

USING LOW DOSE IMMUNOGLOBULIN INJECTIONS FOR ADULTS AND CHILDREN WITH MITOCHONDRIAL DISEASE AND RECURRENT INFECTIONS

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In our allergy/immunology practice, we began to see many adults and children with mitochondrial disease and recurrent infections. This made us wonder if these patients could have an impaired immune system due to their mitochondrial disease. We know, just like many other systems of the body, the immune system requires energy. The immune system is made up of two main branches, the B cells and T cells. Even though there has not been much research in this area yet, we hypothesize that these patients may have an impaired immune system due to the B cells and T cells not having enough energy to fight off infection.

The first two patients we saw in our clinic were both children under 10 years of age with electron transport chain defects. They suffered from repeated ear infections, sinus infections and pneumonias. The infections were frequent and sometimes severe, leading to emergency room visits and even hospitalization. The children were constantly on antibiotics and missing many days of school. Standard treatments with daily preventative antibiotics and vaccine boosters were not working. We decided to start these children on immunoglobulin injections.

“Immunoglobulin” is another name for “antibody.” These antibodies are produced in the body by a cooperative effort from the B cells and T cells. The antibodies attach to the bacteria and kill them. For people that are not able to make functioning antibodies, they can receive immunoglobulin transfusions from human donors. The immunoglobulin can be given through an IV (IVIG) or as an injection.

We decided to try to boost the immune system with small amounts of immunoglobulin by injection every three weeks. With the first two patients, the parents kept logs of the first 6 months of treatment to record the frequency of infections, ER visits, hospitalizations and school absences. They were also asked to recall the last six months prior to treatment. We found a significant decrease in all four of these parameters. Not only did the frequency of the infections decrease, but the infections were less

severe, and antibiotics and emergency care were needed less often. The parents reported that they felt comfortable giving the shots at

home. The only noted side effect was that the children seemed less energetic the day after receiving the injection. These two children have continued on these treatments with continued benefit.

We have seen at least 10 more adults and children with mitochondrial disease and recurrent infections since then. They have also benefited from the immunoglobulin therapy with reduced infections. This therapy has proven to be safe and promising. As with all medical therapies, large clinical trials need to be performed before any general treatment recommendation can be made.

NOT ONLY DID THE FREQUENCY OF THE INFECTIONS DECREASE, BUT THE INFECTIONS WERE LESS SEVERE, AND ANTIBIOTICS AND EMERGENCY CARE WERE NEEDED LESS OFTEN.



The UMDF was awarded the 2007 Advocacy Award of Merit from the Child Neurology Foundation.

(Left to right) Dr. Rajiv Varma, Charles Mohan, Jr., Dr. John Painter, Julie Hacker and Dr. Bruce Cohen

See page 12 for more about this award!

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PHASE 3 CLINICAL TRIAL OF COENZYME Q10 IN MITOCHONDRIAL DISEASES

This is to inform you of a research study being conducted at the University of Florida and other collaborating institutions in North America, entitled "PHASE 3 TRIAL OF COENZYME Q10 IN MITOCHONDRIAL DISEASES."

It will be the first controlled clinical trial of chronic, oral, CoQ10 for patients with genetic mitochondrial diseases. Subjects will not be charged for participation and requisite air transportation throughout the continental U.S. will be provided by Mercy Medical Airlift.

Eligible patients must meet the following criteria:

Inclusion Criteria:

- Age 12 months – 17 years
- Biochemical proof of a deficiency of complex I, II, III or IV of the respiratory chain (RC) or molecular genetic proof of a mutation in mtDNA, or of a nDNA mutation in a gene known to be associated with dysfunction of the RC (e.g., SURF1, MELAS)
- An eligible patient will be able to hold up his/her head when in prone and sitting positions and follow a simple command (such as "clap your hands").
- Patient will stop taking all medically unnecessary medications and supplements as deemed by the study physician when starting study participation.

The prospective participating study sites are:

- General Clinical Research Center, University of Florida, Gainesville, FL. (lead institution)
- Rainbow Babies and Children's Hospital, Case Western Reserve University, Cleveland, OH
- Cincinnati Children's Hospital Medical Center, Cincinnati, OH
- Hospital For Sick Children, University of Toronto, Toronto, Canada

If you have a patient who has a suspected or proven mitochondrial disease whose family might be interested in this study, or if you have additional questions regarding the trial, please contact the following individual:

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WHAT IS A CLINICAL TRIAL?

(Taken from the U.S. National Library of Medicine at ClinicalTrials.gov)

Although there are many definitions of clinical trials, they are generally considered to be biomedical or health-related research studies in human beings that follow a pre-defined protocol. (They are used to determine whether new drugs or treatments are both safe and effective.) Visit ClinicalTrials.gov for more information and listings of current trials.

Why participate in a clinical trial?

Participants in clinical trials can play a more active role in their own health care, gain access to new research treatments before they are widely available, and help others by contributing to medical research.

What should people consider before participating in a trial?

People should know as much as possible about the clinical trial and feel comfortable asking the members of the health care team questions about it, the care expected while in a trial, and the cost of the trial. The following questions might be helpful for the participant to discuss with the health care team. Some of the answers to these questions are found in the informed consent document.

- What is the purpose of the study?
- Who is going to be in the study?
- Why do researchers believe the experimental treatment being tested may be effective? Has it been tested before?
- What kinds of tests and experimental treatments are involved?
- How do the possible risks, side effects, and benefits in the study compare with my current treatment?
- How might this trial affect my daily life?
- How long will the trial last?
- Will hospitalization be required?
- Who will pay for the experimental treatment?
- Will I be reimbursed for other expenses?
- What type of long-term follow up care is part of this study?
- How will I know that the experimental treatment is working? Will results of the trials be provided to me?
- Who will be in charge of my care?

What kind of preparation should a potential participant make for the meeting with the research coordinator or doctor?

- Plan ahead and write down possible questions to ask.
- Ask a friend or relative to come along for support and to hear the responses to the questions.
- Bring a tape recorder to record the discussion to replay later.

Every clinical trial in the U.S. must be approved and monitored by an Institutional Review Board (IRB) to make sure the risks are as low as possible and are worth any potential benefits. An IRB is an independent committee of physicians, statisticians, community advocates, and others that ensures that a clinical trial is ethical and the rights of study participants are protected. All institutions that conduct or support biomedical research involving people must, by federal regulation, have an IRB that initially approves and periodically reviews the research.



**ASK THE
MITO DOCSM**

Living with mitochondrial disease presents many twists and turns and a maze of questions. The 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.

Responders for this issue: Carol Greene, MD, of the University of Maryland Medical Center; Susan Winter, MD, of Children's Hospital of Central California; David Thorburn, PhD, of the Royal Children's Hospital, Melbourne, Australia; and Sumit Parikh, MD, of the Cleveland Clinic.

THE QUESTION IS...

My daughter is 11 years old and has Complex I and IV mitochondrial disease. Her pediatrician was concerned with the curvature of her spine. We just completed an X-ray and found out she has a 24-degree curve. We will be visiting an orthopedic doctor soon. Should we consult our mitochondrial physician as well? What should we be aware of in regard to mitochondrial disease and scoliosis? What questions should we ask the orthopedic doctor as I am concerned they may not know as much about scoliosis and mitochondrial disease?

