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**Coming Soon
A NEW LOOK
for The United
Mitochondrial
Disease Foundation!
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United Mitochondrial Disease Foundation **MITOCHONDRIAL NEWS**

Volume 10 • Issue 4 • Fall 2005

Palliative Care

Living with Mitochondrial Disease

By Catherine A. Kelly-Langen, M.D.
and Sarah Friebert, M.D.

*Haslinger Family Pediatric Palliative
Care Center, Akron Children's Hospital*

Palliative Care is often associated with or defined as hospice care or care of the dying. Contrary to that popular belief, palliative care is defined by the Institute of Medicine as "care that seeks to prevent or relieve the symptoms produced by a life-threatening medical condition or its treatment." It is "care that seeks to help patients with such conditions and their families live as normally as possible and to provide them with timely and accurate information and support in decision-making."

*Hope does not lie in a
way out, but a way
through.*

-Robert Frost



Palliative Care: A Parent's Perspective

By Jennifer Lyman

Each year I attend the UMDF national symposium and bring back resources that may help in assisting in the needs and care of our older eight-year-old daughter, Caroline, who has Complex III-IV Deficiency. The symposium in August 2004 was no different when I attended a session titled *Pain Management and Palliative Care*. I had reservations attending this session – “It’s not like Caroline was expending her last breath!” What I found was an “eye

Continued on page 13

When most families are introduced to the concept of palliative care, it is the former, not the latter definition that comes to mind, and many families fear palliative care services. But the goals of palliative care are far from just the care of a dying child. Prevention and relief of pain and other symptoms, as well as addressing psychological, spiritual, emotional and developmental problems are of utmost importance in the delivery of palliative care. Additionally, care coordination, communication with multiple providers and access to palliative care services at all times and in multiple locations

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Atlanta 2006
Mastering the
Mitochondrial Maze

**Mark Your
Calendars!**

Sheraton Atlanta Hotel

Atlanta, Georgia, USA

June 14-17, 2006

See Pages 8-9 for More

INFO!

Ask the Mito Doc

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

Responders for this issue: Sumit Parikh, MD, The Cleveland Clinic Foundation, Cleveland, OH

The Question is:

After 9 years of tests, doctors and hospitalizations, my son was diagnosed with a complex I defect by a muscle biopsy. He was 9 years old then. He was able to walk then. Today, he is in and out of a wheelchair because of severe pain to his legs and/or feet; sometimes we cannot touch him due to the pain. He is again in the wheelchair due to pain. We've seen more than 50 doctors at this point. It is now suspected that he has a second disease. Two weeks ago he was tested for Fabry Disease. Yesterday those tests came back negative. Now doctors want to have another muscle biopsy to confirm the original diagnosis. I've read before that a muscle biopsy is 100% accurate in diagnosing mitochondrial disease. Now I'm told this is not true. I'm told with the advancement in technology, having another muscle biopsy now would be more accurate than five years ago. No one seems to be able to get his pain under control. He's 14 now and many nights he's up till 2 or 3 in the morning crying with

pain. He bangs his feet on the floor to try to stop the pain (it doesn't work) he shakes his legs to stop the pain (it doesn't work). We've tried so many different medications and nothing works, most cause him to react to the medications. I don't understand how a diagnosis could be made through a muscle biopsy five years ago and now it's questionable. Please offer me some information as to how this works. How many patients with complex I defect actually suffer from this type of pain and to this degree? What methods can be used to stop the pain to allow for a normal life? He can't even go to school because of the pain level. He's home all the time.

Response From: Sumit Parikh, MD

I am very sorry to hear of how much pain your son is in and the recent diagnostic difficulties your family is having. I will try and answer your questions in several segments:

1. The muscle biopsy is not 100% accurate. We do not have perfect numbers yet as to the absolute accuracy of this test - which is why some of us hem and haw about performing it. There is no good research data on "false negative" and "false positive" results of a muscle biopsy.

Each lab that performs muscle biopsies is still trying to further evaluate this. However, until we know all the genes which can cause mitochondrial disease, and then compare an individual who has a known genetic defect and this person's biopsy results - we will not know for sure. Labs that do muscle biopsies have amassed some individuals with a positive mitochondrial DNA mutation -> but not necessarily in enough numbers to report their findings. Our group is still studying this.

All in all - like any test - muscle biopsies will have a certain degree of falsely positive and falsely negative results.

2. What do we know about muscle biopsies ? We believe we know that a muscle biopsy is superior to skin fibroblast testing for mitochondrial disease. We also believe we know that a "fresh" muscle biopsy is superior to testing frozen muscle tissue though the actual figures of "how superior" vary.

3. Is there another diagnosis? This question should always be entertained - especially when a diagnosis of mitochondrial disease is not 100% (i.e., no DNA mutation identified/ clinical course atypical/ muscle biopsy not abnormal for all aspects tested).

We suspect that there is a concept of "secondary" mitochondrial disease -> a primary disease can interfere with how mitochondria work or it can directly injure mitochondria, so if you test the mitochondria - the results are abnormal. However - the primary disease is still the problem. Treating the mitochondrial disease may help alleviate some of the symptoms, but the primary disease remains.

4. We do not know how many individuals with Complex 1 disease - or mitochondrial disease in general have pain - though both brain and nerve disease in mitochondrial dysfunction can lead to pain - and pain is a common symptom in mitochondrial disease.

Chronic pain, regardless of cause, is difficult to treat. There is no one medication that is more beneficial for pain caused in mitochondrial disease. The care of a physician who specializes in pain management needs to be obtained. All available treatments, including safe alternative treatments (acupuncture, relaxation, meditation, biofeedback) need to be tried.

Chairman's Report

I was late submitting this final chairman's report. I wanted it to be special, but unlike the others I found myself laboring to find a topic as well as the words. I have decided to take excerpts from previous reports and to quote those who have said it more eloquently, precisely, and with more meaning than I ever could.

In 1997, I wrote about the difficulty I had learning foreign languages. I always chose the easiest language and instructor for that mandatory high school and college credit. Little did I realize that it would be the English language that would catch my interest and test my skills.

My new English language began at the age of 39 with the word *idiopathic*. *Mitochondrial, MELAS, and Encephalomyopathy* soon followed. Now, 16 years later, I find myself focused only on one four letter word – **CURE!**

Destiny is not a matter of chance, it is a choice; It is not a thing to be waited for, it is a thing to be achieved.
-Shaw

Complacency is the refuge of those who have lost the dream. Give me a stock clerk with a goal, and I will give you a man Who will make history. Give me a man without a goal and I will give you a stock clerk.
- J.C. Penney

When UMDF was five years old, I wrote about having the opportunity to speak to a group of parents and doctors about the goals of UMDF. Afterwards, one of the doctors approached me and wanted to know who I thought I was and what medical background I had qualifying me to discuss the approaches necessary to reach a cure. He really got my attention when he said, "You volunteers are all alike." I told him I consider myself a donkey not a volunteer. A donkey harnessed to a large wagon. I told him he shouldn't spend any time thinking about the donkey, he should be telling this donkey what he needs to find a cure for mitochondrial diseases. I told him I

couldn't develop the complex formulas for treatments and cures and I certainly couldn't design the equipment that would test for the diagnosis

BUT, I could get him the test tubes, the computers, the nuts and bolts that would be essential for his research. I told him to load the wagon and not worry about the donkey. When the wagon gets too heavy for me to pull alone, I would find others that would push and together we could help him find the cure.

The wagon is still here and it's bigger and fuller than ever. Now when I look at the wagon I see more and more people pushing, as well as pulling, and I see movement.

