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United Mitochondrial Disease Foundation

MITOCHONDRIAL EWS

Volume 10 • Issue 3 • Summer 2005

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Mito Doc
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**Physical, occupational,
respiratory, speech, equine and
pet therapies for
mitochondrial disease**

Part II

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By Tracey J. Millhouse-Flourie

Introduction

The following article is Part II of a two part series and continues to review supplementary therapies that have potential to improve some symptoms of mitochondrial disease. Until disease-modifying treatments are available for mitochondrial disorders, there can be a focus on treating symptoms; helping patients to cope with disabilities, and improving quality of life (*Part I covered Physical, Equine and Occupational Therapies*). Part II will address Speech, Respiratory, and Pet Therapies.

Speech Therapy

Speech and language dysfunction can arise from a variety of conditions, including neuromuscular disease, brain injury or deterioration, hearing loss, stroke, etc. Problems may be congenital, developmental or acquired. Speech professionals, known as speech-language pathologists evaluate, diagnose, treat and help to prevent speech and language, cognitive, communication, voice, fluency and swallowing disorders. The entry-level requirement to the profession is a Master's degree, which entails completion of course and clinical work. Speech-language pathologists develop an individualized treatment plan and provide direct clinical services to individuals with communication and



**Congratulations to our 2005
LEAP and Heartstrings Winners!
Alice Adams, Albuquerque, NM
Receives LEAP Award**

Mitochondrial disease has caused total deafness for Alice Adams, pictured left in the above photo, and she is many times confined to a wheelchair. The disease has not stopped Alice from being instrumental in public awareness about hearing loss and mitochondrial disease. She maintains an active chat room to allow people to talk about mitochondrial disease and her main hobby is her fourteen grandchildren. Thanks, Alice, for your continued dedication toward helping others.

**Dana Bruck-Segal, of Cleveland, OH
Receives Heartstrings Award**

16-year-old Dana, pictured right in above photo, is devoted to her family and to the UMDF mission. She has taken up the cause because her mother, Barbara Bruck, has Mitochondrial Cytopathy. She has also grown very fond of children in Ohio who have mitochondrial disease. Dana has been marketing Tomato Face Foods – educating the public and persistently pushing schools to use the sauce. All proceeds from the sauce go to mitochondrial research. Dana has also been pushing for national visibility by trying to be a guest on Oprah. Keep up the great work, Dana!



**Joni & Tim Kirby
(pictured with Chuck
Mohan) presented a
check to UMDF Grant
Recipient, Mair Churchill,
PhD during the St. Louis
Conference.**

**For more Research
Projects, see Page 9**

Continued on page 10



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.umd.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: David R. Thorburn, PhD, Royal Children's Hospital Melbourne, Australia and Carol Greene, MD, Children's National Medical Center, Washington, DC

The Question is:

My 19 month old son was diagnosed with Leigh's disease (through an MRI, spinal tap and muscle biopsy) approximately six months ago. He has the t>g mutation of the disease. We have seen a mitochondrial doctor only one time who did not feel the need to see us back for six months. He did not know a thing about this mutation. He has never treated a patient with this mutation. I was told upon diagnosis that 75% of the children die by the age of 2. Since then, I am finding more children that are alive past this age than I had expected. I would like to know if there is a direct link between mutation and life expectancy. If so, approximately how many years might we have and what kind of things are we headed for down the road. Right now my son has swallowing problems, digestive issues, he still can not sit up (hypotonia) and has high lactic acid levels. He has no seizures, no eye or hearing problems, but has had multiple infections, i.e. colds, ear infections, etc.

Response From: David R. Thorburn, PhD

First of all, I would definitely recommend you find a doctor who has experience with mitochondrial disease.

When you say the "t>g mutation" it is a little ambiguous but I am pretty sure you mean a T to G change in mitochondrial DNA at position 8993. You will know that there are a large number of different causes of Leigh's disease. At the latest count, there were more than 20 different genes in which mutations have been shown to cause Leigh's disease, and no doubt there are quite a few more still to find. That is one of the major reasons why there is a lot of variation between patients. The 8993t>g change is one of the more common causes of Leigh disease, present in about a tenth of all patients. My comments below assume your son has the 8993t>g change.

With mitochondrial DNA mutations, it is not just the particular mutation that is important but how much is present. In patients with the 8993t>g mutation, every cell in the body usually has a mix of healthy mitochondrial DNAs and mitochondrial DNAs containing the 8993t>g mutation. Basically the more mutant mitochondrial DNA there is, then the more likely it is there will be a problem in mitochondrial energy generation. For the 8993t>g mutation, it seems we can tolerate up to about 60% to 70% of our mitochondrial DNA containing the mutation before it has much effect. If more than 90% of the mitochondrial DNA has the 8993t>g mutation, then a patient is almost certain to develop severe symptoms such as Leigh's disease. In between these values, then the risk of symptoms increases with the amount of the 8993t>g mutation. So we refer to this percentage level as the "mutant load" and above the threshold value of about 60% 8993t>g mutation, then the higher the mutant load, the more likely it is that symptoms will be severe.

In Leigh's disease, the particular mutation and the amount of it are major factors that determine disease severity and life expectancy. However, there is also individual variation. Our individual genetic background and things such as childhood infections (how many, what type and when) can have a big influence on disease severity and on life expectancy. That means it is always difficult to give precise information about life expectancy. Hopefully, you can find a physician locally with enough expertise to answer all your questions. If you still have concerns, then perhaps you may want to travel to see one of the national experts.

The Question is:

I have a 9 year old son diagnosed via muscle biopsy with mitochondrial myopathy. Is there a more specific

connection between the brain and learning issues? At school he went from a C average to now an F, especially in reading and math. All of his teachers at school have noticed a lot of regression. I've read that stressors can perhaps cause this. So can his mito cause a loss in knowledge?

Response From: Carol Greene, MD

Yes, mitochondrial disease can cause brain and learning problems in some people, and from what you describe, that is very likely what is going on with your son.

Not everyone with mitochondrial disease has involvement of the brain. Sometimes a person with mitochondrial disease that doesn't directly involve the brain can have learning problems if the mitochondrial disease affects vision or hearing, or causes any other problem that might affect the ability to pay attention in school or at work. For example, if a child is depressed or exhausted because of illness, he might have trouble learning and dropping grades. Also, your son is 9 years old, and if he is in regular school he is probably in the 3rd grade. This is a time when schoolwork becomes more complicated, and some children who have always had a little trouble with learning but did okay in the 1st and 2nd grade can begin to have real trouble with schoolwork.

But you and your son's teachers are using the term "regression", which we doctors use to describe the loss of previous abilities or knowledge. We have to worry that this could be the result of direct effect of the mitochondrial disease on brain cells. Brain cells need a lot of energy, and in mitochondrial disease they can become damaged and can die. Sometimes this damage is visible on a CT scan or an MRI, but there can be brain damage without visible changes on a scan. The brain damage can cause decreasing ability to learn and actual loss of skills or knowledge. Sometimes there is an up-and-down course, with periods of regression and recovery. Sometimes the cell damage slows or stops, and there may be some recovery or there may be permanent loss of abilities. And sometimes the damage continues to get worse, and the regression continues with further loss of abilities. We can never be completely certain about what to expect in the future, but "regression" is a very serious sign. You should work with your health care providers to try to have the very best possible understanding of what is going on and whether there is anything more you could be doing that might help.