RESPONSE FROM CAROL GREENE, MD:

You are asking an excellent question. You do not mention whether your daughter has any neuromuscular problems. Neuromuscular problems (and especially if any hypotonia or hypertonia is asymmetric) do lead to an increased risk of scoliosis. Since mitochondrial disorders can cause neuromuscular problems, there is therefore an increased risk of scoliosis in mitochondrial disease. I am not aware of any other reason that scoliosis would be

increased in mitochondrial disease. Scoliosis is fairly common, and at age 11 your daughter may be in the growth spurt of puberty, and that is a common time for presentation of scoliosis - so the scoliosis may have nothing to do with the mitochondrial disorder. Regardless, it is a good idea to make certain that your mitochondrial physician is aware of what is going on. If your mitochondrial physician is also your neurologist, he or she can help to determine if there is an immediate neuromuscular cause or contribution of the scoliosis, and whether there might therefore be some specific treatment in addition to whatever the orthopedist has to recommend. Your mitochondrial physician can also help you to evaluate if any of the orthopedist's suggestions have any increased risk for an individual with mitochondrial disease. Most treatment for scoliosis is quite low risk, and I hope your daughter will never require any surgery, but if she does it will be your mitochondrial physician who will help the surgeons and anesthesiologists to know how best to help keep her safe.

THE QUESTION IS...

My son is 10 weeks old and was diagnosed with pyruvate dehydrogenase deficiency. He had the disease in-utero and was born with very high lactic acid levels and all the warning signs of the disease. He has received treatment and is on a cocktail of medications as well as the ketogenic diet. He is doing much better now, but I am wondering if there is more we can do to give him a better chance of survival. Can you provide me with a list of medications and treatments that have been used in the past to treat PDH so I can discuss our options with his doctors? I am also interested in dichloroacetate and looking for facilities in our area that could provide us with the drug if needed. I have read quite a bit on the disease and am also curious what the survival statistics are.

RESPONSE FROM SUSAN WINTER, MD:

I was asked to reply to your questions regarding your son with pyruvate dehydrogenase deficiency. It appears, from your letter, that the treatment prescribed is appropriate. The outcome of PDH deficiency is really related to the severity of the metabolic block in metabolism. Some patients with mild disease can live long lives with only slight

disabilities while those with severe deficiency may only survive for a few months. I have treated both types of patients and cannot predict your baby's outcome. The treatment of PDH deficiency is usually a ketogenic diet and use of vitamins such as thiamine and carnitine. I have used dichloroacetate on two neonatal severe patients, and it did not improve outcome. Both boys died by age 3 months. Unfortunately, we do not have a cure for PDH deficiency, and it is a severe disorder. I wish I had a crystal ball for you to look into the future and answer your questions. I know it is very difficult and scary to have a baby with such a life-threatening disorder. My best advice is to hook up with a good metabolic center and follow their advice. There are many ways to treat the disorder and all seem to have a similar outcome. I wish the best of luck to you and your little guy.

THE QUESTION IS...

Is there any new research on mito and the use of cord blood? My daughter, who is 29-years-old, is due to have a baby in Dec. 2007. She is looking into having the cord blood saved and stored. She asked if it could possibly help me with my mito situation. I have no idea if cord blood might be beneficial for mito patients. I read a previous cord blood Q&A posting on "Ask the Mito Doc," but I was informed that it was a couple of years old.

RESPONSE FROM DAVID THORBURN, PhD:

Cord blood stem cells certainly remain an active area of research, including for potential treatment of neurological diseases. I am not aware of any specific research using them for mito diseases nor of any developments that make it likely there will be a breakthrough that would be useful for mitochondrial disease any time soon. In general I think it is a great idea to donate cord blood but not so sure about the practicalities of cord blood storage in the USA, e.g. costs, intention to store for directed use versus donation, etc.

RESPONSE FROM SUMIT PARIKH, MD:

I agree. While there are mitochondria in stem cells (including in cord blood cells) - we do not know how to utilize stem cells in general - and are not close to making use of them for mitochondrial disease (hopefully in 5 to 10 years).

CHAPTER ACTIVITIES

CHAPTER NOTES

ATLANTA CHAPTER

- **September 28, 2007.** The inaugural Music for Megan Charity Benefit Concert was held at Wills Park Equestrian Center in Alpharetta, GA. More than 1,000 people attended and raised more than \$60,000 in honor of Megan Sheridan. A special thanks to the Sheridan family and friends who helped organize such an outstanding event and for the great media coverage. Save the Date – September 27, 2008: the date of the second annual Music for Megan Charity Benefit Concert.
- **September 28, 2007.** In coordination with Music for Megan, the Oreck Stores surrounding Alpharetta, GA donated a percentage of all sales to the UMDF, totaling \$1,096.15. A big thank you to Irene Sheridan for making this happen!
- **October 1, 2007.** The fourth annual Fore-A-Cure Golf Tournament hosted by the Atlanta Chapter was held at The Standard Club in Duluth, GA. The annual event was SOLD OUT and raised more than \$60,000 for the UMDF. Thank you to Chris Swinn and the golf committee members for your hard work on another successful event!

CHICAGO CHAPTER

- **September 16, 2007.** The inaugural UMDF Chicago Area Chapter 5K Walk & Family Fun Day was held along scenic Lake Michigan. More than 500 participants helped raise over \$87,000, and tons of fun was had by everyone! Special thanks to everyone that helped to organize this event!



5K Walk & Family Fun Day

CENTRAL OHIO CHAPTER

- **October 4, 2007.** The second annual Kovalcik & Geraghty Wealth Partners Charity Golf Outing was held at Kinsale Golf & Fitness Club in Powell, OH. The event raised more than \$36,000 in honor of Ellie Kovalcik. Thank you to KGWP for choosing the UMDF as your charity beneficiary again this year!
- **October 7, 2007.** The seventh annual Olivia Steele Memorial Golf Outing was held at Clover Valley Golf Club in Johnstown, OH. Nearly \$5,000 was raised in memory of Olivia Steele. Thank you to the Steele family for your continued support!

DELAWARE VALLEY CHAPTER

- **September 8, 2007.** The eighth annual Go for Mito! 5K Run 1 Mile Walk was held at the Philadelphia Museum of Art in Philadelphia, PA. More than 700 participants raised over \$50,000 this year. Special Thanks to Therese Garvin, the race committee and the Philadelphia Parks & Recreation Department on another successful event!



Go for Mito! 5K Run 1 Mile Walk

- **September 22, 2007.** Jamming for Jamie, a Beef and Beer Dinner and Auction was held at the Avion Restaurant at the Flying W Airport in Medford, NJ. The event was held in honor of Jamie Smith celebrating the First New Jersey Mitochondrial Disease Awareness Week. More than \$6,000 was raised for the UMDF! Thanks to Jamie & Laurel Smith for your hard work on organizing New Jersey Mito Week activities!
- **September 23, 2007.** When asked, friends, colleagues and family members came together to raise more than \$57,000 in honor of Haley, Shannon & Brett Lawrence. The family celebrated their success with a picnic BBQ, raffles and entertainment. Thank you to DeDe Agar-Lawrence for your hard work on your letter writing campaign!



DeDe Agar-Lawrence and Brett Lawrence

HOUSTON CHAPTER

- **October 14, 2007.** The Playitstore Publishing Production of You-Go-Girl – the musical in Houston, TX raised nearly \$3,000 for the UMDF. Dr. Fernando Scaglia spoke after the show while attendees enjoyed a wine and cheese reception. Thanks to all who made this a great Sunday!

KANSAS CITY CHAPTER

- **November 13, 2007.** An Annual Chapter Meeting was held followed by a presentation by Dr. Amy Goldstein. While in Kansas City, Dr. Goldstein also spoke to physicians at Shawnee Mission Medical Center, Children's Mercy Hospital and Providence Hospital.

