Elisabeth was blindsided by a severe acute illness at age 34 that caused autonomic symptoms and GI paralysis. She almost died. Later, her mysterious malady developed into a chronic debilitating disorder that included periods of unpredictable temporary and partial improvement and relapses. During this long and difficult saga, Elisabeth visited over 100 physicians trying to obtain a diagnosis. Seven years later, she received one — Complex II deficiency - a mitochondrial disease.

During one of numerous particularly severe years, Elisabeth was bedridden with little social contact; but she did have a companion, a small woodland snail brought to her in a potted plant by a friend. Unable to do much else, Elisabeth became fascinated with the creature as it explored its new home in the pot and, later, happily settled down to life in a terrarium. She gained a much greater appreciation of how amazing and complex any creature is and that diminutive and slow animals are not dull and boring.

Elizabeth saw the snail’s life as a metaphor of her own. In observing its smaller and unhurried life, she realized “life at any speed” has worth, and when thrown into such a situation, one has to make the most of what options remain.

As a college English major, Elisabeth had taken numerous science courses. Due to her illness, she also got used to reading medical literature. Eventually, working slowly over four years, she used her training in these fields to read scientific literature on mollusks and to write her book. At times, this was an excruciating ordeal. Because books were too heavy, she read photocopies of scientific literature pages while lying flat on her back. She could only sit up for 15 to 20 minutes at a time, so, she broke her writing down into small doable pieces.

Elisabeth knows she may never be the healthy, active person she once was. She is realistic. It is not always possible to be upbeat, but she offers some advice to others who suffer from similar conditions. You must reach out in whatever ways are possible to stay connected to the life around you. Stay in touch with your doctors; learn all you can about your disease so that you can keep your various specialists informed. Maximize what you can still do to balance out, as best possible, what you cannot do. Have a daily plan to do something. Channel your interests; if you can’t be physically active, direct your activity toward something you can do. Connect with someone or something, whether person, animal, or project.

Right now, Elisabeth is doing her own “connecting.” Her book, now in US bookstores, is soon to be released in the United Kingdom and Australia, and she is enjoying giving interviews. She says that this is has been a stimulating learning process in itself. Her book is already finding its way into medical and nursing schools and hospitals where it will bring attention to the critical need to improve patient environments. For more information, go to her book’s website at http://www.elisabethtovabailey.net.
As you read this, the second session of the 111th congress is winding down. As the session comes to an end, it doesn’t appear as though there will be any action taken on the Brittany Wilkinson Mitochondrial Disease Research and Treatment Enhancement Act (also known as S.2858) or its companion bill in the House, H.R. 3502. So what does that mean for our bills? It means we have our work cut out for us when the 112th Congress convenes in January 2011.

H.R. 3502 is before the House Energy and Commerce Committee. During a mid-September trip to Washington D.C., we learned that the committee had no plans to hold a hearing on the bill before the end of the current congressional session. The Senate will also not take action on S.2858. You can rest assured that we will reintroduce the legislation in January 2011.

This is not bad news. We were told that it is not uncommon for some organizations to wait for several years before their bills are enacted.

We shared the sentiment of Douglas Wallace, PhD, a member in the prestigious National Academy of Science. Dr. Wallace, who recently joined The Children’s Hospital of Philadelphia, along with Bruce Cohen, MD, of the Cleveland Clinic, joined UMDF officials for the meetings on the Hill. The doctors provided the elected officials with tremendous background on mitochondrial disease and dysfunction. When told that ‘bills like these sometimes take time,’ Dr. Wallace replied, without hesitation, that we “are running out of time. People are dying.” It made an impact on the staffer. Now you need to make that same impact with your elected officials.

In order to help us get these bills passed in the future, we urge you to continue to get co-sponsors for both through the end of the year. This is critical because once a House or Senate member becomes a co-sponsor, they are very likely to join onto a bill if it is reintroduced. Once the bills are reintroduced in January of 2011, we will need the same energy to secure co-sponsors and move it to the president’s desk.

**IN A NUTSHELL**

- Hospitals and universities tack on a significant line item for overhead, sometimes as much as 50%. This is necessary for hospitals and universities to exist, but it is money spent outside of mitochondrial research. Doesn’t make much of a case for getting maximum bang for your buck.
- When medical and scientific people leave an institution, their support donated by individuals does not automatically follow them.
- UMDF is the largest non-government funder of mitochondrial-specific research. It has set a precedent of funding the most promising research with 30% of funded projects going to researchers outside of the U.S. with whom we are in contact.
Just Got Easier...
Genetic Testing for Mitochondrial Diseases

Testing Services:
- Mitochondrial genome sequencing
- Mitochondrial genome del/dup analysis
- Nuclear gene sequencing
- Nuclear gene del/dup analysis
- Mitochondrial DNA depletion analysis
- Comprehensive phenotypic panels (MELAS, MERRF, LHON, etc.)

Patient Benefits:
- All commercial insurances accepted, no balance bills
- Most tests are performed on blood, thus minimizing the need for a muscle biopsy
- Low-cost family member testing available

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ANNUAL SUMMER NEWSLETTER 2010

DESIRED WEB PAGE FOR LHON (LEBERS)
The UMDF thanks Lissa Poincenot of Carlsbad, Ca, for agreeing to become our Leber’s Ambassador. In this role, Lissa will connect the LHON community with helpful resources and information. Lissa has her own page on the UMDF website for those affected by LHON. The page can be accessed by visiting www.umdf.org, clicking on the ‘Mitochondrial Disease’ tab at the top of the web page, then by clicking on ‘Types of Mitochondrial Disease’ and selecting the LHON title.

TARGETING MITOCHONDRIA 2010
The first World Congress on Targeting Mitochondria 2010 will be held November 18–19, 2010 in Berlin, Germany.
Some of the topics to be addressed are:
• Mitochondrial dysfunctions in chronic diseases: recent advances & conclusions
• Mitochondria into practice: methods & instruments, Evaluating drugs, neutraceutical & nutrients’ efficacy on mitochondria
• Strategies & innovations to target mitochondria
• Targeting mitochondria: recent clinical & therapeutic studies
The conference is being sponsored by the International Society of Antioxidant in Nutrition and Health (ISANH). For information and registration, visit www.targeting-mitochondria.com

2010 HOLIDAY CARD
UMDF California Chapter President, Norma Gibson, is busy working on the artwork for the UMDF’s 2010 Holiday Card. The Holiday Cards will be available to purchase in the UMDF Store in early to mid-November. Visit www.umdf.org often to see when the cards are available!

UMDF MERCHANDISE
UMDF Merchandise is a great way to spread awareness about mitochondrial disease and now is the time to get all of your favorite styles. The UMDF Store has some great deals going on just in time for the quickly approaching holidays. Here are just a few of the great deals you can pick up:
- UMDF Logo Lapel Pin - ON SPECIAL NOW FOR $3 (original price $4)
- UMDF Limited Edition Blown Glass Ornament - ON SPECIAL NOW FOR $10 (original price $14)
- The Official UMDF “Cooking for the Cure” Cook Book - ON SPECIAL NOW FOR $10 (original price $15)
- UMDF Fleece Jackets - ON SPECIAL NOW FOR $30 (original price $50)
- UMDF Novalty T-Shirts - ON SPECIAL NOW FOR $6 (original price $12)

SUBMISSION DEADLINE FOR VOLUME 15 ISSUE 4 IS NOVEMBER 12, 2010!

UMDF's intent is to keep you informed - we ask that you always discuss any diagnoses, treatments, or medications with your personal physician. UMDF assumes no liability for any information in the Mitochondrial News.