*Success isn't a race; It's a marathon.
- Founder Popeyes Fried Chicken*

The thing to try when all else fails is try again.

The achiever never knows whether he is succeeding or failing, only that he is not finished. (Keep pulling the cart!)

I wrote about wanting a remote control and VCR for the shows of life. I want to record the interesting events that I can't attend and I certainly want to ZAP out the boring ones I have to attend! But most importantly I want to *FAST FORWARD*. I want to leap ahead so I can look back on the path UMDF has traveled in its "quest for the cure."

I want to look at an old recording of the office that once occupied a spare room in my home and then *FAST FORWARD* to UMDF occupying a major office building with a staff of 300 servicing 250 chapters around the world. I want to *FAST FORWARD* to the day UMDF awards 150 million dollars each year in research grants. And yes, I want to *FAST FORWARD* to the Academy Awards and see 90% of the participants wearing UMDF's Re-defining Hope lapel pins.

I am still fast forwarding!



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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.

Newsletter Editor

Kara Strittmatter
kara@umdf.org

Chapter Activities

ATLANTA AREA CHAPTER

Atlanta, GA



with Waynette Peek) for donating the dinner and helping raise \$2,300 for *Race for Riley*.

Special Thanks -

- On September 26, the chapter held a *Race for Riley* Kickoff dinner at the Blue-Eyed Daisy Bakeshop. Thank you Steve and Marie Nygren (Steve picture left



2nd Annual Fore-a-Cure Golf Outing Raises More than \$53,000

It was a blustery day but 119 golfers enjoyed the day's event and families spent the evening sharing stories and bringing their kids together for fellowship and fun.



10/24/2005

Attendees had the opportunity to donate for raffles, Putting Contest, Silent Auction and a Live Auction.

The chapter would like to thank all the participants, sponsors, volunteers and the Standard Club for making the day such a success.

Mary and Emily Swinn are pictured above along with Brody Cole's family and Tom Viall. Well done, Atlanta!!!!

Holiday Shopping?

Ashley DiLorenzo is offering discounts to UMDF members for Arbonne products this holiday season. If interested, you can also make this into an easy fundraiser to benefit UMDF. For more information on the discounts or possible fundraiser, please contact Ashley at ashley@myarbonne.com. To check out the products, visit www.pureresults.myarbonne.com.

INDIANA CHAPTER

Indianapolis, IN

Events/Fundraisers:

- **Special Thanks** - The Indiana Chapter found an easy way to raise additional money through an eBay auction of tickets to the Notre Dame/USC game on October 15 – final bid and dollars for UMDF was \$645.99. Keep the great ideas coming!!!
- **Looking ahead** - *Pack the House* night with Indiana ICE is scheduled for February 25, 2006.



President: Sue Ann Bube
Phone: 317-894-9099
Email: INChapter@umdf.org

1st Annual Golf Outing a Success!

Kudos to Tournament Director, Mike Hanlon and committee members Eric and Gina Boling, Sue Ann Bube, Penny Hanlon and Meagan Hartlieb on the first annual Indiana UMDF Golf Tournament. Regardless of the rain, the event raised more than \$20,000 – Outstanding!

Want to Get Involved?!

Contact your local chapter or group today. Chapters and Groups will continue to grow with your HELP. **YOU can make a difference.**

Chapter Activities

DELAWARE VALLEY CHAPTER

Philadelphia, PA

6th Annual "Go! For Mito" Shelly's Heroes Walk Run New Name, New Location and a HUGE SUCCESS!!!!



The Chapter moved their annual event from Harleysville to the Philadelphia Art Museum and enjoyed a beautiful Fall day – **raising nearly \$60,000 to benefit UMDF**. Kids' events included a moon bounce, face painting, magic shows and entertainment – a little something for the entire family.



President: Maripat Shelly
Phone: 215-256-0273
Email: DelValChapter@umdf.org

Thanks to everyone who participated, volunteered or donated for the event.

Special thanks to The Brian Roberts Foundation (Aileen and Brian Roberts) of Philadelphia for contributing \$1,000 in honor of Katie Kerns and the Del Val walk/run.

Crystal Beaded Bracelets

Beautiful crystal beaded bracelets are still available through the chapter. Pictures and order forms are available on the Delaware Valley Chapter web page at www.umdf.org.

ARIZONA CHAPTER

Phoenix, AZ

President: Suzanne Perryman
Phone: 480-419-0167
Email: AZChapter@umdf.org



Designs for Dollars

Chapter President Suzanne Perryman continues with the *Designs for Dollars* fundraiser to benefit AZ UMDF. Please take time to visit www.embroideryjournal.com and check out *Designs for Dollars*.

Good Job!

The chapter applied and received a \$5,000 grant from the International Heart of Variety Textile Division.

KANSAS CITY CHAPTER

Kansas City, MO

October Busy Month for Chapter

- **Special Thanks** - Dr. Bruce Cohen gave grand rounds at Kansas University Medical Center and Children's Mercy Hospital. He then spoke to families and physicians at an evening reception on October 6. **Special thanks also goes to Athena Diagnostics** for sponsoring this special event and helping the chapter reach out to the medical community!

President: Pam Johnson
Phone: 913-631-3070
Email: KCChapter@umdf.org

- **Special Thanks** - Gale's Gig/Kansas City Golf Outing on October 10 raised nearly \$15,000 at the Lake Quivira Country Club. Thank you Pam Johnson and the entire chapter for taking on another event.

- **Looking ahead** - June 10, 2006 - 3rd Annual Mito-What? 5K Run/Walk One Step Closer to a Cure at Corporate Woods Founders Park.

For activity/info for Southern California and New York Metro Chapters, email SCalChapter@umdf.org or NYMetroChapter@umdf.org

Chapter Activities

NEW ENGLAND CHAPTER

Boston, MA

President: Bridget Willis
Phone: 413-593-5920 (Beverly Ingram)
Email: NEngChapter@umdf.org

New England Chapter's Weekend of Hope is HUGE Success

Back to Back Events Raise more than \$66,000

1st Annual Mito-What? 5K Walk
October 1 in Plymouth, MA



6th Annual Mito-What? 5K Walk/Run
October 2 in Longmeadow, MA



CHAPTER MERCHANDISE

The chapter has beautiful gray sweatshirts (with hood, pocket and "open" bottom) embroidered with the UMDF Redefining Hope banner and under it, United Mitochondrial Disease Foundation. Cost is \$30 with a small shipping and handling charge. If interested, please contact Bridget Willis at 508-224-7165 or email NEngChapter@umdf.org.

New England Looking Ahead

- If you love golf or know someone who does, the chapter is asking for help in organizing a golf tournament. Please contact Bill Naughton at 781-982-9350 if you can help!

OHIO CHAPTER

Cleveland, OH

President: Bill Hodges

Phone: 440-235-2451

Email: OHChapter@umdf.org



Special Thanks -

- The Big Bear Farms annual hayride/bonfire event in honor of Ellie Kovalcik in Columbus, OH raised more than \$3,000.
- Clams for a Cure* Ohio Chapter Clambake (group pictured left) at Hoggy's Restaurant at Valley View (Cleveland area) was fun for all who attended on October 16th and the chapter raised \$738.
- More than 120 attended Dr. Bruce Cohen's presentation on November 6. Five local therapists also presented on the "Unique Needs of Children with Mitochondrial Disorders" and "Hippotherapy and Spidertherapy and Mitochondrial Diseases." Notes from the presentations will be posted soon on the Ohio web page.