Chairman's Report

Many of us will be experiencing a multitude of changes over the next few months - kids going back to school, leaves changing colors and falling, and the weather changing from HOT to cooler (at least we hope). Change can be frightening for a parent caring for a child with mitochondrial disease as well as for affected adults who have established a routine in their daily care. Unfortunately, as many of you know, routine is next to impossible in the mitochondrial world and change is usually accepted as just one more challenge to overcome.

UMDF is no stranger to change and we thrive on the challenge that accompanies change! UMDF continues to experience changes on a daily basis in the office - database upgrades, web site upgrades, and new hires. Many ask if our focus remains on the mission by spending dollars on such items? Absolutely! We are growing a business and these internal changes are necessary to meet the increasing demands of our membership. This past June UMDF awarded more than \$1,000,000 in research grant money (see page 9) to nine researchers. UMDF has succeeded in "raising the bar" each year with our grant awards. We all know how important research is in finding those missing pieces to the mitochondrial puzzle. However, we also realize that to continue building on this success, we must broaden our funding resources. The changes in the office will provide the necessary tools to find those resources that will help to continue our mission.

On behalf of the UMDF Board of Trustees, I am pleased to introduce the new Executive Director of the United Mitochondrial Disease Foundation - Mr. J. Thomas Viall. Tom comes to us with over 10 years experience with The International Dyslexia Association (IDA). IDA is one of the oldest non-profit organizations in the U.S. dedicated to the study and treatment of dyslexia.

Tom helped broaden IDA from a relatively small professional society to one that focused on the comprehensive concerns and needs of individuals with dyslexia, their families and communities, as well as the professionals who serve them. During

his tenure, membership in IDA grew by nearly 50 %, its financial support doubled, and the administrative structure revamped. Tom is married and has two daughters. He and his wife, Linda, reside in Level Green, PA. Tom's first day of work was July 5th and he has already demonstrated strong leadership and dedication to the UMDF mission. We look forward to the talent and experience Tom brings to UMDF.

Each fall, monarch butterflies in Maine take an incredible journey to the hilltops in Mexico. Each day they set off - guided only by their instincts and desire to reach their destination. They accept what comes - some winds blow them off course, others speed them along. They keep flying until, one day, they arrive (author unknown).

With each new challenge brought on by changes, UMDF will continue to stay on course in our mission to find a cure - our instincts and desire will help us reach our destination. Take flight with UMDF this fall and help us continue to make a difference.

Yours Toward a Cure,



Charles A. Mohan, Jr.



Research Grant Review 2005

On May 12, 2005, doctors traveled from across the USA to Atlanta volunteering their time to UMDF. They were sequestered in a small room for hours reviewing over 40 grant applications. Nine were ultimately selected for recommendation to the UMDF Board for funding. Their time, talents and commitment is admirable and deeply appreciated by all those affected by mitochondrial disease.

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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

President: Holly Capp

Phone: 770-506-7441

Email: AtlChapter@umdf.org

Special Thanks -

- The First Presbyterian Day School in Macon, GA sold energy bands and raised \$1,469.05.
- The Mars Hills Acres neighborhood in Acworth, GA, held a block party on June 25th and raised \$800 in memory of their neighbor, eight-year-old Matthew Southern. Thank you, David and Julie Shockley, for bringing your community together for such a great cause!
- 7th grade students from The Epstein School in Atlanta participated in a program called "Nediv Lev" and donated a portion of their Bar/Bat Mitzvah money, totaling \$2,961 to the Ty Seldes Research Fund/UMDF. Your *Generosity of the Heart* is deeply appreciated by all those affected!

- Siemens Energy and Automation Company held a bake sale and raised \$700 in honor of Megan Grace Sheridan.

Upcoming Events:

- **October 24** - 2nd Annual Fore-a-Cure Golf Outing at The Standard Club in Duluth, GA. For information, please contact the Event Chairman, Chris Swinn at (404) 817-0999. We are looking for Golfers, Sponsors, and Volunteers. Please join us and visit www.foreacuremito.org.

Final totals for the Race for Riley and the Atlanta Dinner are \$84,022.91 for the race and \$5,782.48 for the dinner. Go Atlanta!!!

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*.

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.**

DELAWARE VALLEY CHAPTER

Philadelphia, PA

President: Maripat Shelly

Phone: 215-256-0273

Email: DelValChapter@umdf.org

Brew at the Zoo, held at Elmwood Park Zoo in Norristown, PA, raised more than \$5,600 on June 11.

Matthew Gore donated \$200 of his 9th Birthday money to the Brew at the Zoo. Thanks Matthew, and Happy Belated Birthday!

Special thanks to The Polsky Family for organizing this fun event!

- **Special Thanks** - Alex Reber, a junior at Cherry Hill High School East in Cherry Hill, NJ, raised \$206 by selling energy bands in honor of his 13-year-old neighbor, Sydney Breslow. Great job, Alex!!!

Upcoming Events:

- **September 10** - Go for Mito Shelly's Heroes Walk/Run - 6th Annual DelVal UMDF Walk/Run. Join the chapter at the Philadelphia Museum of Art, Martin Luther King Drive on September 10th at 9:00 a.m. For more information, visit www.goformito.org.

- **Date TBA** - 8th Annual You Go Girl Golf Outing. Visit Chapter web site at www.umdf.org for official date, time and location.

Coins for a Cure

In honor of Abel & Averal Cruz, Dr. William Mennies School raised \$638.21.

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.

Chapter Activities

INDIANA CHAPTER

Indianapolis, IN

Events/Fundraisers:

- **Special Thanks** - On August 15, the chapter held its first golf outing. Watch for pictures and the total amount raised in the Fall issue.
- **Recipes for Hope** - In honor of Kyliegh Hope Parrish, of Plainfield, IN, Kay Ross and friends are selling cookbooks to benefit UMDF and raise awareness of mitochondrial disease. For more information, please contact Kay at kayross@comcast.net or by calling 317-837-9609.
- **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



Miles for Mito

These dedicated individuals raised more than \$25,000 in June as they traveled from Indianapolis to St. Louis. Special thanks to the riders: Bob Thomas, Marc Reich, Ron

Martin, Karen Rossi, Mike Hanlon, Eric Boling, John Fleck, Nicole Kernan, Ryan Shatto, Bob Jenks and Dr. Larry Walsh. Hope to see you all in Atlanta 2006!

KANSAS CITY CHAPTER

Kansas City, MO



**Kansas City Chapter
Run/Walk Raises
\$23,025.37 on May 14,
2005 – Outstanding!**

**Pictured left, volunteers
hang with the King of
Rock n' Roll during the
festivities!**

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

Events:

- **October 10** - Gale's Gig/Kansas City Golf Outing at the Lake Quivira Country Club. The outing is in memory of Pam Johnson's father Gale McKenzie.