NEW ENGLAND CHAPTER

- **August 26, 2007.** The fourth annual Friends of Cameron picnic was held at the Chicopee Falls Moose Family Center in Chicopee, MA. Nearly \$9,000 was raised for the UMDF in honor of Cameron Genie. Special thanks to the Genie family and friends for your hard work!
- **October 6-7, 2007.** This year's Weekend of Hope in New England was a great success! The weather was beautiful at both walks, and the events raised close to \$60,000 so far with donations still coming in. Once again, the chapter received extensive media coverage. A beautiful article about Rose Mandill, an affected adult, and her journey was featured in numerous local newspapers. Thanks to Maureen McCarthy for heading up the media again! Thanks to everyone who participated and wished us well. Mark your calendars for the 2008 Weekend of Hope, October 4th in Plymouth and the 5th in Longmeadow!

NEW YORK METRO CHAPTER

- **August 24, 2007.** The Michelle Mohan Sweet 16 Benefit started off with a golf outing at Pelham/Split Rock Golf Course and finished up with a BBQ Dinner at the Turtle Cove Family Fun Center in Bronx, NY. The fun-filled day raised \$14,044 for the UMDF in honor of Michelle Mohan. The Mohan family and friends also raised over \$2,500 with their Coins for a Cure campaign in local businesses! Thanks to the Mohan family for your support!

OHIO CHAPTER

- **August 2, 2007.** A Bike Night was held at the J & J Smokin' Café in Akron, OH. The event was held in honor of Joey Ricci.
- **August 4, 2007.** The Shadow Woodstock was held in Auburn Twin Oaks, OH. The activities included a 5K trail run, 1 mile fun run, volleyball, face painting and hot air balloon rides. Various bands played and an outdoor movie at dusk was played. A portion of the proceeds benefited the UMDF in honor of Kyle Kobunski. Thanks to the Schabel family for including the UMDF as one of the charity recipients again this year.
- **August 24, 2007.** New Image Haircutters of Willowick, OH, held a hair cut-a-thon during the Lake County Captains' game in honor of Jonathan Kucaric. Special thanks to all who helped organize these monthly events this summer!
- **September 29, 2007.** The second annual Delta Gamma Walk was held at the University of Miami Campus in Miami, FL. The event was held in honor of Bobby Arnold and raised over \$2,000 for the UMDF. Special thanks to Kelly Pierce and the ladies of Delta Gamma at the University of Miami for organizing the event again this year.
- **October 21, 2007.** Kim Zak of Ohio participated in the Columbus Marathon in honor of Bobby Arnold and raised \$375. Great Job Kim!

OTHER NOTABLE EVENTS

- **June 9, 2007.** The fourth annual Ally Brunk Memorial 5K Run/Walk was once again a great success! \$4,000 was donated to the UMDF in memory of Allyce Danielle Brunk.
- **August 25, 2007.** Rosendo's Fight for a Cure Benefit Day was held at Trenton View Plaza in McAllen, TX. Local retailers donated a portion of sales equaling \$1,653.35 to the UMDF in honor of Rosendo Robles.
- **September 8, 2007.** A Charity Softball Tournament was held at Randazzo Softball Park in Severn, MD. The event was held in honor of Ally Yates.
- **September 16, 2007.** The KRAVE Salon in Kimberly, WI hosted the Elena's Hope Cut-a-Thon for the Elena Welhouse Research Fund. \$1,167 was raised for the UMDF in honor of Elena Welhouse.
- **September 23, 2007.** The second annual Steps to a Cure Walk benefiting the UMDF through the Brittany Wilkinson Research Fund was held at Woodward Park in Fresno, CA.
- **September 25, 2007.** The HLNY Healthcare Classic Golf Outing was held at Hampshire Country Club in Mamaroneck, NY. A portion of the proceeds were donated to the UMDF through The Zachary Foundation in honor of Zachary Friedberg.
- **September 28, 2007.** The second annual Elena's Hope Research Fund Benefit Dinner was held at Liberty Hall in Kimberly, WI. More than 200 people attended the event raising more than \$26,000 for mitochondrial disease research in honor of Elena Welhouse.
- **September 29, 2007.** The MPS & Mito Walk/Run was held at Thomas Lake Park in Eagan, MN. Partial proceeds will benefit the UMDF in honor of Patrick Luskey and all affected by mitochondrial diseases.
- **October 6, 2007.** The seventh annual Mito-What? Golf Classic was held at the Oaks Golf Course in Kentucky. Proceeds benefited the UMDF in honor of Brayden Suman, raising \$1,923.
- **October 7, 2007.** Emily Fischer of Milwaukee, WI participated in the LaSalle Bank Marathon in Chicago, IL. Emily raised more than \$5,800 for the UMDF in honor of her cousins Zachary and Sam Juhlmann.
- **October 13, 2007.** The inaugural Kure for Kat 5K Run 1 Mile Walk was held at Southlakes Park in Denton, TX. The run raised more than \$15,000 for the UMDF through the Katherine Dickens Research Fund in honor of Katherine Dickens.
- **October 18, 2007.** The third annual Chris Schindler Memorial Celebration was held at The Briscoe Manor in Richmond, TX. The attire was Texas "chic" and the evening included exciting live & silent auctions, a delicious dinner and much more.
- **October 21, 2007.** The Zachary Foundation fourth annual 5K Run & 1 Mile Walk was held at The Marlboro Recreation Center in Marlboro, NJ. A portion of the proceeds will be donated to the UMDF through The Zachary Foundation in honor of Zachary Freidberg.
- **October 31, 2007.** The Valenti Family held a Haunted House at their home in Chicago, IL in honor of Kristen Charleston and raised over \$1,000.



Haunted House in Chicago

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For more information about a chapter, group or ambassador near you, contact the UMDf office at 888-317-UMDF!

MITO FACTS

- Defects in mitochondrial function have now been linked to aging diseases such as Parkinson's Disease, Alzheimer's Disease, Heart Disease and cancer.
- The disease particularly affects parts of the body that need the most energy - the heart, brain, muscles and legs.
- A child with a mitochondrial disease is at the highest risk for neurological and organ damage during and two weeks after an illness.

EAST MEETS WEST

A Day in the Life of the Fogel and Zuzzolo Families

Two young girls with the same rare genetic mitochondrial disease met for the first time when one family from California traveled to New York Sept. 29.

The parents of five-year-old Taryn Fogel, from California, and four-year-old Mary Zuzzolo, from New York, thought that their children were the only ones in the world diagnosed with a combination of Bjornstad



Taryn Fogel and Mary Zuzzolo

and Gracile syndromes, both extremely rare diseases caused by genetic mutations in the BCS1L gene, a gene responsible for encoding an important mitochondrial protein. Mitochondria are responsible for creating more than 90 percent of the body's energy necessary to sustain life and support growth, making this condition, like many other mitochondrial conditions, life-threatening.

But while attending the United Mitochondrial Disease Foundation's (UMDF) annual symposium in San Diego earlier this year, the Fogels came across a poster regarding Taryn's condition. They were confused to find that the poster had another little girl's picture, Mary, diagnosed with the same condition.

"Taryn was the only one diagnosed with this unfortunate combination in the genetic world," Debbie, Taryn's mother, said. "A nurse once told me that her case was one in five trillion, and there would probably never be a diagnosis like this again."

"We were told that Mary was the only known case and she would essentially be the teacher," Kim, Mary's

mother, said.

With the help of Dr. Bruce Cohen, a member of the United Mitochondrial Disease Foundation's Scientific and Medical Advisory board and the doctor who diagnosed both girls, the families united.

"We felt very alone in our struggle," Kim said. "Finally, someone to talk to."

THE BIG DAY

The families met in New York Sept. 29 to attend the UMDF New York Metro Chapter's Inaugural Picnic and Fun Day Sept. 30 at Van Saun Park in Bergen County. Their union was a celebration of their daughters' lives, lives that could be lost at any given time due to the severity of this disease. It was a time for two families to cope, raise awareness and fight for a cure to save Taryn and Mary.