Mark Your Calendars!

5th Annual KFC/UMDF

5K Run/1 Mile Walk - One Step Closer to a Cure

Saturday, June 3, 2006



Anger Well Channeled

From the Executive Director - J. Thomas Viall

"I have learned through bitter experience the one supreme lesson to conserve my anger, and as heat conserved is transmitted into energy, even so our anger controlled can be transmitted into a power that can move the world."

The quote above is from Mohandas K. Gandhi. I think it captures a very real component of human nature and gives us pause to examine our own behaviors and actions. Tragedy and sadness of any sort can fuel a torrent of emotions - among them anger.

It's not unreasonable for parents to be extremely angry on learning their child has been diagnosed with a mitochondrial disease. While not all prognoses are dire, there is still the reality that your child may face a lifetime of challenges not faced by other children.

It's not unreasonable for medical professionals to feel anger at the sometimes helpless feeling they have as they treat mitochondrial disorders. Few things are as frustrating and anxiety producing as the sense of being powerless.

It's not unreasonable for patients with a mitochondrial disease to, at times, feel extreme rage because of their illness. After all, the silent lottery of genetics singled out some and not others . . . it's not unreasonable to be angry at holding that number.

Finally, it's not at all unreasonable for each of the above to seethe over the lack of societal awareness and understanding of mitochondrial disease.

The challenge (as we all know) is to not let the anger consume us. No matter what the daily trial -- a problem with a spouse, a less than thoughtful neighbor, or a fearful diagnosis -- we know that if we allow anger to control our thought process . . . we have lost. However, the intellect doesn't always control our behavior and if we always made rational decisions, there would be far fewer therapists and counselors in the phone book.

For me, this is where Gandhi's quote becomes useful. If I can use my anger's energy to address a root cause of that anger - that is anger well channeled.

Over the past few weeks I have had the privilege of getting out from behind my desk to meet many UMDF families, members, supporters, and researchers around the country. To be sure, I cannot presume to know the inner thoughts of these good people; I don't know where the anger lies, how deep it may run, or if it is even there at all. However, I have seen people "well channeling" their energies and I am hazarding a guess that some of it is out of frustration and anger. And my message today is a simple one . . . that's OK. You have every right to be mad -- real mad -- and as a result, that energy (well channeled) is fueling research as well as public awareness. That anger has become an empowering, liberating force. Few of us have the strength of a Gandhi who stood his ground and brought the British Empire to its knees - but we can strive and learn. None of us will know with any certainty if we will be the one to, as Gandhi's quote suggests, "move the world." I dare say that Rosa Parks never thought of herself as an American icon - but in her quiet and dignified way - she changed America for the better. She moved the world and I suspect she used a little "anger well channeled."

Ours is a big task and I'll use almost any tool I can to succeed in that task. So if it takes a little collective "anger well channeled," I'm all for it.

With all best wishes,

J. Thomas Viall

MATCHING GIFTS

Your Gift Can Mean Twice as Much!

You may be able to double the amounts of your recent and future gifts to the United Mitochondrial Disease Foundation if you work for a firm that has an employee matching gift program.

To make your match, simply obtain a form from your company's Matching Gift Coordinator (start with the personnel or community relations department) and send it to UMDF office. Your company's Matching Gift Coordinator can also answer any questions you may have about this program.

Your company may have a matching gift program even if you haven't heard about it. You'll never know unless you ask. Matching gifts help raise additional funds for your favorite organization. Double your gift by taking advantage of your company's Matching Gift Program today.

Atlanta 2006

Mastering the Mitochondrial Maze

Mark Your Calendars for UMDF's 2006 Conference!

Sheraton Atlanta Hotel
Atlanta, Georgia, USA
Family Meetings
June 16-17, 2006

Preliminary Family Program Topics

- Talking to Your Health Care Professional
- Mito Basics
- Advanced Mito Basics
- Journaling and Writing: Therapeutic for Adults and Children Alike
- Symptom Management
- Nurturing the Healthy Siblings
- The Future of Mitochondrial Medicine
- Keeping a Marriage Healthy
- Service Dogs
- Mitochondrial Disease and Psychiatric Issues

A Special Group Rate of \$139 is available to attendees. Visit <http://www.starwoodmeeting.com/Book/umdf> to make reservations or check out the hotel!

Meeting Format

The 2006 meeting format will change from previous years to give attendees more choices and repeat sessions for those who do not want to miss anything! We will also open and end each day together before splitting into separate tracks – giving attendees more opportunities to network.

Friday Night Banquet ***Magic, Mystery and Music***

Watch for BIG changes at the 2006 Friday Night Banquet. The UMDF will take you on a magical journey and celebrate our accomplishments as we continue to work toward a brighter future for all those affected by mitochondrial disease. The evening promises to captivate attendees with magic, mystery and music.

If you know of a company that would benefit from sponsoring or exhibiting at the Atlanta 2006 UMDF Conference, please email owenm@umdf.org. Thank You!

If you missed Mitochondrial Medicine 2005 and would like to purchase audio CDs or DVDs of the sessions, please call the office at 412-793-8077 or email barb@umdf.org for an order form. Forms are also available at www.umdf.org.

Scientific Meetings

Dates: June 14-17, 2006



The 2006 UMDF Conference will Focus on
Developing Rational Approaches to the
Treatment of Mitochondrial Disease.

Course Objectives:

- Basic mechanisms of mitochondrial disease
- Clinical recognition and diagnosis of mitochondrial disease
- Concepts of mitochondrial disease management

Invited Speakers:

- Britton Chance, PhD, ScD, MD, *Eldridge Reeves Johnson University, PA*
- Bruce Ames, PhD, *Children's Hospital Oakland Research Institute, CA*
- Salvatore DiMauro, MD, *Columbia University, NY*
- Eric Shoubridge, PhD, *McGill University, Quebec, Canada*
- Arnold Munnich, MD, PhD, *Groupe Hospitalier Necker-Enfants Malades, Paris, France*
- Jan Smeitink, MD, PhD, *University Medical Center Nijmegen, Netherlands*
- Giovanni Manfredi, MD, PhD, *Weill Medical College of Cornell University, NY*
- Carlos Moraes, PhD, *University of Miami, FL*
- Antoni Barrientos, PhD, *University of Miami, FL*
- Takao Tagi, PhD, *The Scripps Research Institute, La Jolla, CA*
- John Guy, MD, *University of Florida, FL*
- Margaret Sedensky, MD, *University Hospitals of Cleveland, Case Western, OH*
- Bernard Trumper, PhD, *Dartmouth Medical School, NH*
- Peter Thorsness, PhD, *University of Wyoming, WY*
- Grazia Isaya, MD, PhD, *Mayo Clinic, MN*

The committee is in process of inviting more of the top experts to fill four full days of meetings. Don't miss this exciting new format -- join us in Atlanta!

Call for Abstracts: Visit www.umdf.org after December 1, 2005

2006 SYMPOSIUM PLANNING COMMITTEE:

John Shoffner, MD, *Course Director, Horizon Molecular Medicine*

Bruce H. Cohen, MD, *The Cleveland Clinic Foundation*

William Copeland, PhD, *NIEHS, Research Triangle Park, NC*

Richard H. Haas, MB, BChir, *University of California, San Diego*

Charles L. Hoppel, MD, *Louis Stokes Veterans Affairs Medical Ctr*

Keshav K. Singh, PhD, *Roswell Park Cancer Institute*

This activity has been approved for AMA-PRA credit and will be administered through joint sponsorship by Children's Healthcare of Atlanta

Palliative Care: Living with Mitochondrial Disease

Continued from page 1

provide important pieces of an increasingly complex medical puzzle.