NEW ENGLAND CHAPTER

Boston, MA

Special Thanks -

- The *Recharge Your Energy and Redefine Hope Dinner*, organized by Elizabeth and Greg Sullivan, raised \$20,000 on June 4 in Milton, MA.
- *AJ's First Annual Fundraiser*, in honor of AJ Floriano of Fall River, MA, was a success – sending UMDF \$2,420 to help sustain research and family support. Thank you AJ, and your friends too!
- The *2005 Lego Walk* raised \$1,652 to benefit UMDF in memory of Matthew Bailey and Stig Toftguard.
- In honor of her sister, Hayden, Logan Kursh made pearl bracelets and raised \$790 to help raise awareness and research money. Thanks Logan!

Events:

- **October 1** - 1st Annual Mito-What? 5K Walk in Plymouth, MA at Nelson Field. Visit www.mitowhat.org for both the Oct. 1 and Oct. 2 races.

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

- **October 2** - 6th Annual Mito-What? 5K Walk/Run in Longmeadow, MA at Baypath College on Route 5.
- **October 28** - Wine Benefit Dinner at Hampden Country Club. For more info, contact the chapter.

Coins for a Cure

In honor of Hailey Charbonneau, Meetinghouse School & Westminster Elementary in Westminster, MA, raised \$700.



**June Yard Sale Fun for Shoppers and Chapter –
Raises more than \$300. Pictured above is Janice
Geigle and Bridget Willis!**

Chapter Activities

NEW YORK METRO CHAPTER

Manhattan, NY

President: Mary Pisani
Phone: 203-287-0655
Email: NYMetroChapter@umdf.org

Special Thanks -

- The 2 Mile Walk to Create Awareness in Chatham, NJ raised \$2,684.54 on May 21. Special thanks to the Shubeck Family.
- The 5K Race and 1 Mile Fitness Walk at North Haven Middle School in Connecticut raised \$11,670.47. Thanks Pisani Family!!

- Kain's 5K Walk in Greenwich, NY raised \$485 on June 4. Thank you, Buell family!

Events:

- October 15, 2005 - *Benefit Dinner/Comedy Show* at Middle Falls Fire Hall in memory of Kain. Event Contact: Bethany Buell.

OHIO CHAPTER

Cleveland, OH

President: Bill Hodges
Phone: 440-235-2451
Email: OHChapter@umdf.org

- **September 2** - *Cut-a-thon during the Lake County Captains game*, Thank you New Image Haircutters, of Willowick, OH.
- **September 17** - *UMDF Ohio Chapter Picnic*, 2:00 p.m. at Glenn Chamberlin Picnic Shelter #1, 10260 Ravenna Road, Twinsburg. Bring a dessert or side dish to share. RSVP to Sheila Rady by September 11, 2005 at 330-425-1829 or smrady@alltel.net.
- **November 6** - *SAVE the DATE!* Dr. Bruce Cohen Presentation at Solon Community Center at 2:00 p.m. More information to follow.
- **October 8** - *The Big Bear Farms (BBF) Neighborhood Hayride and Bonfire* in honor of Ellie Kovalcik
- **October** - *Clams for a Cure* Ohio Chapter Clambake is also in the planning process. Sounds delicious! Fliers for the clambake and Dr. Cohen's talk will be mailed to chapter members soon.

Shadow Woodstock Raises \$7,590

More than 400 attended this first-time event and three bands played - Arisen, Centerpiece, and Pat Bacon - to entertain the crowd as well as hot air balloon rides, volleyball, kids games, bon fires and more.



Thank you Jay & Beth Schabel



**FOURTH ANNUAL
KFC/UMDF
5K RUN-1MILE WALK
RAISES \$131,122.46
OUTSTANDING!!!!**

SOUTHERN CALIFORNIA CHAPTER

Lakewood, CA

President: Linda Cooper
Phone: 714-921-2324
Email: SCalChapter@umdf.org



Wine Tasting Raises \$12,500 with 75 People in Attendance

The chapter hosted its second annual Wine Tasting Garden Party and Silent Auction on May 14, 2005 in Pasadena. It was a great

afternoon of family and friends. Special thanks to our sponsors, The Safranek Family, The Cooper Family, CRP Group, Final Film, Smith-Cooper International, Yvonne Rich, Patit Creek Cellars, Michael Baietti, Craig Ruggless and all our wonderful family and friends. Big thanks to all our volunteers that helped set up and clean up after the event. You all are TERRIFIC!

Brotherly Love

In honor of his brother Chad, Kyle Cooper, age 16, and his friends at the Canyon High School Key Club in Anaheim Hills passed out UMDF Energy for Life Bands before and after school raising awareness and \$400 to benefit UMDF. Kyle said, "the best part about the experience is each day I saw more and more students and teachers wearing the UMDF Energy for Life Band. It was great." Thank you Kyle - you and the entire Canyon High School Key Club are GREAT!

Meeting Announcement

The next Chapter Family Group Meeting will be held October 22, 2005. Please contact the chapter for your "Calendar of Events."



There are Two Ways to Reach the Top of an Oak Tree From the Executive Director - J. Thomas Viall

In the few weeks that I have had the privilege to work with and for so many dedicated and inspiring people I have learned some very valuable lessons:

Courage comes in a variety of forms and it is not the "size of the package" that determines the depth of the courage. Rather, it is often displayed by something as simple as the ability to laugh when tears seem more appropriate. The kind of courage I'm talking about is often exemplified by a Mom who has the strength of character just to get out of bed, knowing that today will most likely be more of a challenge than yesterday.

Happiness is a choice. We can, in fact, choose our attitude. So many people I've met these past few weeks have chosen to find joy every day and use that joy to face the challenges of tomorrow.

Seeking help is not a sign of weakness. Some of the strongest people I have met know that they need support and friendship to grow. Loneliness is a terrible malady and the person who learns to reach out and give or take a helping hand is a better person for doing so.

Ignorance breeds fear . . . and what we understand the least is often feared the most. Almost daily at UMDF, I see or talk to courageous people who listen and learn, and thus empower themselves. By shedding light on his or her darkest fears, the empowered person takes control.

So, what are the two ways to get to the top of an oak tree and (you may ask) what is my point?

You can either climb the oak tree or sit on an acorn and wait! There is a similar adage from China telling us that the person who sits and waits for a roast duck to fly into his mouth will be a very hungry person.

My point is fairly straightforward. What energizes me about UMDF is

the fact that I have met many "climbers" and almost no "sitters." And I don't know anyone who is waiting for the duck! Rather, I see people who are taking action - empowering themselves and doing something to make a difference. I see a synergy between affected adults, the families of affected children, the researchers, and the clinicians who all know they are in a race.

I see a courageous collaboration to fulfill the 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."*

I am proud to join you in this most important struggle.

Sincerely,

J. Thomas Viall

UMDF Conferences



The United Mitochondrial Disease Foundation has officially sponsored six conferences since the year 2000 and played a role in two earlier meetings in Indianapolis and Philadelphia. With each year, the programs bring new insights to those in attendance and provide a common meeting ground for physicians, researchers, allied health

Atlanta 2006 Mastering the Mitochondrial Maze

Mark Your Calendars!

Sheraton Atlanta Hotel
Atlanta, Georgia, USA
June 14-17, 2006

professionals, patients and families.

As we plan for 2006, we will incorporate feedback from both physicians and families in hopes of taking the UMDF conference to the next level. Dr. John Shoffner is the course director for the Atlanta conference, June 14-17, 2006. The scientific meetings will run four full days – June 14-17 and the family

meetings will run June 16-17.