Taryn and Mary with New York Firefighters

"THIS WAS AN EMOTIONAL TRIP FILLED WITH SUCH INCREDIBLE JOY," DEBBIE SAID. "IT WAS NICE TO BE AROUND PEOPLE THAT UNDERSTAND OUR SITUATION AND HAVE SO MUCH LOVE FOR THEIR SPECIAL LITTLE GIRL LIKE WE DO."

"THERE IS STILL ROOM FOR OTHER CHILDREN IN OUR FAMILY LIKE TARYN AND MARY," KIM SAID.

"This was an emotional trip filled with such incredible joy," Debbie said.

Taryn and Mary's similarities bonded them in a way that made them seem like "old friends reunited," according to EJ, Taryn's father. Although the girls likely didn't comprehend the situation fully, they were happy and good natured.

"When they were together they laughed at

pretty much the same things," he continued. "They looked at each other, but since they both can't speak, it was a visual thing, and they got along really well."

Even the two families' dynamics were similar. Both families have other children, Taryn's sister, Payton, 4, and Mary's sister, Grace, 7, who are struggling to understand their sisters' rare conditions. The fathers, Edward Joseph (EJ) and Anthony Joseph, Mary's father,

(continued on page P8)

FROM THE CHAIRMAN

For most of us, the season of fall and the start of winter bring up many feelings. We watch as the leaves fall from the trees and wait for the first snowflakes. We reminisce about the year that has passed and think about the changes that have occurred in our lives over the last 12 months. At the UMDF, we are coming to the mid-point of our current fiscal year. It is with great pride that I can tell you that for the fiscal year that ended in June, we have exceeded the following goals set for in our strategic plan!



To refine and complete the implementation of a comprehensive marketing and communications plan.

It is critical that we tell the UMDF story and your stories to a much broader audience. Our marketing and communications committee has developed a plan that meets the objectives of reaching new target audiences. We're reaching out to physician's offices nationwide to communicate with newly diagnosed patients. While our overall plan is under review, we are working hard to reinforce the UMDF brand nationwide with our goal of making mitochondrial disease more readily recognizable.

To have a robust, effective and proactive committee structure.

Our committees remain vibrant and in touch. We have met the need to create robust and proactive committees. We must understand that our challenge is to retain and attract new volunteers. As you know, the United Mitochondrial Disease Foundation is a "volunteer led" organization. When a volunteer or a family member is affected by a mitochondrial disease, health must take a priority.

To present to the board a recommendation to upgrade the UMDF's IT infrastructure.

We recently contracted with Kintera to upgrade our infrastructure. The capabilities of this system are outstanding. We continue to work to train the staff on its multiple uses.

To successfully include language for government support of mitochondrial disease.

Before we seek government support, we need to understand how to approach members of Congress for funding for research. With this underway, we can now move to the next steps to advance our work to research funding with the ultimate goal of building a coalition to allocate more federal dollars towards research.

To raise \$2.6 million in FY 2006.

I am happy to report that we have exceeded this goal by more than 10%.

To increase net membership by 25 percent by the end of FY 2006.

I am also very proud to report that this goal was exceeded. We now have 1045 members, which is a 27% overall increase!

Restructure the Scientific Advisory Board and the Scientific and Medical Advisory Board.

We have accomplished this goal by finding a proper mix between the medical community and scientists to help us further the UMDF mission of promoting research and education that will lead to a cure.

Reaching and exceeding goals always gives great satisfaction and a sense of accomplishment. But it also reminds us that we have much work to do and far more to accomplish.

Warmest Regards,



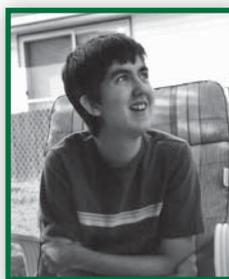
Stanley Davis, UMDF Chairman

DONOR SPOTLIGHT - Fran Russell

Fran Russell believes in consistency. The retired special education teacher is truly an inspiration. Since 1999 she has consistently made donating to the UMDF part of her life.

Fran began sending donations to the UMDF when her sister-in-law, Carolyn Russell, was diagnosed with the mitochondrial disease MELAS. Shortly after Carolyn's diagnosis, her son, Tim Russell, was diagnosed with MELAS. Fran decided that the best way she could support her family members was by donating to the UMDF for research in hope for a cure. She hopes that her donations will fund education and support for those with a mito disease and their families and friends.

"Every day there is hope," Fran said, who often gives her donations in honor or memory of others. She also gives donations in place of birthday or anniversary gifts, stating "people say that they don't want gifts, but you still want to give them something meaningful."



Tim Russell, Fran's Nephew

donate to the UMDF."

An example of this was Fran's 60th birthday celebration. She requested donations to the UMDF rather than gifts, raising approximately \$500 for the foundation. Fran noted: "People are extremely generous; just ask, and they will give."

Fran plans to continue her regular donations, claiming that donors have the "easy part." "It's the everyday caregivers that inspire me." She believes that the UMDF makes it simple

Fran is involved in fundraising efforts for the newly formed UMDF Minnesota Chapter. "You can't do enough," Fran said. "We have to keep coming up with creative ideas to encourage others to

by mailing her the donation envelopes. All that she has to do is write the check and mail the donation. The honoree then receives a letter from the UMDF stating the reason for the donation and the name of the donor. The donor also receives a confirmation of their tax deductible contribution from the foundation stating that a letter has been sent to the recipient confirming the donation.

"What could be easier?" Fran said regarding her choice to donate to the UMDF. "Why would I not contribute to a foundation that is helping to support research to find a cure for a disease that affects my family members?"

The UMDF thanks Fran for her consistent donations, and Fran remains dedicated to doing as much as possible to help the cause. "There is such a need for more money to research finding a cure for mitochondrial disease.

"Any amount we give, especially given consistently, will help find a cure."

UNITED MITOCHONDRIAL DISEASE FOUNDATION

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SUPPORTING OUR CAUSE



Parker Quarles' Holiday Card Design

HOLIDAY CARD ART CONTEST

The UMDF will hold its second annual Holiday Card Art Contest. The winning artwork will be featured on the 2008 holiday card solicitation and the artist will receive a gift certificate. Blank holiday cards also will be available for purchase.

The winner is selected by a group of judges. Each artist also is required to write a short explanation about what their drawing means to them and how they are affected by mitochondrial disease. Participants do not have to be diagnosed with a mitochondrial disorder to enter. Each contestant will receive recognition for his or her work. Participants can enter more than one drawing.

The theme of the drawing(s) should be holiday or winter spirit, rather than reflect a specific holiday.

Check the UMDF web site for contest rules and an entry form.

Last year's winning entry from Parker Quarles of Georgia is featured on this year's holiday card. The cards are available for purchase through our web site at www.umdff.org.

FOUR SEASONS ART CONTEST

For another contest, participants can enter drawings of the four seasons. The winning artwork will be featured on special projects for the UMDF in the future. Please check the web site for details soon.

As with the holiday contest, the winner is selected by a group of judges. Each participant also is required to write a short explanation about what their drawing means to them and how they are affected by mitochondrial disease. Participants do not have to be diagnosed with a mitochondrial disorder to enter. Each contestant will receive recognition for his or her work. Participants can enter more than one drawing.

NEW COMMUNITY HEALTH CHARITIES CODE

For those of you who donate to the UMDF through Community Health Charities campaigns, please take note of our new 5-digit code. The UMDF's new code is 10250. We appreciate all of you who donate through the CHC.