As families with members with mitochondrial disease, you know only too well the difficulties that come with a disease that cannot yet be cured. Mitochondrial diseases can affect all body systems and organs, causing innumerable symptoms and problems. Any disease that causes such a variety of problems necessitates multiple specialists and wide-ranging therapies. Managing the healthcare system with a simple illness is difficult enough. With a complex, mysterious disorder like mitochondrial disease, which is as poorly understood by most physicians as it is by most lay people, the journey can be even more stressful and overwhelming for families to navigate.

So where can you turn for help? Palliative Care services strive to address the complexities of mitochondrial disease by providing care coordination and case management to help stream-line the process of seeing multiple providers for multiple issues. We provide support for family members as well as the affected child or children, offering psychosocial and chaplaincy support. Symptoms that do not fall in other realms are also addressed. We try to work with other members of the medical team to look at the whole picture of health and illness instead of focusing on each system or organ individually. In other words, the primary goal of the palliative care team is to take that journey with you.

Certainly with an illness such as mitochondrial disease, there is the reality that no cure has yet been found and that eventual decline is possible or even expected. Palliative Care services address the needs that accompany this as well. As recurrent significant illnesses or decline occurs, Palliative Care strives to address the illness at hand, as well as to provide support as families work to make decisions in their child's best interest. Our goal is to promote quality of life and informed choices as the end of life nears, so that no family feels unsure of decisions they have made for their child after he or she is gone. When a child has died, we work toward assisting all family members in their grieving process.

A practical example illustrates how Palliative Care services can be beneficial to a family with a member with mitochondrial disease.

Caroline is an eight-year-old girl who was diagnosed with mitochondrial disease at three months of age. She had multiple care providers addressing all of her different symptoms, including a neurologist, a gastroenterologist, an orthopedic

surgeon, a pulmonologist, a cardiologist, an ear/nose/throat surgeon, a kidney specialist, an endocrinologist, a urologist, an ophthalmologist, a mitochondrial disease specialist, and a primary care provider. She was on a laundry list of medications. When she had symptoms or issues, her parents were often unsure whom to call. She spent almost all of her time in the hospital or at multiple visits to specialists, and her care was becoming overwhelming. Because so much of Caroline's care was focused on her medical management, her parents had little time or energy left for enjoyment of life or time with Caroline's younger sister.

Caroline's mother heard of Palliative Care and referred herself for services. A Palliative Care physician and a Clinical Nurse Specialist/Case Manager came to their home to review Caroline's medical issues and practical issues, as well as the demands of the household and the impact her illness had on the family. Her symptoms and other needs were assessed and her care was streamlined to include the mitochondrial disease specialist and the Palliative Care Team. Caroline's primary care doctor, who also cares for her sister, remains in the loop of care as well.

Since the time of her introduction to the Palliative Care Team, Caroline has done well and her medications and therapies are much more manageable. She has only been hospitalized for one brief stay and has been able to spend the rest of the time at home with her family. This has meant a great deal of stress relief for Caroline's parents, giving them more time and energy. When issues arise, her parents call the Palliative Care Team or the mitochondrial disease specialist as appropriate. As decline has occurred or sensitive issues have arisen, honest and open conversations have been held to address how each of her parents feels as well as their questions and concerns. We have provided a safe haven to discuss end-of-life topics and quality of life for the whole family in the context of Caroline's best interest.

Working together, we have all benefited from getting to know and helping to care for Caroline and her family, and we continue to do so. It is our hope that her family can continue to enjoy life with Caroline and to feel that Caroline is enjoying her life, too.

Fundraisers



5th Annual Cruisin' Toward a Car Cruise attracts hundreds of cruisers and raises more than \$12,000

Pictured above is Lynda Merola and friends shaking up some fresh squeezed lemonade for attendees at the Car Cruise in Monroeville, PA!



Wine & Dessert for Ladies Raises more than \$8,000

Tova Sido and friends held a Wine & Dessert for Ladies Only in Dallas, TX, on November 6. From left to right, pictured is raffle prize winner, Ellen Snuffer, with hostesses Tova Sido and Piper Wyatt!

Special Thanks to Dallas City Market for the superb desserts and to Classic Wine Distributors, LLC/Jeff Kaye for the delicious beverages!



Golf Cart Decorating? You Go Girl!

The 2nd Annual Pittsburgh You Go Girl Golf Outing added another unique contest to the day and the ladies went wild. Yes, those are palm trees pictured left. The event raised more than \$6,900 and Murrysville Golf Club may never be the same!

Special Thanks to LaCava's Italian Market and Mohan's Restaurant!



If you have an event announcement or an idea for an article for the Mitochondrial News, please email kara@umdf.org. We want to hear from YOU!

For information on starting a fundraiser in your area, email jodie@umdf.org.



- In lieu of wedding favors, Tina Carrier (pictured above with Allie) and husband Brian Zadrozny donated \$675 to UMDF in honor of Allie Danner. The couple also supported the Plymouth, MA walk – we wish you both a lifetime of happiness!
- Peggy Westfall of Charlottesville, VA and friends volunteered at several Friday After Five events, a series of outdoor concerts, raising \$1,140 in memory of her daughter, Melissa Westfall.
- The Halliburton Foundation donated \$300 in honor of Larry

Gifts from the Heart - Thank You ALL

Klein through a Volunteer Incentive Program. Larry submitted hours for a “collection campaign” he ran in honor of his grandson, Logan Palmer - which raised \$157.25.

- Stephanie Larson and Cheryl Moen held a rooftop party in August in memory of Stephanie’s sister Carrie Mack. Thirty guests attended and had a bird’s eye view of the Chicago Air & Water Show. The event raised \$1,605 through donations and raffles. Mom, Ardy Quolette sold UMDF cookbooks too. Awesome!
- Franklin Regional High School in Murrysville, PA donated \$500 to UMDF.
- **Special Thanks** - More than \$3,500 was raised at a Fall Ball at Longwood Gardens in honor of

Caleb B. Krug (pictured above right with mom, Stephanie, and dad, Brian, and sister, Lucy).

Thank you, Stephanie and Tracy Fleming for organizing this event!



- **Caleb Krug “energy bands”** - Stephanie Krug and friends raised more than \$1,700 by selling these special “orange” bands. Why orange? Orange was chosen as a tribute to Caleb’s beautiful carrot top hair. Great Job!
- Tea for Mito - new totals from Sr. Clara Mohan’s fundraiser stand at \$3,345 with more coming in.

Runs/Walks

The Newton Family
Busy in August with Two
Successful Events



Pictured above is Carson Rogers (R) and Alex Newton (L) with the Clemson Tiger – the 1st Annual Step Towards a Cure Raised \$6,910

Back to back events - on
August 25th, Ron Nonneberg and Angie Newton helped coordinate the *1st Goobers/UMDF Golf Classic* at Boscobel Golf Club in Clemson, SC in honor of Alex Newton. The golf outing raised \$8,882, and then, on August 27, the Newtons were at it again with the 1st Annual Step Towards a Cure at Jaycee Park in Clemson. Kids activities included face painting, the Wheelie Fun Bus, gymnastic activities and a tot trot.

Daddy Runs the Extra Mile, or 26.2 Miles, for his Girls

Scott Bruder, of Sudbury, MA, participated in the Chicago Marathon on October 9th. He continues to collect donations from friends and family on behalf of his daughters, Hannah and Emma. To date, he has raised more than \$6,491 – Thanks Scott!!!