Watch for BIG changes for the Friday Night Banquet. 2006 will be a Celebration of Life for all those in attendance.

Upcoming issues of the *Mitochondrial News* will provide more information about the Atlanta conference as the program develops.



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ST. LOUIS MEETING EMPOWERS ATTENDEES

- **Scientific Meetings:** Let me begin by congratulating you and the UMDF for hosting such a well organized meeting. As an attendee, I feel that the talks and personal interactions with other scientists and physicians working on mitochondrial diseases were well worth the trip. – *Alfred Lewin, PhD*
- **Family Meetings:** I had the chance to speak with Dr. Shoffner, Dr. Whiteman, Dr. Parikh as well as Dr. Varma, and although in some cases they answered my challenging questions very differently from one another (questions pertaining to my abnormal test results and their significance), it made me realize that there are not always easy and straightforward answers (especially in the world of mitochondrial diseases) and there is a lot that we still don't know! – *Steven Peller, UMDF Member, Glen Head, NY*



"Ask the Mito Doc" panelists (R. Haas, MB, BChir; R. Saneto, DO, PhD; D. Whiteman, MD; and J. Shoffner, MD) responded to attendees' questions on Saturday morning and were a big hit.



Exhibitors, like Sigma Tau Pharmaceutical, answered questions from both families and physicians.



Family attendees find comfort talking with others who face similar experiences in the battle against mitochondrial disease – and making new friends is priceless!



The "Doctor is In" program gave attendees the opportunity to speak one-on-one with mitochondrial specialists. Pictured above Dr. Amy Goldstein, of Pittsburgh, PA, and Waynette Peek from Atlanta.

If you know of a company that would benefit from sponsoring or exhibiting at the Atlanta 2006 UMDF Conference, please email kara@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 kara@umdf.org for an order form. Forms are also available at www.umdf.org.

2005 UMDF Grant Recipients

\$162,878 **Patrick Francis Chinnery, PhD**, *University of Newcastle Upon Tyne, UK*

Project Title: The population prevalence of ten mtDNA mutations

Summary: The research team plans to determine the prevalence of mutations in mitochondrial DNA in the general population and compare it with mutations in mitochondria from affected individuals in the same region.

\$141,027 **Michael Frohman, MD, PhD**, *Stony Brook University, Stony Brook, NY*

Project Title: MitoPLD, novel enzymatic regulator of mitochondrial morphology and fusion

Summary: The research team has discovered a new gene that regulates the fusion of mitochondria, a process that helps keep defective mitochondria functional, and they will investigate how the gene carries out its regulation.

\$126,500 **Elena Rugarli, MD**, *Telethon Institute of Genetics and Medicine, Naples, Italy*

Project Title: The mechanism of mitochondrial dysfunction in paraplegin-deficient mice

Summary: The research team has developed an animal model for the study of hereditary spastic paraplegia, a severely debilitating disease in humans, and will use it to study the effects of the disease on mitochondrial function.

\$116,133 **Mair Churchill, PhD**, *University of Colorado Health Sciences Center, Aurora, CO*

Project Title: Molecular Basis of Mitochondrial Gene Regulation

Summary: They will use X-ray crystallography methods to determine the molecular structures of regulatory molecules that transcribe the information in mitochondrial DNA into RNA, a step required prior to synthesis of mitochondrial proteins.

\$110,980 **Linda Spremulli, PhD**, *University of North Carolina, Chapel Hill*

Project Title: Biochemical and structural studies on mitochondrial disease mutations in methionyl-tRNA

Summary: Transfer RNAs are molecules that ensure the proper placement of amino acids during protein synthesis. Their lab will investigate a mutation that leads to a defective transfer RNA in the mitochondrion.

\$109,991 **Richard H. Haas, MB, BChir**, *University of California, San Diego*

Project Title: Diagnostic Utility of DHPLC in Mitochondrial Disease

Summary: Using blood and saliva samples from patients, they want to develop simple, more reliable methods for detecting mitochondrial DNA mutations that can lead to disease.

\$94,000 **Luca Scorrano, MD, PhD**, *Venetian Institute of Molecular Medicine, Padova, Italy*

Project Title: Role of mitofusin-2, a mitochondria-shaping protein mutated in Charcot-Marie-Tooth 2a, in controlling mitochondrial function and apoptosis

Summary: A disease that severely impairs the ability to walk has been linked to a mutation that causes the synthesis of a defective version of a protein required for normal mitochondrial structure. Their lab will investigate how mitochondrial ATP synthesis is compromised by this mutation.

\$86,455 **Jan-Willem Taanman, PhD**, *University of College London, London, UK*

Project Title: The assembly pathway of human cytochrome-c oxidase studied with RNA interference

Summary: They will characterize in greater detail the assembly pathway of cytochrome-c oxidase, an important enzyme involved in mitochondrial ATP synthesis.

\$70,525 **Tal Mia Lewin, PhD**, *University of North Carolina, Chapel Hill*

Project Title: Barth Syndrome: A mitochondrial disease with insights into cardiolipin synthesis

Summary: They will investigate the role that an enzyme plays in regulating the synthesis of cardiolipin, an essential component of the mitochondrial membrane that, when defective, causes serious muscle weakness.



Five of the grant recipients received their grant checks during the Friday Night Banquet in St. Louis. UMDF members presented checks on behalf of UMDF and all those affected by mitochondrial disease.

Summaries provided by Steven G. Bassett, PhD, Associate Professor of Biology, Seton Hill University, Greensburg, PA

Physical, occupational, respiratory, speech, equine and pet therapies for mitochondrial disease, Part II

Continued from page 1

swallowing disorders, in a variety of settings such as schools, clinics and medical facilities.

Mitochondrial disease may have a direct impact on speech when the muscles of articulation, the tongue, palate and the lips weaken, significantly affecting intelligibility, a speech condition known as dysarthria. Breath support, too, is vital for sound and speech production, as air rushing between the vocal chords causes vibration, which generates sound. When respiratory function compromises the ability to take deep breaths, a patient may be unable to speak with volume or produce prolonged utterances. Working with physical, occupational and respiratory therapists, exercises, activities and other interventions may be used by the speech-language pathologist to help the patient strengthen speech and respiratory musculature.

When functional speech remains but is problematic, adaptive strategies can be taught to increase intelligibility. Slowing the rate of speech, shortening utterances, pausing between words and phrases, and the use of simple gestures can be taught. A low-technology alphabet board can cue the listener as to what is attempting to be said and can also reduce misinterpretation of sounds. Sign language may be appropriate if the hand muscles function adequately. If and when speech is lost, alternative means with which to communicate are recommended and implemented. High-tech augmentative and alternative communication devices may substitute for speech. Communication devices may be useful, also, for patients with hearing loss. Primary goals of speech therapy include functional adaptation and compensatory strategies to enable on-going communication by the patient.

When mitochondrial dysfunction disturbs higher cortical function, language disorders may ensue. Deficits can be expressive with an inability to generate speech, or receptive with an inability to decode the speech of others. Motor planning may be affecting the brain's ability to plan speech production, resulting in apraxia, an inability to sequence and say sounds, syllables and words. Aphasia, an impaired ability to produce or understand language, may result from stroke or a degenerative neurological condition. Language development can be significantly impacted by developmental delay as well as by hearing loss. Each of these language dysfunctions can be treated with speech therapy.