*Owen Hollar, a three-year-old with
Leigh's Disease*

WHAT THE DEVELOPMENT CAN DO FOR YOU

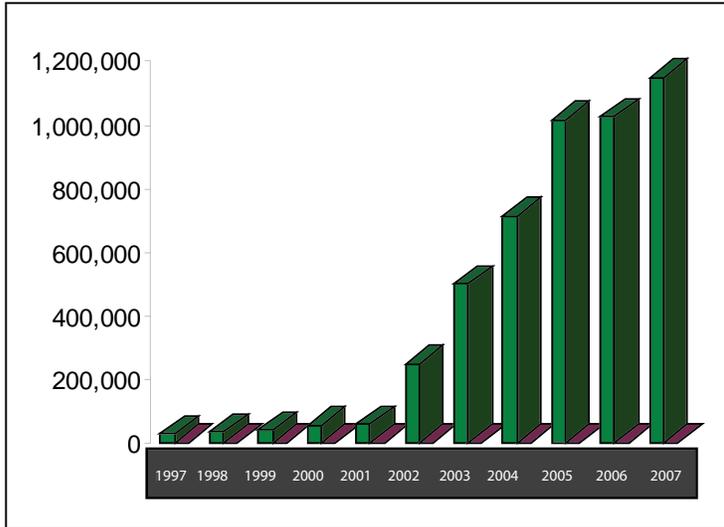
- Help write requests and gather any necessary attachments for organizations that might donate to your event
- Help approach potential donors and prepare sponsor materials
- Assist in gathering requests for workplace giving programs
- Follow up on leads to charitable foundations that might donate to the UMDF

WHAT YOU CAN DO FOR DEVELOPMENT

- Inquire at your workplace about programs that match gifts or volunteer hours
- Write the UMDF on your workplace giving pledge card (i.e. United Way or Community Health Charities)
- Let us know if you hear of any grant opportunities in your area

RESEARCH

The United Mitochondrial Disease Foundation funded more than **\$1.1 million in research projects in 2007**. **UMDF is the leading non-governmental contributor of grants focused on mitochondrial disease research.**



The National Institutes of Health (NIH) spends \$29 billion dollars each year on research into a multitude of diseases. NIH provides \$11 million dollars for mitochondrial research. Only 1/3 of that money is earmarked for primary mitochondrial research. Out of the entire budget, NIH spends only 4/100ths of one cent for primary mitochondrial disease research.

Since 1996, the UMDF has funded over \$5 million as part of our Research Grant Program. In the 2006-2007 grant cycle, the UMDF received more than 200 letters of intent. Proposals were approximately 94% basic research and 6% clinical research.

SERVICE AND SUPPORT

The UMDF has 14 chapters and 17 Mito groups around the United States. After one year in existence, the Mito Ambassador program has doubled in number from 13 in 2006 to 26 at the end of FY 2007.

AWARENESS

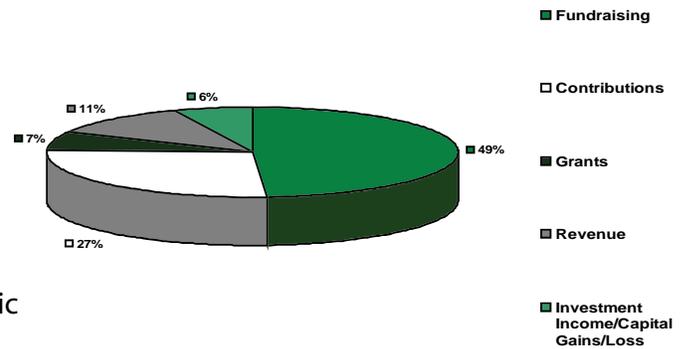
The UMDF continues its mission of raising awareness by exhibiting at annual medical meetings and hosting grand rounds programs. Grand Rounds feature an information session to a large group of physicians by a mitochondrial disease expert.

SYMPOSIA

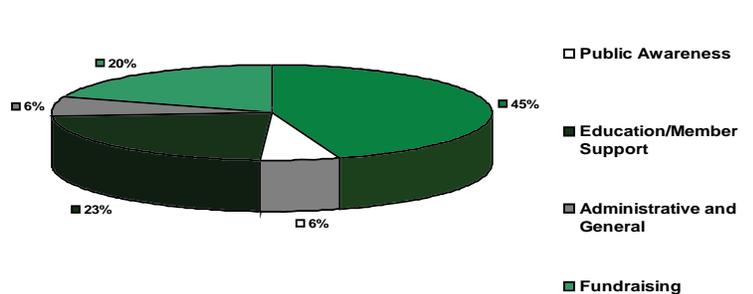
In 2007, the UMDF staged its seventh annual symposium on mitochondrial diseases. The symposium was held in San Diego, CA and provided the most up-to-date information on mitochondrial disorders to families, researchers, scientists and physicians. The UMDF symposia remain the most recognized symposia on mitochondrial disorders in the world.

UMDF will hold its eighth annual symposium June 25-28, 2008 at the Hyatt Regency in Indianapolis, IN.

2007 REVENUE SOURCES



2007 EXPENSES



One woman's efforts to help a six-year-old girl with mitochondrial disease raised over \$42,000 for the United Mitochondrial Disease Foundation on July 28, 2007 at the second Race for Ellie.

Wendy Ivany coordinated the event, a 5K run/1 mile walk held at Adventure Park in Powell, Ohio, to raise money for the UMDF in honor of Ellie Kovalcik, Wendy's neighbor, who suffers from Complex IV deficiency and Leigh's Disease, both forms of mitochondrial disease.

"I think the race has been so successful, in large part, because we have an amazing and supportive community," Wendy said. "So many people want to help; they just didn't know how to go about doing it before."

After the first race, Wendy realized that they had the ability to help not just Ellie, but others living with similar conditions. She had the opportunity to meet others with mitochondrial diseases and to develop a better sense of the UMDF's mission to promote research and education for the diagnosis, treatment and cure of mitochondrial disorders and to provide support for affected individuals and families.

After this year's successful race, the Race for Ellie 2008 is in the works, with a fundraising goal of \$65,000!

"Ellie is the main motivator in making the race a continued success," Wendy said.



Ellie Kovalcik at the Second Annual Race for Ellie

The first race, which raised approximately \$5,000, started in the spring of 2006. Wendy first approached Ellie's parents, Matthew and Kris, with the race suggestion, hoping to do something to help find a cure for Ellie, who was not expected to live beyond the age of 10. "I knew that I could put together a fundraiser that would help drive awareness and money," Wendy said. "My goal all along has been to drive towards a cure."

With the Kovalciks' permission, Wendy organized a group of volunteers within the neighborhood. Wendy planned all of the race details, from mapping out the race route to making sure everything came together on the day of the race.

"What she has done to promote awareness in the community has been so important," Kris, Ellie's mom, said. "She has done such a good job of putting the word out about mitochondrial disease."

Wendy continues to gain the most she can out of her volunteer efforts, stating that the most meaningful part of volunteering for the UMDF is the knowledge that she is giving back, setting a good example for her kids and seeing the kindness in people. Conversations with sponsors, friends and total strangers have shown her a "refreshing side of humankind."

Wendy's personal philosophy is to try to bring energy to at least one person each day. "I am honored to use my time, legs and my



Participants in the Race for Ellie 2007



**UNITED
MITOCHONDRIAL
DISEASE
FOUNDATION®**

HOPE. ENERGY. LIFE.

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UMDF MISSION

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

voice to help Ellie, her family and everyone else who has been touched by mitochondrial disease."

"We are so blown away by what she has done," Kris said. "It is much more than we ever could have hoped for."

DONORS - THANK YOU!

APPRECIATING THOSE WHO HAVE HELPED ALONG THE WAY!

