

A "Probable" Diagnosis

Anne Juhlmann, RN and Mito Mom

The following is adapted from Anne Juhlmann's response to a frustrated parent whose child was diagnosed with a "probable" mitochondrial disease. Specific details have been changed for privacy reasons and to broaden its impact.

First of all, I want to be clear that I am not speaking as a physician, but I can speak to how I understand the choice of the word "probable." My understanding is that the physician feels it is very important not to label something as X if we don't know for certain it is X. This is not just a scientific exercise, although I know some perceive it as such.

Remember that making a diagnosis of mitochondrial disease is an integrative process. That means there is not one test that makes the diagnosis. If a child has hemophilia B we can do blood tests that definitely tell us the child has hemophilia B. But with mitochondrial disease, dozens of things need to be examined in order to get a good picture of what may be going on with the patient.

The way I think about it is that diagnosing these diseases is like putting together a puzzle. In fact I use puzzle pieces to teach this when I give hospital in-service seminars. When you think of a puzzle, the goal is to find all the right pieces so that in the end there is a picture. As you connect the pieces, even before they are all in place you can say, "Oh, that looks like a picture of Donald Duck." Likewise, the goal with diagnosis is to look at all the test results

and symptoms and fit them together to make the most accurate picture possible. If mitochondrial disease is the suspicion then the puzzle pieces, when put together, should look like a "picture" of mitochondrial disease even if some pieces are missing. The puzzle pieces are test results such as muscle biopsy, spinal tap, blood work, imaging (like MRI), as well as signs and symptoms, etc. Depending on the test results and the signs and symptoms, more or fewer pieces will be added to the mitochondrial disease puzzle.

Sometimes you can't figure out if a puzzle piece fits or not so you put it off to the side. But later, after you've connected a few more pieces, suddenly you can see exactly where that piece fits. Using the word "probable" is similar. It basically says that right now it looks like the puzzle pieces, when put together, are forming a picture of mitochondrial disease. It also recognizes that some pieces are missing or do not fit. Sometimes a negative test result is the reason. Sometimes it is just because that information has not been obtained. (For example, my son could not have

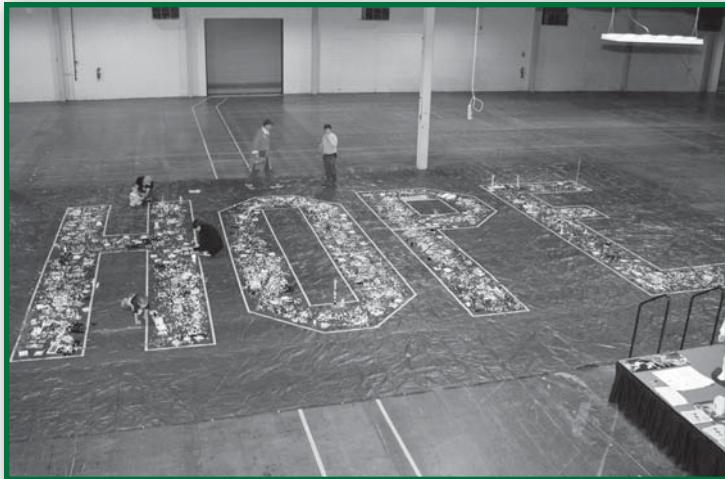
an MRI so his doctor did not have that piece of the puzzle.) Usually by the time the physician writes the final report, the

reason for missing puzzle

pieces is simply that we don't have the scientific knowledge today to complete the puzzle.

We have a long way to go towards understanding this group of diseases. Having said that, when I look at how far the field of mitochondrial disease has come in the ten years since my kids were diagnosed it is absolutely dazzling. We will continue to learn more at an accelerated rate so that the puzzle pieces you cannot find today may be found tomorrow. And

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HOPE spelled out in LEGOs at the Mito Walk and Family Fun Day held at the LEGO Campus in Enfield, CT on September 27, 2008. The event raised over \$20,000!

See pages 4-7 for more events and fundraisers!

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they may or may not fit into the mitochondrial disease picture.

If your child's diagnosis is "probable," then it sounds as if right now the majority of the puzzle pieces are forming a mitochondrial disease picture. Therefore, mitochondrial disease is the best way to describe "the picture" that the puzzle pieces are making. But you can't complete the puzzle today. You may some day. You may not. Using the word "probable" allows you to remember that there are some missing pieces. From my perspective, it gives hope because you never know what pieces you may find some day. Once located, the missing pieces may change the picture. For example, you thought your puzzle was going to be Donald Duck. It is - but Daisy Duck is in the picture too. Figuratively speaking, this might mean your child has a mitochondrial disorder but it is secondary to some other problem you did not know about. Or, the pieces may not fit into the mitochondrial disease puzzle that you have had all these years. They may start a new puzzle. (It's not a picture of Donald Duck at all. It's Daffy Duck.) It may turn out that your child does not have a mitochondrial disorder but some other metabolic problem we did not even know about in 2008.