Speech-language pathologists are also educated in the anatomy of the oral cavity, larynx and pharynx, and may specialize in the evaluation and treatment of swallowing problems. The same muscles used for

voicing are involved with swallowing and can weaken in patients with mitochondrial disorders leading to dysphagia, the inability to swallow correctly. Patients with dysphagia are at risk for malnutrition and dehydration as well as respiratory problems. Symptoms of dysphagia include coughing or choking while eating or drinking, excessive drooling, food and liquid spilling from the mouth or nose, vomiting during meals or frequent respiratory infections, particularly aspiration pneumonia.

In conducting an assessment of swallowing ability, the speech-language pathologist may request, oversee and interpret barium X-ray studies which provide visualization of the pharyngeal phase of swallowing and offer important information about the safety and efficacy of oral feeding. A feeding team, also comprised of a physical and/or occupational therapist, a physician and a dietician, may then recommend therapeutic interventions to improve swallow function. These may include exercises to strengthen the muscles of the mouth and implementing safety strategies such as tucking the chin when swallowing or swallowing twice instead of once. Diet modifications may include varying food textures or supplementing the diet to be sure nutritional and fluid needs are met. The goals of swallow therapy are to keep the patient eating as long as is safely possible and to educate and prepare the person for changes in swallowing competence that may occur as disease progresses.

Speech therapy treats a wide range of dysfunction common with mitochondrial disease. From weakness in the motor function necessary for speech and swallowing, to the cognitive deficits that impair language, this therapy is vital for development and maintenance of communication skills and safe swallowing. Through interventions, strategies, exercises and adaptations, many patients with mitochondrial disease can benefit from therapy administered by a speech-language pathologist.

Respiratory Therapy

Cells with high metabolic rates, such as those of the skeletal muscles are especially susceptible to mitochondrial dysfunction. Diseases commonly associated with mitochondrial myopathies and encephalomyopathies can weaken the skeletal muscles that support breathing. Pulmonary manifestations of mitochondrial disease, then, are respiratory weakness or failure (Clay et al., 2001). Although unusual in adults, respiratory failure in

Continued on page 13

Fundraisers

“Coins for a Cure” Campaigns



■ Cecil Intermediate School in MacDonald, PA, raised \$375 in honor of Austin Manz



■ Holiday Park Elementary School in Plum Boro, PA, raised \$941.93 in memory of Eric Withum.



Energy Bands for Sale!

Ann, Keith and Sean Clark, of Canton, MI, have been working hard raising awareness of mitochondrial disease by selling the UMDF Energy Bands and thus far have raised more than \$6000. The Clark Family has contacted local restaurants, doctor offices, and schools asking for them to sell the bands. Fantastic!!!!

Runs/Walks



Pittsburgh 5K Run/Walk Raises \$28,325.34

Pictured left is the family of Austin Manz. Austin was one of the top pledge collectors. Keep up the great work, Austin! This was Pittsburgh's 3rd Annual walk/run and for the first time, we had SUN!!!

St. Louis One Step Closer to a Cure Walk/Run Raises \$8,588.25

Pictured left is the Mighty Mito mascot entertaining the children in attendance. Special thanks to Marsha Hohe and Mary Anne McGlynn for organizing such an outstanding event once again!



Wipe Out Mito Walk Raises \$17,729.50 in memory of Sam Juhlmann and in honor of the Juhlmann Family.

Casa Grande High Walk-a-Thon Raises \$1,253.85

Erica Meier and Robert Fausto, of Petaluma, CA, and the senior class of Casa Grande High School orchestrated this first time event in honor of Casey Sibbaluca. Best of Luck to all the graduating seniors and know that you have touched the lives of thousands of children and adults affected with mitochondrial disease.

Gifts from the Heart - Thank You ALL

- In lieu of wedding favors, Jessica Cabourg and Billy Falkenstern donated \$350 in honor of their cousin, Nicholas Nunno.
- UMDF member, Andy McDonald, who organized and promoted a mitochondrial disease benefit concert in Hamilton, Ontario in April 2005, donated \$1,000 (U.S.) to UMDF.
- For his 8th Grade Graduation and Confirmation Party, Jamieson Smith, of Medford, NJ, requested donations for the UMDF and Make-a-Wish. Jamieson donated \$965 to UMDF and \$445 to Make-a-Wish. That is one amazing 14-year-old! The Smiths have also been the driving force behind the NJ Mitochondrial

Disease Awareness Week legislation. Thank YOU ALL!

- 7-year-old Kaila Bolden sold decorated peanut butter containers and did a coin collection – raising \$20.25 in honor of her cousin, Logan McCartney.
- Cameron Huffman, of Murrysville, PA, asked for donations in lieu of birthday gifts and contributed \$400 in memory of Paul Buczynski. Happy Birthday, Cameron!
- Fifth grader Matt Johnston, of Dallas, TX, organized a bake sale for Charlie Sido's Fund and raised \$190. You are terrific, Matt!
- Amanda Turi (pictured above right with friends), daughter of UMDF staffer, Sandy Turi, raised \$400 at



her 13th Birthday Party for UMDF. You rock, Amanda!

- Sixth graders at Hester Junior High School in Franklin Park, IL, donated \$2 each for UMDF energy bands and donated \$22 to UMDF.
- Mossie Middle's 6th Grade Class in Monroeville, PA, held a Sundae Sale and raised \$129.45.

Golfing



Volunteers ham it up with UMDF Chairman, Chuck Mohan, at the **8th Annual Pittsburgh Golf Outing**. The event raised \$21,332. Special thanks to Lexus for donating the golf trip for this year's outing. Thanks also goes to Bruce Dice and John DiCecco for donating their winnings back to the foundation!

The 6th Annual Ohio Golf Outing at The Country Club in Pepperpike, OH, raises more than \$100,000. Thank you Stan and Carole Davis, Jill Platt and Amy Rogoff for your hard work in making this annual event a success!

Special thanks to **Fifth-Third Bank, John & Bonnie Osher, and Hal & Ronna Uhrman for their continued support and dedication to the UMDF Mission.**

Attention Federal Employees!
You can now donate to UMDF through the Combined Federal Campaign. UMDF has been approved under the CFC Code 2921.

Fundraisers

Emma's Angels, Inc. of Wilmington, DE, held a Wine Tasting/Silent Auction in April and raised \$8,175 in memory of Emma Sajewski, daughter of Lisa and Paul Sajewski. Special thanks to 9-year-olds Melissa Mizell and Emma Skilton for donating birthday money to the fundraising total.

The friends and family of Emma are a very special group - Thank You ALL!



Kites for Kristen Raises \$20,000

In honor of Kristen Charleston, children at St. Daniel the Prophet decorated kites, made donations, sold raffle tickets, candy, energy bands and had a few items for silent auction. Kristen's cousin, Caitlyn, sold candy at her high school and contributed \$300 to the total. Kristen's 3rd cousin, Paige, organized a bake sale at the middle school all by herself!