We would like to give a very special thanks to the Minnie Waldman Estate for the generous donation of \$258,671 in loving memory of Megan Camaiani, daughter of Bob and Lori Camaiani and granddaughter of Nina Nachman.

While we would like to list ALL of our donors individually, please understand that it would be very difficult to do so with 4,541 names that donated \$1-\$99 (**THANK YOU!**), 1,132 names that donated \$100-\$249 (**THANK YOU!**) and 305 names that donated \$250-\$499 (**THANK YOU!**).

Please know that we have not forgotten and we deeply appreciate each and every individual, organization and corporation that has generously donated money to support our mission. We know who you are, and we thank you! Your contributions continue to make a difference in the lives of those affected with mitochondrial disease.

The following acknowledgements include donations of \$500 or more entered into the system between Jan. 1, 2007, and June 30, 2007. If your name or company's name is incorrect or not listed, please contact info@umdf.org.

BENEFACTOR \$10,000+

Corporations, Organizations and Foundations:

Cleveland Clinic
Commonwealth of PA/Dept. of Health
Edith Trees Charitable Trust
Matthew Dudgeon Memorial Fund
Office of Rare Diseases - NIH
Rehoboth Beach Writers Guild Association, Maribeth Fischer
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'EAST MEETS WEST'

(cont. from page one)

share not only a middle name but also similar occupational backgrounds. EJ works as a heavy equipment operator, and Anthony worked for many years in the same role before becoming an engineer.

"I remember looking at Anthony and saying that this meeting was the best thing we have ever done," Kim said. "Also, Grace feels much better knowing that she is not alone and her feelings are normal."

"It was nice to be around people that understand our situation and have so much love for their special little girl like we do," Debbie said.

The Fogels expressed interest in moving East to be near the Zuzzolos, claiming that it felt like "a big happy family." The Zuzzolos added that from the moment they met it "felt like a family had come for a visit." This visit brought together two families that ultimately are looking for a cure to save their children.

The Fogels and Zuzzolos don't know if there are any others to join their family, a family that came together to rejoice and be happy, because they do not know what tomorrow will bring with this condition. "We thought we were alone," EJ said. "This may be it, but only time will tell." Kim added, "There is still room in our family for other children like Taryn and Mary.

"This all came about through the UMDF," EJ said. "I think it's a testimony which relates how compassionate and caring we are as a UMDF family."

ATLANTA CHAPTER

- **March 2008.** The Beta Club will host a St. Patrick's Day awareness fundraiser in Roswell, GA. Organizer Michelle Meddin and the club will be selling the UMDF energy bands in honor of Anna Lewis.
- **March 8, 2008.** A "Mito Madness" gala event will be held at the Peachtree Club in Midtown Atlanta, GA. Music, food, cocktails and a silent auction are being planned. The event will be hosted by Bernard & Leslie Reynolds and Chris & Mary Swinn.
- **March 29, 2008.** Lisa Higgins is organizing the Atlanta walk and family fun day activities in Norcross, GA. If you are interested in volunteering, email Lnhiggins@bellsouth.net.

CENTRAL OHIO CHAPTER

- **March 1, 2008.** The fifth annual Bet on Baylee Casino Day and Auction Night will be held in honor of Baylee Thompson in Roseville, Ohio. Contact Jody Thompson at 740-982-1244 or email gthompson008@columbus.rr.com.

HOUSTON CHAPTER

- **February 9, 2008.** Christopher's Heart Fun Run will be held at Sam Houston Park in downtown Houston. Visit www.umdf.org/christophersheartfunrun or email memories@christophersheart.com.

AROUND THE COUNTRY

- **January 2008.** St. Bernadette's Catholic School in Monroeville, PA will participate in

the Coins for a Cure campaign. The school will collect coins in January in memory of Gina Mohan.

- **January 13, 2008.** 26.2 for Alex at the Walt Disney World Marathon in Orlando, FL. Angie Newton and Karen Edwards will participate in honor of Alex Newton. Visit www.umdf.org/alex or email mike1newt@nctv.com.
- **February 2008.** Theodore Judah Elementary School in Sacramento, CA will participate in the Coins for a Cure campaign. The school will collect coins in February in honor of Lora Wasielewski.
- **February 2, 2008.** Chesapeake Physical & Aquatic Therapy will sponsor the fifth annual Curl-o-Rama in Laurel, MD. For more information about this event, call 301-498-2212.
- **March 14-16, 2008.** The fourth annual Writers at the Beach: Pure Sea Glass, a three-day writers' conference, will be held in Rehoboth Beach, DE, in honor of Sam and Zachary Juhlmann. Contact Maribeth Fischer at info@writersatthebeach.com or visit www.writersatthebeach.com.
- **March 15-16, 2008.** Preston's March for Energy in honor of Preston Buenaga will be held on March 15 during the Shamrock Sportsfest in Virginia Beach, VA. The Shamrock Marathon will be held the following day. Contact Deb Buenaga at dsb689@comcast.net or visit www.shamrockmarathon.com.



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.

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GIFTS FROM THE HEART

- Ellie & Jimmy Kovalcik's 6th birthday party in Columbus, OH raised \$200 in honor of Ellie Kovalcik.
- Jordan Davis had his Bar Mitzvah and sent \$100 to the UMDf in honor of his cousin Carly Platt.
- It's party time! A PartyLite Party in Arizona raised \$288.33, and a Silpada Jewelry Party raised \$50 in honor of Derek Swanson.
- Makenzie & Morgan Massey's 1st Birthday Party raised \$110 for the UMDf in honor of their friend Derek Swanson.
- Marlo White of Canada celebrated her 2nd birthday and her family donated \$300 to the UMDf in her honor.
- Seneca Valley High School in New Jersey held a Denim Day in honor of Jamie Smith and raised \$366.14 for the UMDf.
- The Mazzucco family of Vermont held an annual charity golf tournament and donated \$600 to the UMDf in memory of Palmer Quarles.
- The Redneck Yot Club of Ohio contributed \$100 to the UMDf in honor of Mercedes Sawyer.



Tom, Mercedes and Susie Sawyer

- Ackerman, Link & Sartory of West Palm Beach, FL, donated \$100 in proceeds from a weekly dress down day in honor of Michael Link.
- In lieu of gifts, \$90 was donated for Ed & Karen Feeney's 40th Wedding Anniversary in honor of Ellie Kovalcik of Ohio.
- Jimmy McKay celebrated his 1st Birthday on November 1st; \$300 was contributed to the UMDf in honor of Jimmy.

ONGOING FUNDRAISERS

COINS FOR A CURESM

The following families participated in the Coins for a CureSM campaign and sent in funds raised in the months of August and September:

- The Withum Family *in memory of Kevin and Eric Withum and in honor of Tina Withum*
- The Kovalcik Family *in honor of Ellie Kovalcik*
- The Mohan Family *in memory of Gina Mohan*
- The Leach Family *in honor of Brandon Leach and for the Brandon Leach Research Fund*
- The Nieves Family *in honor of Nicole Nieves*

TEA FOR MITOSM

The following families participated in Tea for Mito and sent funds raised in the months of August and September:

- The Trottier Family *in honor of Ian Trottier*
- The Keithline Family *in honor of Westley Clapp*

2008 ENTERTAINMENT BOOKS

The UMDf is offering 2008 Entertainment Books for sale, and now is the time to buy! Save money on things you do every day and support the UMDf at the same time. Dine, Shop, Travel and SAVE!

Entertainment Books make great gifts and are available throughout the United States and Canada in more than 150 editions. Entertainment Books will be shipped directly to your house at no additional cost, and the UMDf will receive a percentage of each book purchased!