Fundraisers

Christopher Schindler Events Raise Dollars and Awareness in Houston

Joe Schindler, Christopher's dad, ran a *Horse Cutting* event this past summer and raised more than \$35,000. Thanks, Joe!

In August, Debbie Andrews, friend of Christopher held a Powder Puff Poker Party in memory of Christopher and his 12th birthday. \$2,000 was dealt to the UMDF/Christopher Schindler Fund. Great job, Debbie!



Christopher's 1st Annual 5K Fun Run was held October 30 at Sam Houston Park and the event raised more than \$18,000! Friends and family of Christopher Schindler organized this first time event to raise funds for research into the disease that took Christopher's life at the age of 11. To read Christopher's story, visit www.christophersheart.com. (Mom, Deb Schindler, is pictured above in the middle with friends Lucy Caire and Francine Fleming).

Colleagues of UMDF Board Vice President, John DiCecco, collected \$2,430 in honor of John's birthday and donated it to the Foundation. Happy Birthday, John - you've got GREAT friends!

Special Thanks to MORE

★ Fundraising Stars ★

- Eric Chiffriller and the staff at Ameriquest (Paramus, NJ location) raised \$5,246 by holding a car wash – now, that is what we call cleaning up!!! Thanks, Ameriquest!!!
- LB Foster Company in Pittsburgh held a denim day to benefit UMDF in October and raised \$260 in honor of Austin Manz.
- 9th Grader Craig Leslie, of Dallas, TX is once again collecting pledges for “A’s for Charlie & Louisa.” Craig is Tova and Tofer Sido’s neighbor and for every “A” he earns in school, people will donate money to benefit Charlie & Louisa’s Fund/UMDF. Pure Genius, Craig - thank you!
- Six-year-old Alyssa Rogers, sister to Carson of Greer, SC, ran a lemonade stand and raised \$13 for UMDF. What a great sister – thanks, Alyssa!
- Jessica Cabourg and Billy Falkenstern were married in August and, in lieu of wedding favors, donated \$350 to UMDF in honor of their cousin Nicholas Nunno. Congrats Jessica & Billy and thank you for sharing your special day with us.
- In honor of Logan Palmer, the JC Penney Store and JC Penney Salon at White Mountain Mall in Rock Springs, WY raised \$333 through a “Coins for a Cure” campaign. Special thanks to Beverly Lyndes, Kris Morrison, Jennifer Cook and all the stylists at the salon who gave up their tips for the campaign and Logan!

More Fundraisers on Page 18!!

Palliative Care: A Parent's Perspective

Continued from page 1

and ear opening session.” It was as if the information presented was tailor made to describe “a day in the life of Caroline.”

In a nutshell, Caroline’s mitochondrial disease has affected her life in numerous ways. Caroline is wheelchair-dependent, non-verbal, requires TPN via her central line to provide the necessary calories and nutrients to sustain growth, a G-tube for other medications and supplements...the list goes on and on.

Despite all the medical baggage, Caroline is our pride and joy – who warms the hearts of many with her sweet smile and adoring blue eyes.

Just as mitochondrial disease is under-recognized, palliative care is just the same. During the past year, the majority of Caroline’s care is now directed by the palliative care center at our local Children’s Hospital. To appreciate the concept of palliative care, you must first understand what it encompasses and how palliative care has monumentally enhanced the quality of Caroline’s life and our family as a whole.

Palliative care is for children and families facing life threatening illness. Pediatric palliative care improves the quality of life, facilitates informed decision making and minimizes suffering. Palliative care is child-focused, family-oriented and relationship centered care. It focuses on early identification of care issues and impeccable assessment and treatment of pain and other problems, including spiritual, social and psychological concerns.

Often when people hear the words “palliative care,” they fall into a misconception that your child has been handed over a “death sentence” or “you are giving up on your child.” Nothing could be further from the truth. Palliative care is about making life be as good as it can be for as long as your child is alive. It’s about maximizing symptom management to minimizing physical suffering – it’s caring beyond curing.

Caroline has been part of the palliative care center for over a year. The team has been the backbone for her on-going care. Although we downsized the number of specialists or “cooks in the kitchen,” the palliative care team has managed Caroline’s care more effectively in a variety of ways. We now have fewer trips to specialists, a marked reduction in hospital stays and a streamlined, collaborative approach to managing her care.

The palliative care team has been a tremendous find for our family, largely because they involve us in all aspects of decision making and the necessary comprehensive care planning. It’s a team that has addressed Caroline’s pain and distressful symptoms proactively. It’s a team who responds to our grief and

sadness during difficult times. It’s a team that celebrates the smallest of milestones with us!

Palliative care has afforded us more time to “be a family” and provides Caroline with more opportunities to do the things little girls enjoy doing. As her mother, our time together is precious. Our experiences with palliative care have continued to keep a thought close to our hearts – *Each day is a gift, so use it wisely...tomorrow isn’t promised.*

Palliative Care is an approach that improves the quality of life of patients and their families with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual. The goal of palliative care is achievement of the best quality of life for patients and their families.

-World Health Organization

Editor's Note:

The UMDF office has been asked specifics as to what a palliative care team will do - does an entire team visit the patient every day, every week or every month? What do they do when they visit - administer meds, physical therapy, or provide family counseling? Do they come to the home? If you or your loved one contacts a local palliative care facility/provider, they will be able to answer these questions. Every facility manages patients differently and most of the care will be based on the initial assessment.

If a family needs help with administering meds daily or do physical therapy twice a week, then the team would work with the family on those issues. You and the team work together to assess your needs and schedule visits and appointments accordingly. Services provided will vary from facility to facility.

For more information or to find a provider in your area, visit www.nhpco.org or
http://www.medicalhomeinfo.org/publications/palliative_fam.html.

Donors - Thank YOU!

Appreciating the People Along the Way

"We are often so caught up in our destination (a cure and better treatments) that we forget to appreciate the journey – especially the goodness of the people we meet along the way."

- Margaret Malone

The United Mitochondrial Disease Foundation has not forgotten and deeply appreciates each and every individual, organization, and corporation that has generously donated money to support our mission. While we would like to list ALL our donors in the newsletter, please understand that it would be difficult to do so. If we did, we would need to list 8,720 names that donated \$1-99 (THANK YOU); 2,099 names that donated \$100-249 (THANK YOU) and 573 names that donated \$250-499 (THANK YOU). That is a lot of names - we know who you are and you are appreciated. 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 between July 1, 2004 to June 30, 2005 (Fiscal Year 2005)**. If your name or company's name is not listed, please contact kara@umdf.org. We continue to move through a database transition and we need to hear from you if our information is not accurate!

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Announcements

Two New Faces at the UMDF Office



Member Services

The UMDF office would like to introduce our two newest employees. Bethany Bassett has replaced Alisia Verenna on the Member Services staff – Alisia decided to go back to school for nursing, and we all wish her well in her new endeavors.

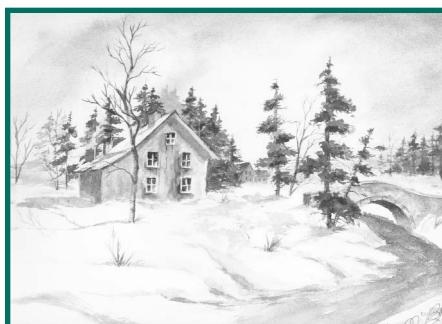
Special Events/Fundraising

Since a large portion of our research dollars come through special events and fundraising, the Foundation has hired a full-time Special Events Assistant, Gillian McTiernan, to help provide support for the fundraising activities throughout the country.