Pat Charleston's (Kristen's mom) friend donated \$1,160 to the fundraiser in memory of her dad, William Milton.

"In today's busy world, there are still so many wonderful people who care. From the bottom of our hearts, we thank everyone." - *The Charleston Family.*

Special Thanks to MORE

★ Fundraising Stars ★

- Sr. Clara Mohan, of St. Vincent Ferrer Convent in New York sent out special "Tea for Mito" letters to family and friends and raised \$1,550 (with more coming in). The letter included an "ask" for a donation and a teabag as a thank you. You are wonderful, Sr. Clara!
- The Mohan's held their annual 4th of July party and raised \$460.
- George and Mary Martin, of West Palm Beach, FL, held an Open House in honor of Adelaine Laney Cooper and raised \$425.
- 2005 Day Chevrolet Corvette Cruise raises \$1,767 for UMDF. Thank you Ron & Donna Miklos, Day Chevrolet and the Corvette Club of Western Pennsylvania.

Gibson's 12th Annual Potluck/Barbecue Raises \$6,100 in June of 2005

Thank you Norma and Morgan Gibson, and all your family and friends, for continuing this wonderful event in memory of Heidi Marie Daniel.

Tomato Face Foods

YOU can help **Tomato Face Foods** continue reaching thousands across the U.S. Do you know someone in your local supermarket, school cafeteria, college food service, or grocery chain? If so, please contact Barbara and Allen at 216-382-0232 or seebrook1@aol.com.

Allen, Barbara and Dana are still working on their goal to catch Oprah's attention as well as other national television production companies. Keep up the great work, Tomato Face Foods!

Physical, occupational, respiratory, speech, equine and pet therapies for mitochondrial disease, Part II

Continued from page 10

children with mitochondrial myopathies is common (Carroll et al., 1995). Symptoms of weak respiratory function include shortness of breath, poor sleep, morning headaches, weak voice and cough, and aspiration of food and liquid.

Respiratory therapy is an allied health field engaged in the evaluation, treatment, management and care of patients of all ages and with all manner of breathing disorders. These therapists are certified professionals educated in respiratory anatomy, physiology and pharmacology, who, in conjunction with the referring physician, work to maintain or improve a patient's respiratory function. Toward this goal, a comprehensive evaluation measuring baseline pulmonary function determines which interventions are best suited to a particular patient.

Using specialized instruments, lung capacity is measured along with the volume and flow of oxygen during inhalation and exhalation. Arterial blood gases are analyzed for pH levels and oxygen and carbon dioxide concentrations, and the results relayed to a physician. Oximetry can measure oxygen saturation. Polysomnography may be indicated to assess the presence of sleep disordered breathing. Results can be compared with normative readings to determine the presence of lung deficiencies.

In developing an approach to support weakened respiratory muscles, therapists may recommend various aides and techniques to increase ventilation and augment efforts to cough and mobilize secretions. Treatments, according to a physician's orders, may include the use of oxygen and oxygen mixtures, chest physiotherapy, aerosol and humidity therapy, intermittent positive pressure breathing therapy, incentive spirometry and both invasive and non-invasive mechanical ventilators. Respiratory therapists will educate patients and their caretakers in the proper use of respiratory devices and will inspect, adjust and maintain the equipment in both medical and home settings. When indicated, the therapist will instruct patients in the performance of exercises that might help keep the respiratory system functioning as effectively as possible. The respiratory therapist assumes primary responsibility for all respiratory care, as designated by the physician.

Levels of treatment provided by the respiratory therapist cover a wide range. Severe cases of respiratory problems may necessitate permanent ventilation support, while the patient with mild difficulties might require occasional oxygen supplementation. Although there have been no trials of therapeutic oxygen in patients with mitochondrial myopathy, there is a single case study suggesting that

patients can perform higher levels of cardiopulmonary work with less lactic acid build-up using oxygen supplementation. It is postulated that the oxygen use may improve functional capacity as well as reduce mitochondrial stress, which is thought to increase the proportion of mutant mitochondria (Winograd and Newman, 2002).

Ventilation issues vary from patient to patient. For some, non-invasive options are sufficient. Respiratory therapy may slow the need for tracheostomy, but when necessary, the respiratory therapist will facilitate ventilation decision making.

For patients with suspected Leigh's syndrome, mechanical ventilation should be considered to allow for diagnostic results, give time for patients and caregivers to adjust to diagnoses and prognoses, or because respiratory insufficiency might be associated with a recoverable illness (Chinnery and Bindoff, 2003). Long-term ventilation for early onset MELAS might improve a patient's overall quality of life (Carroll et al., 1995). Ventilation for the patient with infantile COX deficiency might provide support for the child who could experience a late recovery of the myopathy (Chinnery and Bindoff, 2003).

Sleep apnea has been diagnosed in patients with mitochondrial disease, especially those with cytochrome c deficiency, Leigh's or NARP (Clay et al., 2001). Apneic events may be central or related to muscle weakness. If polysomnography yields a diagnosis of nocturnal hypoventilation, the respiratory therapist can recommend breathing assistive devices such as Bi-PAP and VPAP. Determining the correct settings for these machines and fitting the patient for nasal pillows, nasal or full facial masks and mouthpieces are also the responsibility of the respiratory therapist.

Respiratory therapy is of the utmost importance for the mitochondrial patient with respiratory difficulties who undergoes anesthesia and surgery. Anesthetic agents depress respiration and may place the patient with significant mitochondrial disease manifestations, such as hypotonia, bulbar dysfunction and diminished respiratory capacity at great risk for developing postoperative pneumonia. These patients should be closely observed for signs of infection and the respiratory therapist should perform chest physiotherapy to keep the lungs clear and improve cough efficiency, using manual or mechanical means.

Any patient with a weakened respiratory system is more prone to infection and difficulty coughing. Such physical stressors place the patient with mitochondrial

Continued on page 14

cytopathies at risk for exacerbation of the disease process. Respiratory function should be monitored for changes by the respiratory therapist. Often, prophylactic airway management measures ranging from breathing exercises to cough assist devices to ventilatory support may reduce emergency situations and hospitalizations for respiratory distress.

Pet Therapy

Pet therapy is a centuries old treatment approach to physical and mental disabilities. Animals were first used in a therapeutic setting in the United States in the early 1900s, and today medical and mental health programs routinely use animals in various treatment programs. Research has shown that a relationship between animals and people promotes human physical and emotional well being (Bardill and Hutchinson, 1997). Some studies suggest that physical contact with animals can lower blood pressure and slow the heart rate, thus promoting cardiovascular health. Other studies indicate that petting animals releases endorphins, the body's natural pain suppressors (Laun, 2003). Relationships with animals provide companionship, affection, nurturing and physical closeness, all of which may fill important emotional needs.

Pet therapy is a broad term that encompasses two primary types of animal-based treatments. The first of these, animal-assisted therapy is a formal treatment program designed to promote improvement in physical and cognitive functioning, using animals as a therapeutic modality. Therapy animals, usually dogs, are certified by a national organization and the pet therapist is also specially trained.