To purchase an Entertainment Book and have the proceeds go to the UMDf, go to www.umd.org or use the following URL: www.entertainment.com/discount/?groupID=642223

WE NEED YOUR HELP!

Do you know a principal, teacher, teacher's aide or someone who works in a school district? The UMDf can provide you with information on the Coins for a Cure campaign to take to the school districts in your area! It is an easy fundraiser and a great mito awareness project that any school can do! Contact Tania at 888-317-UMDF or taniah@umd.org for more information!

FUNDRAISING HIGHLIGHTS

MITO GROUP EVENTS

CAROLINA FOOTHILLS MITO GROUP

- **August 30, 2007.** The third annual Goobers/UMDF Golf Outing was held in Clemson, SC and raised about \$7,500 for UMDF in honor of Alex Newton. Thank you Goober (Danny Nichols) for your continued support!

GREATER JACKSON MITO GROUP

- **October 2007.** This Halloween, people across the country were being asked "What are YOU?" The Dressed for Mito Awareness campaign was a huge success! Dozens of mitochondrion costumes were made and sent to families across the country. Over 400 people dressed for Mito Awareness. T-shirts were sold and awareness stickers were provided. Several companies and/or schools participated in the Dressed for Mito Awareness campaign on October 31st. Donations are still coming in! Special thanks to Julie Manley and everyone who helped in making the mitochondrion costumes!

IDAHO MITO GROUP

- **September 22, 2007.** The Idaho Mito Group held a Bowl-A-Thon in Boise, ID and raised over \$900 for the UMDF in honor of Luke Bender & Westley Clapp.

VIRGINIA MITO GROUP

- **September 15, 2007.** Owen's Pumpkin Palooza at Lohr Pumpkin Patch was held in Broadway, VA. Over 200 people participated in the fun-filled day which was held in honor of Owen Hollar and raised

\$7,500 for the UMDF. Thanks to the Harrisonburg Junior Women's Club for hosting this event!

WESTERN PA MITO GROUP

- **August 11, 2007.** The first annual Brew at the Zoo was held at the Pittsburgh Zoo & PPG Aquarium in Pittsburgh, PA. More than 800 people attended and \$18,590 was raised for the UMDF. Thank you to all who helped in making this event a success!
- **September 15, 2007.** The first annual Sip and Savor the Moment for a Cure LaCasa Narcisi Wine Pollak's Candies Chocolate Tasting Event was held in Gibsonia, PA. More than \$24,000 was raised in honor of Hannah Pallas.



Sip and Savor the Moment

- **September 30, 2007.** The seventh annual Cruisin' Toward a Cure car cruise at CCAC Boyce Campus in Monroeville, PA raised nearly \$4,000 for the UMDF.
- **October 20, 2007.** Martinis at the Mendelson was held at the Mendelson Art Gallery in Pittsburgh, PA. The event raised nearly \$5,500 for the UMDF. Thank you to Susie & Rick Leach for making this event possible!

MEMBER RESOURCES

COMPASSIONATE FRIENDS WORLDWIDE CANDLE LIGHTING

Remember all children that have died of any cause by participating in the national Compassionate Friends Worldwide Candle Lighting on Sunday, Dec. 9 at 7 p.m. local time. Held annually, the lighting lasts for one hour to remember and honor all deceased children.

The UMDF encourages you to join in this mass candle lighting by attending one of the hundreds of formal candle lighting events or thousands of informal candle lightings held in homes to create a 24-hour light, honoring the young that will never be forgotten.

For more information on this candle lighting or events in your area, visit the Compassionate Friends website at www.compassionatefriends.org.

SAVE THE DATE!

*Annual Membership Meeting
Monday, January 28, 2008
10:00 a.m. – 12:00n EST*

MARK YOUR CALENDARS NOW FOR

INDY 2008



Setting the Pace in Mitochondrial Medicine

**Hyatt Regency • Indianapolis, IN
June 25-28, 2008**

Course Co-chairs: Salvatore DiMauro, MD, and Bruce H. Cohen, MD.
Call 888-317-UMDF or visit www.umdf.org for more information!

UMDF ADULT ADVISORY COUNCIL TEAM FORMED

A new advisory council has been formed with a mission to ensure equal representation and service of the affected adult community and to provide advice and guidance to the UMDF on adult-related issues. The Adult Advisory Council Team (AACT) will make its recommendations directly to the UMDF Board of Trustees. AACT recently wrapped up its first national conference call with a full agenda and many issues to be reviewed. The advisory council is chaired by Sharon Shaw (AZ), and co-chaired by Gail Wehling (IL). In addition to Shaw and Wehling, other council members include Marge Calabrese (AZ), Linda Cooper (CA) and Pam Johnson (KS), David Hamm (MD), Bob Brief (NY), Greg Yellen (MD) and Cynthia Rosen (NM).

Some of the items the AACT will review are the UMDF's print materials including the newsletter, brochures and flyers. It will develop a list of resources in the medical community specific to adults, make suggestions for adult specific workshops and activities at symposium; together with outreach & education strategies to adults, the medical community and other adult services that would be beneficial.

"It took me over 15 years to get a diagnosis. In my eight years of involvement with the UMDF, I have yet to meet an adult or parent that has told me that they found their diagnoses within a few weeks," Shaw said. "This is why I am excited about serving on this advisory council. I have a passion to help close this gap. This council will 'AACT' by being the voice of the affected adult."

AACT will primarily serve adults currently diagnosed with a mitochondrial disease as well as those suspected of being affected. They will also represent the support system (spouses, partner, siblings, other family members and friends) of the affected adult. In addition, AACT will represent the interests of the parents of an affected child.

After fact-finding and reviewing these areas of interest, the council will formulate its recommendations, which will be reported to the UMDF board of trustees by Shaw.

"For some time, the UMDF has initiated a number of programs, including this column, to try to make everyone aware that mitochondrial diseases affect everyone, adults and children," said Kara Strittmatter, Director of Member Services. Strittmatter will serve as the staff liaison for AACT. "We are excited about the formation of this council because we think it will help us continue to find new opportunities to promote awareness for and about affected adults."

CALLING ALL MITO ADULTS!

Mitochondrial News Needs YOU! Please consider submitting an article on your experiences with a specific topic that would be of interest to other mito adults. If you want to contribute, please contact the UMDF at info@umdf.

WHAT ADULT MITO MEANS FOR ME

By Charles Marsteller

Until I hit my 50's, I always viewed myself as basically a healthy guy. Yes, I had my share of ailments. My nose ran constantly, and I had hyper-oily skin. I had a heat and humidity intolerance, perspired heavily and watched what I ate due to a sensitive stomach. Despite my appetite, I only weighed 135 pounds with 2% body fat at 6'4"!

The body ache (myalgia) was the worst, but I thought this was from my dogged quest in the gym to gain weight. I got certified as a trainer to find out why I didn't respond normally to exercise.

At age 39 and 153 pounds, the doctors intervened and put me on steroids to fight the myalgia and boost energy and recovery. They also put me on low-dose insulin to gain fat as my body still was less than 6%. This did not solve the mystery; I was still a low-energy guy who required a lot of rest.

Suddenly, in 2003, at age 52, I was hit by palindromic swellings and the myalgia dramatically worsened to a point that I could not stand or sit up for more than a total of three hours per day.

General medical professionals were perplexed by my appearance and conditioning from 20 years in the gym as my physical and lab work did not confirm my symptoms.

Still in pain, I could hardly accept the conclusion that nothing was wrong. Ten doctors consulted on my case. Some speculated that a portion of the problem was that I was maladaptive to aging or was simply aging fast.

In retrospect, I now know that all of my life I have been maladaptive to physical stress, and I am physically over-reactive to stimuli which made me chronically ill.