Welcome Aboard, Ladies!!!

2005 Holiday Card Campaign



For more information on the Holiday Card Campaign, email jodie@umdf.org

Chris O'Brien has provided another beautiful painting for this year's holiday card campaign and members should be receiving a card soon in the mail. Additional cards are available upon request!

Fundraising Tips RE: eBay and Walmart

UMDF has developed a relationship with eBay that can help raise dollars to support the UMDF mission. Did you know that Walmart can provide matching dollars for your next fundraiser?

For more information, contact Jodie Tabano at 412-793-8077, ext. 106 or jodie@umdf.org.



UMDF Web Site and Database Still a Work-in-Progress

You will notice a new look to the UMDF web site. Our crack team of computer consultants has worked diligently to upgrade the web site to make surfing easier and to integrate the web with the UMDF office to improve our productivity – which means more dollars for research!!!

We ask for your continued patience during our transition period in upgrading the UMDF computer system and web site.
Thank you!

The Compassionate Friends Worldwide Candle Lighting December 10, 2005 7:00 P.M. Around the Globe



...that their light may always shine.

The *Compassionate Friends Worldwide Candle Lighting* unites family and friends around the globe as they light candles for one hour to honor and remember children who have died at any age from any cause. As candles are lit at 7 p.m. local time, hundreds of thousands of persons commemorate and honor children in a way that transcends all ethnic, cultural, religious, and political boundaries.

When Jeremy Jone's Stomach Stopped Working: A Story for Children with G-Tubes

As a parent and a child psychologist, Anne Reckling, of Boca Raton, FL, felt there was a need for a children's book to help kids (and parents) cope with living with a child with a g-tube so she wrote the above titled book. However, she is currently seeking a publisher -- if anyone has tips or connections for Anne, please email her at areckling@aol.com.

Anne hopes that the book helps children recognize their strengths, understand more about their g-tubes and g-tube surgery, and accept their g-tubes as an important part of their growth and continuing strength.

Good Luck, Anne, and let us know when you get published!!!

Mito Adults Corner - by Barbara Bruck



How Palliative Care Gave Me Back My Life: Dispelling the Myths of Palliative Care

I was honored when Kara Strittmatter called to see if I would be willing to write a few words on the subject of Palliative Care and Hospice. I leaped, or more realistically for a Mito patient, sat up slowly to accept the opportunity.

As an adult mitochondrial patient, I have lived for more than 17 years with the often devastating consequences of this disease. And while the quality of my life has been severely compromised, debilitating neuropathic pain did not enter the picture until several years ago. Like the progression of my disease, the increase in my pain was insidious, so that my body simply adapted over time. Last spring, however, following a significant metabolic crisis, my level of discomfort changed radically. I began to experience intense pain, emanating from the nerve roots in my neck and spine. I also developed peripheral neuropathy in my hands and feet which made it difficult to stand – to weight bear was excruciating. If I moved so much as a finger, intense pain radiated up both arms into my shoulders and neck. Quite simply, I was in agony.

Nothing I attempted provided any relief – including increasing my dose of neurontin, trying new anti-inflammatory agents and soaking my hands and feet in hot paraffin. My health continued to deteriorate rapidly, as my pain exacerbated exponentially. On mother's day, I sat my 17 year old daughter down on my bed and told her I could no longer live in this state. "No one could," she responded empathetically, followed by a resolute stand, "it is not your time, Mommy." Infused with my daughter's words, I contacted my friend Jennifer Lyman whose experience with her eight-year-old daughter and palliative care has been superb. Jennifer responded to my desperate call for help and was instrumental in connecting me with the *Palliative Care Program at The Hospice of Western Reserve* in Cleveland.

Contacting *Western Reserve* was undoubtedly one of the most difficult calls I have ever made. In my mind, the word hospice was synonymous with

endings, not beginnings. Affiliating with any branch of Hospice, to me, was preparing to die. I spoke with an insightful and compassionate intake worker who explained the program protocol. The first step was a site visit to our home from a nurse who would assess our needs. Waiting the few days for my scheduled appointment, I wrestled with a litany of emotions. Although I had always resented and rejected the metaphor of illness as war, I somehow felt that I had lost the battle. And while cognitively I knew my feelings were disingenuous with reality, I felt like a quitter.

Fortunately, the palliative care program appealed to the rational part of my brain and was quick to point out that "none of the medications that I had been taking came close to touching my neuropathic pain."

My wonderful nurse Lisa recommended that I consider beginning methadone, a drug with relatively few side effects that is not damaging to the mitochondria and has been proven effective in controlling neurogenic pain. Lisa also felt that working with the program's massage therapist might alleviate some of my discomfort. During this initial assessment, Lisa responded not only to my plight with deep compassion and respect, but demonstrated great sensitivity to my family's questions and feelings as well.

Confronted with a difficult decision, I responded as I often do, by procrastinating. I again engaged in irrational thinking, feeling that I was perhaps a weak person because I required a narcotic to cope with pain. Additionally, I feared becoming dependent on methadone. My nurse attempted to ease my concerns and was highly supportive during the approximate month it took me to make my decision.

Three months ago, I began taking methadone and started working with the massage therapist on a weekly basis. After becoming an invalid, seeking palliative care was one of the best decisions I have made in a very long time. Within one month of beginning low dose methadone, I was virtually pain free – with my quality of life improving significantly. Ironically, rather than the ending that I feared, palliative care renewed my hope and gave me back me life.

Mito Adults Corner

Calling All Mito Adults: The *Mitochondrial News* Needs YOU!

UMDF could use more helpers. Please consider submitting an article for review or sending us your experiences with a specific topic of interest. If you are willing to help, please email Kara Strittmatter at kara@umdf.org or call 412-793-8077, ext. 114. We look forward to hearing from you!

Fundraisers

★ THANKS ★



- Ten-year-old Renee Trottier, along with help from her 8-year-old brother, Chipper, directed a circus called Cirque De Renee in August. She gathered a group of children in the neighborhood (pictured above) who all performed in the circus to raise \$550 in honor of Ian Trottier, Renee and Chipper's cousin. Renee directed, performed, created costumes and ran a concession stand for the circus event. What a girl – thanks Renee and Chipper!
- Stacy Block held her first eBay auction in memory of her daughter Aspyn and raised \$1,536 for the foundation. Stacy has provided pointers for those interested in organizing an eBay auction event. Thanks, Stacy!
- William Kozuch, of Bay City, MI, sold merchandise on eBay and donated \$118.38 to UMDF in honor of his daughter, Morgan. Thanks, Will.
- The Welcome Wagon in Solon, OH held a fundraiser and donated \$1,000 to UMDF in honor of the Probert Family.
- The Olivia Steele Memorial Golf Outing in Columbus, OH, raised \$3,805 - Thank you, Shawna & Jason!
- Andrew Pisani, of North Haven, CT, donated his birthday money to UMDF in honor of his brother Nicholas. The Pisani Family are part of the New York Metro Chapter of UMDF. Thanks, Andrew and Happy Birthday!!!

Marketing Mitochondrial Disease

The Marketing Committee has been busy over the past six months working on strategies to "brand" the United Mitochondrial Disease Foundation which will help us "Tell our Story!" The first major task was evaluating our current marketing/publicity tools. Immediately, the committee concluded that a new look was over due and that using the acronym UMDF does not help tell the story. For people to embrace the mission, we must keep putting the words "Mitochondrial Disease" in the forefront and what better way than through our logo and name.