Under the supervision of another professional, such as a physical, occupational or speech therapist, mental health practitioner or social worker, the therapy dog is assigned a specific therapeutic protocol. If improved strength or enhanced motor function were a goal, for example, activities with the therapy dog might include physical play such as throwing a ball or walking the dog, or simply petting or grooming. An example of a cognitive goal such as sequencing or memory would include chains of events such as putting on a collar and attaching a leash prior to walking the dog. Speech goals may include giving oral commands and praise to the dog, or recalling and verbalizing information (name, age, breed, etc.) about the animal. Often the therapy dog is a catalyst for social interaction as well as a motivator for patient participation, all the while promoting general feelings of well-being.

The second form of pet therapy are animal-assisted activities which provide interactional opportunities with

animals that can be motivational, educational and/or recreational and are designed to enhance the quality of the life for the participants. The most common animal-assisted activities are generalized visits by animals to hospitals, clinics, convalescent homes and other such facilities. Unlike animal-assisted therapy, there are no specific treatment protocols or goals and no special training is required of the animal or its volunteering handler.

An animal visit can offer entertainment and a welcome distraction from pain and illness. It can promote socialization and cognitive stimulation, leading to increased activity and responsiveness. It can provide the opportunity for positive, nonthreatening physical contact.

No discussion of animal-based treatments for persons with disabilities would be complete without mention of the assistance or service animal, legally defined by the American Disabilities Act as one that has been 'individually trained to do work or perform tasks for the benefit of a person with a disability.' The types of duties these animals, normally dogs, perform are: (1) guiding persons with visual disabilities; (2) alerting persons with hearing impairments to specific sounds; (3) muscle work, such as pulling a wheelchair or providing balance and support to a person with mobility disabilities; and (4) alerting and responding to people with seizure disorders.

Finally, "social dogs," not legally recognized as true assistance animals, do not complete training due to health, dispositional or other factors, but are made available as companion animals to people with disabilities. These dogs can supply ongoing comfort and support and reduce loneliness during adversity and stress, contributing to emotional and social well being throughout the life cycle (Sable, 1995). Social dogs are often beneficial for persons with disorders that limit interaction, such as autism or Alzheimer's and can provide an ongoing source of social stimulation. Companion animals offer unqualified acceptance of their owners, regardless of age or disability.

Pet therapy, in its various forms and settings uses the human-animal relationship to improve a patient's physical and emotional health. It is an emerging treatment modality that is gaining acceptance among medical practitioners and health care administrators (Howell-Newman and Goldman, 1993). As an adjunct to other forms of therapy, pet therapy is a valuable intervention that can be utilized by patients with mitochondrial disease.

Physical, occupational, respiratory, speech, equine and pet therapies for mitochondrial disease, Part II

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Table 2. Contact information for professional associations of allied health providers

Physical Therapy	The American Physical Therapy Association www.apta.org
Occupational Therapy	The American Occupational Therapy Association www.aota.org
Speech Therapy	The American Speech-Language-Hearing Association www.asha.org
Respiratory Therapy	The American Association for Respiratory Care www.aarc.org
Hippotherapy	The American Hippotherapy Association www.americanhippotherapyassociation.org
Pet Therapy	Delta Society www.deltasociety.org

Conclusion

The comprehensive medical care of the patient with a mitochondrial disease is best coordinated through a multidisciplinary approach. The role of the allied health professions discussed here should be emphasized in the treatment of these complex diseases. Contact information for professional associations of physical, occupational, speech, respiratory, equine and pet therapists is provided in Table 2. Other professionals to be considered include audiologists, dieticians, vision therapists, recreational therapists and social workers. The primary goals of any therapeutic program are to preserve, and where possible, improve function. Treatment should be based on cooperative efforts between the medical and allied health professionals to maximize benefit for the patient.

Funding for these therapies may be problematic as mitochondrial disorders lack standardized billing codes. Insurers may deem supportive therapies 'inactive care' and be reluctant to cover maintenance services. Providers do have grievance and appeal procedures and may be persuaded that there are benefits to regular therapy such as prolonged strength, pain relief and minimized hospitalizations. Early intervention programs service the needs of children three years of age and under with developmental problems under the Individuals with Disabilities Act. Likewise, the law requires that an Individualized Education Plan for school aged

children includes the necessary supports and services designed to meet a child's unique needs and provide a free and appropriate education. In general, it is difficult, but not impossible to get Medicare reimbursement for these supplementary services.

With the potential for ongoing medical and psychosocial complications of mitochondrial disease and with the goal of improving the quality of a patient's life, an integrated team of experts should be available. Referrals for physical, occupational, speech and respiratory therapies, as well as consideration of equine and pet therapies should be made before functioning is lost, not after.

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Further Reading

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Mito Adults Corner

Mitoldies is an online group for adults with mitochondrial disease and their caretakers (mitoldies@yahoo.com). Members put their heads together and provided some tips to make life easier. Part 1 of the list was provided in the last issue of *Mitochondrial News* and the following provides a continuation of that list.

ADAPTATIONS TO MAKE LIFE EASIER

PERSONAL CARE

- Dry hair with arm supported by doorframe or something similar or dry it while sitting with head down and arms supported on knees. Light weight hairdryers and use of hairdryer stands.
- Shower handrails and bath seat. Handrail clamped to tub if more permanent handrails aren't an option.
- Raised toilet - a toiletvator which is added below the toilet is safer than a ring for the top of the toilet and is easily removed if the house is sold to someone who doesn't want a high toilet. A raised ring is good if you are going to some place other than home and will need to use the toilet.
- Portable potty next to bed.
- Computer Tips - track ball instead of mouse, screen that can be adjusted, word recognition program, ergonomic keyboard, wrist rests for keyboard and mouse, customizing various buttons to do complete commands, desktop with short cut icons, e-mail program that opens when computer is started.

HINTS FOR MOBILITY AIDS

- "S" hooks (those used for hanging plants) to hang on scooter or wheelchair - these are great for carrying plastic grocery bags while shopping or a small purse.
- Bottle holder meant for a bike for either a scooter or wheelchair - much cheaper than one designed for chairs.
- Bags from bike, luggage, car or sporting goods departments - much cheaper and more available than those meant for wheelchairs
- Clips for keys (like teens use on backpacks and look like those clips used for mountain climbing). These can be clipped to purse, back pack purse, scooter or wheelchair. They are always handy and in sight.

- Folding reacher to use with walker, scooter or wheelchair. Make a sling to hold reacher on wheelchair, walker or scooter and attach with the velcro cord holders
- Bag under front of wheelchair between legs for those who can bend over and get back up.
- Hanging bag attached to wheelchair armrest - zippered areas are good. This can be used for wallet, cell phone, grocery lists, PDA
- Baby stroller net bag for back or wheelchair in place of backpack
- Lap tray for wheelchair that is clear (can see what is down in front) with raised edges (prevents items from falling off)

MISCELLANEOUS

- Velcro computer cord holders for attaching things in a handy place, but are still removable.
- Positioning is critical - have washer and dryer at height appropriate for your means of using them. The elevators can be removed or added if mobility needs to be change. Make sure you have a work surface that is the proper height so arms are supported. This can be achieved by using a table at the right height or adding a surface on legs to place on a counter or table. Make sure feet are on floor, footrests or stool
- PDA - good to have handy to add to grocery list or access phone number. Carry it with you at all times. A pad of paper and pencil will also work.
- List of meds on the computer desktop that can be easily printed for a doctor's appointment or trip to ER. Much easier than trying to remember them. Keep a list (can be printed in small font) in wallet or purse.
- Cloth book carrier - can be made more easily than finding one to buy. It is the size of a paperback if this is what you read. It is like any book cover with handles added. This is especially good for those using a walker, can or crutches.
- Network of people you can call on for help.
- Senior Services (not always a need to be a senior) for cleaning, repairs, yard work, bath assistance)

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!