Up to a point, I could "adapt" by working my way around symptoms. I took sinus medicine, showered, used anti-microbials, ate carefully, got plenty of rest and relied on amino acids and ibuprofen. Many Americans do the same—I just had more symptoms than most.

But, in Adult Onset Mito, aging is a co-factor. At 53, I found myself in acute crisis where I could no longer stand or sit, much less adapt. My coping mechanisms no longer worked to address my bewildering array of symptoms.

When my cousin was hit with the same symptoms in 2005, my family realized that we were on the same path as our parents and maternal grandmothers who ended up bed and chair bound the last 20 years of their lives. We had a genetic disease!

This finally led to the deep muscle biopsies that detected the same Complex IV Cytochrome Oxidase abnormalities in both of us. Genetic testing is to follow.

It now seems that the aches and pains of aging may not be so natural after all: the rate of aging and its qualities seem to tie, in part, to cellular efficiency governed by one's genetic make-up.

So, my treatment to date is supplementation with the various cofactors which boost cellular efficiency.

In the meantime, I will continue to find new ways to work around what I now know to be a genetic disease. I will persevere by reading each lab report carefully, doing research on the internet and by asking informed questions.

For if I had not done what I have, I would not have solved my family mystery—a fact which makes me proud.

United Mitochondrial Disease Foundation Heartstrings Award Recognizing a youth commitment that tugs on the heartstrings

Purpose: To recognize a child or teen who has donated or raised funds for UMDF, enabling UMDF to continue its mission.

Eligibility: The individual recognized must be under 18 years of age at the time of the donation or fundraising activity.

Criteria: The winner is chosen based on related criteria of age, time invested, talents demonstrated, effectiveness, and generosity. For nominees who implement fund raising projects, the judges will consider the uniqueness and creativity of the project, communication, the time invested, and the amount raised in comparison to the age of the individual. 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.

Instructions: Any UMDF member can nominate an individual for this award. Fill out the form below and attach the requested information. UMDF will announce the winner at the annual symposium and will present the winner with a plaque. The Heartstrings Award winner will be featured on the UMDF web site and recognized in the UMDF Mitochondrial News newsletter.

In 100 words or less, please explain how this individual has "tugged at your heartstrings" through fundraising for or donation to UMDF. Identify important features of the nominee's activity, such as the time invested, creativity, communication skills, determination, effectiveness, and generosity. You may also attach supporting information on the fundraising project (published articles, pictures, comments from others involved with or participating in the project) or the communications of the nominee (letter explaining intended use of the gifted funds, thank you letters, letter sent with the donation, and so forth).

Please type your essay and attach it to the nomination form. Mail the nomination by April 25, 2008 to:

Heartstrings Award

UMDF

8085 Saltsburg Road, Suite 201

Pittsburgh, PA 15239

Or fax to 412-793-6477 or email the nomination by April 25, 2008 to info@umdf.org.

Person Nominating

Name: _____

Address: _____

Phone: _____

Email: _____

Nominee for the Award

Name: _____

Address: _____

Phone: _____

Diagnosis (if known): _____

Age (must be less than 18 years old at time of donation or event): _____

United Mitochondrial Disease Foundation LEAP Award

Living, Encouraging, Achieving & Persisting

Purpose: To recognize an individual living positively with mitochondrial disease, highlighting the person's accomplishments and volunteer service.

Eligibility: Age 14 years or older

Criteria: Individual with confirmed or suspected mitochondrial disease who overcomes daily challenges to achieve goals in career, family, and volunteer service. The individual demonstrates a positive attitude, hope for a brighter future, and an enthusiasm that inspires others.

Instructions: Any UMDF member can nominate an individual for this award. Fill out the form below and attach the requested information. UMDF will announce the LEAP Award winner at the annual symposium and will present the winner with a plaque. The LEAP Award winner will be featured on the UMDF web site and recognized in the UMDF Mitochondrial News newsletter.

In 100 words or less, please explain how this individual overcomes daily challenges to achieve goals in career, family, and volunteer service. Please provide examples of how the individual demonstrates a positive attitude, hope for a brighter future, and an enthusiasm that inspires others. You may also attach copies of articles about the nominee and lists of projects, activities, or clubs the nominee is involved with.

Please type your essay and attach it to the nomination form. Mail the nomination by April 25, 2008 to:
LEAP Award
UMDF
8085 Saltsburg Road, Suite 201
Pittsburgh, PA 15239

Or fax to 412-793-6477 or email the nomination by April 25, 2008 to info@umdf.org.

Person Nominating

Name: _____

Address: _____

Phone: _____

Email: _____

Nominee for the Award

Name: _____

Address: _____

Phone: _____

Diagnosis (if known): _____

Age (must be at least 14 years old): _____

ANNOUNCEMENTS

CHILD NEUROLOGY FOUNDATION SELECTS UMDF RECIPIENT OF PRESTIGIOUS AWARD

The United Mitochondrial Disease Foundation has been named the recipient of the 2007 'Advocacy Award of Merit' from the Child Neurology Foundation. The prestigious award was presented to UMDF Executive Director and CEO Chuck Mohan during the annual meeting of the Child Neurology Society in Quebec City, Quebec Canada, October 10-13, 2007.

The award recognizes a not-for-profit patient support organization making outstanding achievements on behalf of patients and families with neurological and developmental disorders. "This award is the result of the hard work, dedication and results of volunteer leaders who remain focused on our mission in providing support and advocacy for children and adults who suffer from mitochondrial disorders," Mohan said in accepting the award. "We are very thankful the committee selected the UMDF because it demonstrates their support for our mission and our ultimate goal of finding a cure."

NEW UMDF STAFF MEMBER

Our professional office staff continues to grow at the national office. It is our pleasure to introduce you to Cliff Gorski, who is our marketing and communications director.

Cliff joined the UMDF in October. He will be responsible for all marketing of the UMDF brand, developing public relations opportunities locally and nationally and the management of the communications department. The Duquesne University graduate comes to the UMDF from a Pittsburgh advertising agency where he managed the marketing and

PR for several health related, governmental and non profit clients.

CLEVELAND CLINIC OFFERS REMOTE SECOND OPINION SERVICE

Cleveland Clinic offers patients a 'remote' second opinion service from the comfort of your own home. Cleveland Clinic experts review your medical records and diagnostic tests and render an opinion that includes treatment options or alternatives and recommendations regarding future therapeutic considerations. Both Dr. Bruce Cohen and Dr. Sumit Parikh are listed as eConsultants. Patients or parents can obtain a formal opinion without making a trip to Cleveland. The 'single' consult is often covered by insurance companies and walks the family through the information submission process. If insurance denies payment, the fee is \$500. For more details, or to obtain a consult, a parent or patient must sign up at elevelandclinic.org and click on MyConsult.

WHERE IS MICHELLE?



Evelyn Mary Lawler

In September, the UMDF's Director of Development, Michelle Lawler, made a decision to devote her time to being a first-time mom. Start date of her new job: Thursday, October 4 at 10:59 p.m. upon the arrival of a beautiful little girl named Evelyn Mary Lawler. She was 8 pounds, 12 ounces and is growing by leaps and bounds. Best wishes, Michelle, Todd & Ev!

SUBMISSION DEADLINE FOR ISSUE 1 IS JANUARY 31, 2008!



UNITED
MITOCHONDRIAL
DISEASE
FOUNDATION®

HOPE. ENERGY. LIFE.

IN THIS ISSUE:

**Infections?
Read page 1!**

**Curious about Mito and cord
blood?
See page 3!**

**What is new in my area?
Check out pages 4-5!**

**Cast your vote for the 2008 LEAP
and Heartstrings awards!
Check out pages 10-11!**

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