Watch for changes in future publications and make sure you test the staff – we will now answer the phone with *The United Mitochondrial Disease Foundation*, instead of UMDF. Yes, it is a mouthful but we need to take the lead and put mitochondrial disease and mitochondrial medicine on the map!

Special thanks to the Marketing Subcommittee Members: Allison Rogers, chair, Jason Conte, Jeff Salt, Alison DeVriendt, Heidi Bailey, Dave Stahler, Darcy Zehe and Karen and Bill Wilson. Thank you also goes to Richard Kubach, Jr., board member and chair of the Planning and Marketing Committee which oversees the Marketing Subcommittee.

Finally, a big thank you goes to Jason Conte's company, The CRP Group in Hollywood, CA, for donating its creative team's talents to the logo redesign. The logo will be unveiled in the Winter 2006 issue of the *Mitochondrial News* and we are thrilled to have such a prestigious company that does design work for Hollywood studios – recently completing the graphics for the new Harry Potter movie – working on our new look!

United Mitochondrial Disease Foundation Annual Membership Meeting

On November 7, the United Mitochondrial Disease Foundation held its annual membership meeting.

The Agenda included a vote on proposed changes in the bylaws, elections of new board members, and reports from the Chair and Executive Director. Please help us welcome three of our newest board members:

- Marty Lyman
- John Osher
- Robert Polsky

A slate of new officers will be nominated and voted on within the next month by the board. More information about our new board members and new officers will be highlighted in the Winter 2006 issue.

Chairman's Report

Continued from page 3

The great end of life is not knowledge, but action
-Aldous Huxley

You gotta have a dream. If you don't have a dream, how you gonna make a dream come true?

-Bloody Mary, in the movie South Pacific

In 2001, I wrote about how life continues to show us the futility of "set plans." John Lennon described life perfectly when he said, "Life is what happens to you while you're busy making other plans." We don't plan lives, we live them and deal with them the best way we can.

The strengths we develop, not the passing of time, will enable us to cope with our challenges and losses in the years to come. We will sense forever a commitment to affirm what is really important in our daily lives, which many never truly get to sense and feel.

I wrote about the story of Donatello, an apprentice of the renowned sculptor, Michelangelo. Donatello, after spending many years under the guidance of the master sculptor, decided it was time for him to move on and open his own studio. He would put to use all the skills that he learned from his teacher, the world-respected sculptor, Michelangelo.

After setting up his studio, he ordered and received his first large slab of marble. This would be the slab that he would use to sculpt his first piece of art. Upon inspection of the slab he noticed a flaw that started at the top and ran all the way to the bottom of the marble. He was furious as he concentrated on the flaw shouting out loud, "how could I ever turn something like this into a piece of beauty?"

At this moment, Michelangelo visited Donatello to see how he was progressing at his new shop. Donetello, frustrated and near tears, pointed out the flaw in the piece of marble he had just received. Michelangelo looked at the marble and said to Donatello, "I will take this piece if you would rather look for

another." Donatello agreed.

It was from this flawed piece of marble that Michelangelo sculpted his famous David. Michelangelo chose to concentrate on the good rather than the flawed, he saw beyond the imperfections to the potential the marble had to offer.

*The second easiest thing in life to do is to criticize,
The easiest thing in life?
.....to give up.*

*The future belongs to those who believe
In the beauty of their dreams.*
-Eleanor Roosevelt

"I'm sorry, but there is nothing more we can do. There is no cure, there is no hope and there is nothing more you can do." Bull! There is no man or woman living who is not capable of doing more than he, or she, thinks he can do.

Not every goal will be fully achieved. Not every job will end successfully. Not every relationship will endure. Not every hope will come to pass. Not every love will last. Not every endeavor will be completed. Not every dream will be realized. But when you fall short of your aim, perhaps you can say, "Yes, but look at what I found along the way! Look at the wonderful things which have come into my life because I tried to do something!"

Lance Armstrong, four time winner of the Tour De France, in his book, *It's Not About the Bike* writes;

Pain is temporary. It may last a minute, or an hour, or a day, or a year, but eventually it will subside and something else will take its place. If I quit, however, it lasts forever.

In my most painful moments on the bike, I am at my most curious, and I wonder each and every time how I will respond. Will I discover my innermost weakness, or will I seek out my innermost strength?

What an insight into to life's problems! Do we face our demons and

fight or do we bury our heads, cross our fingers and hope? Do we say, "There's nothing I can do," or do we search for the things we can do?

In 1997, UMDF presented \$30,000 in research grants. In 2005, UMDF presented \$1,000,000 in research grants. In 1996, I submitted a \$25,000 Budget to the UMDF Board of Trustees. This past September, 2005, I submitted a \$2,700,000 budget to the UMDF Board of Trustees.

Look at a stone cutter hammering away at his rock, perhaps a hundred times without as much as a crack showing in it. Yet at the hundred-and-first blow it will split in two, and I know it was not the last blow that did it, but all that had gone before.

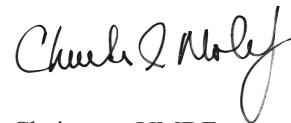
-Jacob A. Riis

I won't give up! Will you?

I want to take this opportunity to express my deepest and sincerest love to my wife Adrienne and my son Chuck whose sacrifice, patience and support allowed me to commit the last 10 years toward a cure as chairman of UMDF.

Other things may change us, but we start and end with family
-Anthony Brandt

Charles A. Mohan, Jr.



Chairman, UMDF

Editor's Note: Two of our treasured board members, Chuck Mohan and Nick Rillo, have completed their terms and will be stepping down this January. We will have a special feature in the next newsletter honoring their accomplishments and announcing the new officers.

Help the United Mitochondrial Disease Foundation ...

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 nominees is involved with.

Please type your essay and attach it to the nomination form. Mail the nomination by April 1, 2006 to:

LEAP Award

UMDF

8085 Saltsburg Road, Suite 201

Pittsburgh, PA 15239

Or fax to 412-793-6477 or email the nomination by April 1, 2006 to bethany@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): _____

... Identify Everyday Heroes

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 1, 2006 to:

Heartstrings Award

UMDF

8085 Saltsburg Road, Suite 201

Pittsburgh, PA 15239

Or fax to 412-793-6477 or email the nomination by April 1, 2006 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): _____

UMDF Merchandise

Energy Bands - still Available in Youth and Adult Sizes

Visit www.umdf.org for more information on how to order or call 412-793-8077.



Awareness Car Magnets

Awareness magnets are also available and can be purchased online at www.umdf.org. The cost is \$5 each or 10 for \$25 (postage and handling included). The magnets are UMDF green with yellow trim and wording.



UMDF Windshirts

The windshirt is green nylon and cost \$30 (includes shipping).

UMDF Throw Blankets

The blankets come in Black, Royal Blue, Khaki, Forest Green colors and cost \$20 (shipping included).

Visit www.umdf.org for more information on how to order or call 412-793-8077.