Announcements



Vacation Toward a Cure

Courtesy of

AmericanAirlines®

Official airline of the
United Mitochondrial Disease
Foundation

And the winner is . . .

Tom Viall, UMDF's new executive director, drew the winning ticket during the Friday Night Banquet in St. Louis on June 17, 2005. Congratulations to:

Patrick Oriatti
Downers Grove, IL

Thank you to **EVERYONE** who purchased or helped sell tickets. This year's Vacation Toward a Cure raised **\$20,395** which brings a total of more than **\$65,000** over the past three years.

The support group or chapter that raised the most in sales was the Atlanta Chapter. The Chapter will have \$1,000 in scholarship money to help members in their area attend the 2006 conference in Atlanta, GA. Special thanks to Sheri Seldes from Atlanta who sold more than \$5,600 in tickets! Great job, Atlanta Chapter!

UMDF Web Site Takes on a NEW Look!



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. Your patience is appreciated.



*...that their
light may
always shine.*

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

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.

NOTICE

UMDF Annual Membership Meeting

UMDF National Office
Pittsburgh, PA

Monday, November 7, 2005
1:00 p.m. to 2:00 p.m.

How to make United Way work . . .

The United Way campaign in your local area is designed to meet a diversity of health and human care needs. You may give an unrestricted gift and, in some areas, you may designate UMDF as the recipient of your gift to United Way.

Contact your local United Way office to find out if there is a DONOR CHOICE program in your area. We will acknowledge each gift received unless otherwise indicated or if no address is provided.

Simply complete the appropriate form (available through your employer) as follows:

**United Mitochondrial
Disease Foundation**
8085 Saltsburg Road, Suite 201
Pittsburgh, PA. 15239
Phone: (412) 793-8077
Fax: (412) 793-6477
Attention: Toni Beasley

September Special on Car Magnets - Buy one, get one FREE

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.



Fundraising Tips RE: Ebay and Walmart

UMDF has developed a relationship with Ebay that can help raise dollars to support the UMDF mission and 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.

★ Mark your Calendars ★

See pages 4-6 for more details on chapter events

- August 20, 2005 - *Rooftop Party*, in Chicago, IL, in memory of Stephanie Larson's sister, Carrie Mack.
- August 25, 2005 - *Goobers/UMDF Golf Classic at Bosobel Golf Club*, in Clemson, SC, in honor of Alex Newton.
- August 27, 2005 - *Step Towards a Cure Walk*, Clemson, SC, in honor of Alex Newton.
- September 2, 2005 - *Hair Cut-a-Thon*, Lake County Captains Game (Ohio Chapter).
- September 10, 2005 - *Go for Mito! Shelly's Heroes Walk/Run - 6th Annual DeVal UMDF Walk/Run* (Del Val Chapter).
- September 10, 2005 - *2nd Annual Pittsburgh You Go Girl Golf Outing*, Murrysville Golf Club, Murrysville, PA. For more information, contact kara@umdf.org.
- September 13, 2005 - *HECC Golf Outing* - In Honor of the Zachary Foundation, Mamaronek, New York. Event Contact: Michael Friedberg.
- September 24, 2005 - *Dinner/Dance at Longwood Gardens*. Event Contact: Stephanie Krug of Westchester, PA..
- September 25, 2005, *5th Annual Cruisin' Toward a Cure* car cruise at CCAC Boyce Campus in Monroeville, PA. For more info, email Ron and Donna Miklos at cruzmeisters@alltel.net.
- October 1, 2005 - *1st Annual Mito-What? 5K Walk* at Nelson Field in Plymouth, MA (New England Chapter).
- October 2, 2005 - *6th Annual Mito-What? 5K Walk/Run* in Longmeadow, MA. (New England Chapter).
- October 2, 2005 - *Annual Olivia Steele Memorial Golf Outing* at Westchester Golf Course in Canal Winchester, OH. Event Contact: Shawna Steele.
- October 10, 2005 - *Gale's Gig/Kansas City Golf Outing* at the Lake Quivira Country Club. (Kansas City Chapter).
- October 15, 2005 - *Benefit Dinner/Comedy Show* at Middle Falls Fire Hall in memory of Kain. Event Contact: Bethany Buell. (New York Metro Chapter).
- October 16, 2005 - *The Zachary Foundation 2nd Annual 5K Walk & 1 Mile Run/Walk* at the Marlboro Recreation Center, NJ benefitting UMDF and mitochondrial research. Event Contact: Michael Friedberg).
- October 24, 2005 - *2nd Annual Fore-a-Cure Golf Outing* at The Standard Club in Duluth, GA (Atlanta Chapter).
- October 28, 2005 - *Wine Dinner* at Hampden Country Club, Pioneer Valley Culinary Association (New England Chapter).
- October 30, 2005 - *1st Annual Chris' Walk*, Houston, TX. Event Chair: Deb Schindler.

UMDF Chapters & Groups

ARIZONA

★Arizona Chapter

President: Suzanne Perryman
Email: AZChapter@umdf.org

CALIFORNIA

★Southern California Chapter

President: Linda Cooper
Email: SCalChapter@umdf.org

FLORIDA

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★Atlanta Area Chapter

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★Indiana Chapter

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Chicago Area Group
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★New England Chapter

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Email: NEngChapter@umdf.org

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Contact: Ann Clark
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Contact: Suzanne Marous
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★Kansas City Chapter

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Email: KCchapter@umdf.org

St. Louis Area Group

Contact: Marsha Hohe
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NEW YORK

★New York Metro Chapter

President: Mary Pisani
Email: NYMetroChapter@umdf.org

New Paltz Group

Contact: Beth and James DeArce
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OHIO

★Ohio Chapter, Cleveland, OH

President: Jennifer Lyman
Email: OHChapter@umdf.org

Columbus Group

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Cincinnati Group

Contact: Tim DisBennet
Email: cincyumdf@yahoo.com

OREGON

Contacts: Seeking new leaders
Emails: info@umdf.org

PENNSYLVANIA

★Delaware Valley Chapter

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Email: DelValChapter@umdf.org

Pittsburgh Group

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Email: bwilson@cvzoom.net

SOUTH CAROLINA

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Carolina Foothills

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TEXAS

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VIRGINIA

Richmond/Norfolk

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

WISCONSIN

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 Rhode Island, Southern Florida, Northern Florida, 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:

The Member Services Department is excited about the response to our call for members interested in building the UMDF network of support groups and chapters! If you are interested in starting a support group or chapter in your area which includes anything from licking stamps to physician awareness, please let us know at info@umdf.org or call us at 412-793-8077. Even if you don't want to be the leader, we will connect you with others and help you get started. We look forward to talking to you soon.

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

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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.



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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.

Deadline for next issue is 10/1/05