★ Mark your Calendars ★

See pages 4-6 for more details on chapter events

- November 17, 2005 - *Max & Erma's Night for UMDF* on Sawmill Road in Columbus, OH in honor of Ellie Kovalcik. The restaurant will donate 20% to UMDF.
- December 11, 2005 - Tova and Topher Sido will be running in the *Dallas White Rock Marathon*. They will collect pledges to benefit UMDF/Charlie & Louisa's Fund.
- February 11, 2006 - *"Mito-What?" Post Holiday Gift Recycling Party* in memory of Anthony. For more information, contact Krista Wakefield of Sayre, PA, at 570-882-7132.
- February 25, 2006 - *3rd Annual Bet on Baylee Casino Night* at Roseville Community Center, Roseville, OH. From 6:00pm-11pm, enjoy casino games, Texas Hold'em and a live auction! For more information, contact Jody Thompson at 740-982-1244.
- February 25, 2006 - *Pack the House @ Indiana ICE* (Indiana Chapter)
- February 25, 2006 - *Scrapbooking Party* - organized by Allison Rogers of Greer, SC. For more information, contact Allison at allisonrogers@hotmail.com.
- March 3-4, 2006 - *2nd Annual Writers at the Beach: Pure Sea Glass*, in Dewey Beach, DE. Organized by Maribeth Fischer. 150 people expected. Free registration will be given to the writer of the best poem, short story and creative essay that center around a coastal theme. For more information, visit www.writersatthebeach.com.
- March 18-19, 2006 - *Preston's March for Energy*. Participants in the Shamrock Marathon in Virginia Beach are raising funds for UMDF in honor of Preston Buenaga. For more info, contact Deborah Buenaga at 302-478-2535.
- April 15, 2006 - *3rd Annual "One Step Closer to a Cure" 5K Run/Walk*, in Bellville, IL. For information call, Marsha Hohe 618-233-6919.
- April 29, 2006 - *2nd Annual Race for Riley 5K Run/Walk and 1 Mile Fun Run/Tot Trot* (Atlanta Chapter)
- April 29, 2006 - *Break the Barriers Dinner* hosted by Brittany Wilkinson, a mito teenager in Fresno, CA. For more information, contact Brittany at 559-299-1767.
- April 30, 2006 - *Golf Outing* (Brighten Golf Course) - also hosted by Brittany. For more information, contact Brittany at 559-299-1767.
- May 19, 2006 - *2nd Annual Wipe Out Mitochondrial Disease Walk* at Merrill Crest Park/Bethesda Elementary in Waukesha, WI. 1 Mile Walk and 5K Run in memory of Sam Juhlmann. For more information, contact Deb Grabow, Bethesda PTO at 262-574-1550.
- May (date TBA), 2006 - *Mito-What? Ty's Trot Toward a Cure* in Atlanta, GA (5K Walk). For more information, contact Sheri Seldes at 404-885-4882. (Atlanta Chapter).

UMDF Chapters & Mito Groups

ARIZONA

★Arizona Chapter

President: Suzanne Perryman
Email: AZChapter@umdf.org

CALIFORNIA

★Southern California Chapter

President: Linda Cooper
Email: SCAlChapter@umdf.org

FLORIDA

Contacts: Christine Golden
Carrie Waters
Email: Goldenfamily5@aol.com

North Central Florida Mito Group

Contact: Alicia Kaminski
Email: limitlesschildrenx4@yahoo.com

Southern Florida Mito Group

Contact: Anne Reckling
Email: areckling@aol.com

GEORGIA

★Atlanta Area Chapter

President: Chris Swinn
Email: ATLchapter@umdf.org

INDIANA

★Indiana Chapter

President: Sue Ann Bube
Email: INchapter@umdf.org

ILLINOIS

Chicago Area Mito Group
Contact: Gail Wehling
Email: GaiMW333@aol.com

MARYLAND

Contact: David Hamm
Email: admin@datm.org

MASSACHUSETTS

★New England Chapter

President: Bridget Willis
Email: NEngChapter@umdf.org

MICHIGAN

Contact: Ann Clark
Phone: 734-416-1115

Western Michigan Mito Group
Contact: Suzanne Marous
Email: marousx4@icsdata.com

MISSOURI/KANSAS

★Kansas City Chapter

President: Pam Johnson
Email: KCchapter@umdf.org

St. Louis Area Mito Group

Contact: Marsha Hohe
Email: marshamarshamarshah@charter.net

NEW YORK

★New York Metro Chapter

President: Mary Pisani
Email: NYMetroChapter@umdf.org

New Paltz Mito Group

Contact: Beth and James DeArce
Email: dearcj@earthlink.net

OHIO

★Ohio Chapter, Cleveland, OH

President: Bill Hodes
Email: OHChapter@umdf.org

Columbus Mito Group

Contact: Shawna Steele
Email: ssteele817@sbcglobal.net

Cincinnati Mito Group

Contact: Jeff & Cindy Salt
Email: salthouse@aol.com

OREGON

Email: info@umdf.org

PENNSYLVANIA

★Delaware Valley Chapter

President: Maripat Shelly
Email: DelValChapter@umdf.org

PENNSYLVANIA

Pittsburgh Mito Group
Contact: Karen Wilson
Email: bwilson@cvzoom.net

SOUTH CAROLINA

Contact: Karis Mott
Email: karismott@yahoo.com

Carolina Foothills Mito Group

Contact: Allison Rogers
Email: allisonrogers@hotmail.com

TEXAS

Contact: Tova Sido
Email: ttsido@hotmail.com

VIRGINIA

Richmond/Norfolk

Contact: Seeking new leaders
Email: info@umdf.org

OUTSIDE OF THE UNITED STATES

AUSTRALIA

Contact: Rob Ryan
Email: grra@austarnet.com.au

New groups are forming in Houston (TX), Raleigh/Durham (NC), Louisville (KY), Northern California, New River Valley (VA), and Central Pennsylvania. Interested in starting a group in your area? Contact becky@umdf.org.

From the Desk of Becky DiLettuso

Director of Member Services:

What's in a name? Well maybe a lot! Recently we have been soliciting feedback and looking at our future plans for Support Groups. Most of our Support Groups do MORE than educational and personal sharing meetings – they tackle community awareness, physician awareness programs, special events and social activities. All such activities bring together affected individuals and families for sharing and caring. Because most of our Support Groups do more than just hold "meetings" – and many times our potential members are afraid of the term Support Group – we are changing the name to (drum roll.....please):

MITO GROUP

So don't be surprised to see these two little words in UMDF literature and on the web site and don't be surprised if people ask you what a **MITO GROUP** is.....so be ready with an answer to Mito What?

The UMDF Office Staff We're Here to Help You! 412-793-8077

Executive Director

J. Thomas Viall, tomv@umdf.org, ext. 111

Chief Financial Officer

Mark Campbell, markc@umdf.org, ext. 110

Director of Member Services

Becky DiLettuso, becky@umdf.org, ext. 101

Director of Communications

Kara Strittmatter, kara@umdf.org, ext. 114

Manager of Special Events

Jodie Tabano, jodie@umdf.org, ext. 106

Fundraising/Special Events

Gillian McTiernan, gillian@umdf.org, ext. 102

Development

Owen McGrann, owenm@umdf.org, ext. 112

Member Services

Bethany Bassett, bethany@umdf.org, ext. 104
Melinda O'Toole, melinda@umdf.org, ext. 103

Data Processing

Tania Hanscom, taniah@umdf.org, ext. 107
Lindsay Houston, lindsayh@umdf.org, ext. 107
Donna Nameth, donna@umdf.org, ext. 109

UMDF Research Grants Program

Jean Bassett, jean@umdf.org, ext. 105

Administration

Barbara Podowski, barb@umdf.org, ext. 100



UNITED MITOCHONDRIAL DISEASE FOUNDATION®

8085 Saltsburg Road, Suite 201
Pittsburgh, PA 15239
Phone 412-793-8077
Fax 412-793-6477
email: info@umdf.org
<http://www.umdf.org>

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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.

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.

Deadline for next issue is 1/15/06