Now the hope is that as more is learned over time, physicians caring for the patient on a day-to-day basis will continue to evaluate the situation, checking to see if the new pieces they have found fit into the picture.

The reality is that some doctors do not think this way. They become set on a diagnosis they make for an individual and then refuse to consider anything else even when evidence suggests otherwise. Using the puzzle analogy, they try to jam a puzzle piece into the picture where it really does not fit. Or, they refuse to look at a piece of the puzzle that should be examined. This deprives a patient and their family of better understanding and can even harm the patient.

As physicians, nurses, parents, or patients ourselves, we all have to keep an open mind and not become so convicted and certain that we know what is wrong unless/until we truly have all the pieces of the puzzle. Having said that, I do think any good doctor realizes that there is also a need to take the information we have today and do the best we

can. Think of mitochondrial disease as the working diagnosis. Today, it is the most accurate description of everything seen to date. Today, the best way to treat your child is to do what makes sense for that working diagnosis - which is to treat your child as if he has a mitochondrial disease.

If your child's doctor did not feel that a mitochondrial disease diagnosis was the most accurate clinical diagnosis on which to base decisions and treatment, he would not put those words on the report. So don't let someone tell you that the word "probable" means your child does not have a mitochondrial disease. It means no such thing. In fact, you can be assured it is currently the most accurate diagnosis because mitochondrial disease specialists tend to put puzzles together more carefully than many doctors. They find puzzle pieces others don't find, look at the pieces closely, and can see where they fit (or don't fit) when others cannot. If the test results and clinical signs and symptoms did not suggest mitochondrial disease, a mitochondrial specialist would not put those pieces into the mitochondrial disease picture.

I know the word "probable" upsets many people, and I understand that. Most of the time, people

arrive at a mitochondrial disease specialist's office after long months or years of hearing "we don't know what is wrong" or "nothing could possibly be wrong." Being undiagnosed is a nightmare all its own - I've

been there during my son's first six years - and I was deeply sensitized to how hard that uncertainty is to live with. Try to remember that a diagnosis is nothing more than an explanation. Your child's doctor gave you an explanation for what is wrong - a mitochondrial disease diagnosis. For today, that is your child's diagnosis and you can use that explanation to decide on treatments and approaches to care.

"Probable" simply reflects the limitations of our understanding. We just don't know everything we need to know today. But we learn more every day. So the word "probable" reminds me not to stop hoping. It reminds me that there is so much more we will learn. It's actually a great word when you think of it.



Anne's children - Sam, Brittany, Abby and Zach



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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.

ASK THE MITO DOCSM



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

Responder for this issue: Sumit Parikh, MD, of the Cleveland Clinic, OH, and Russell Saneto, DO, PhD, of Children's Hospital and Regional Medical Center, WA.

THE QUESTION IS...

Can someone have a mild form of autism spectrum disorder (ASD), specifically pervasive developmental disorder (PDD), with mitochondrial disease? What would be the diagnostic assessment tools to confirm the diagnosis of ASD? Are the signs and symptoms different with someone with a mitochondrial disorder?

RESPONSE FROM SUMIT PARIKH, MD:

The question of how autism and mitochondrial disease relates is a complex, complicated and evolving one. In trying to simplify the issue, we can think of autism as a set of symptoms that impair 3 areas of development, including speech, socialization and behavior. If only 2 areas are impaired, a diagnosis of pervasive developmental delay (PDD) is given [also known as autism spectrum disorders]. Both autism or PDD can be mild, moderate or severe.

Autism and PDD are clinically diagnosed using a variety of tools. Many times, an experienced clinician recognizes that an individual has autistic symptoms and brings up the issue with parents. In addition to clinical judgment, there are a variety of formal diagnostic tools. The one recognized by the American Academy of Pediatrics

and recommended for use in all children prior to age 2 is the M-CHAT - which is a short one-page questionnaire that is completed by a parent and scored by the physician. A formal diagnosis is made by a psychologist who specializes in autism diagnosis and there are several formal clinical tools available to them.

In regards to the cause of autism/PDD, there is no one cause. Just as a fever is a symptom that can have hundreds of varied causes, PDD and autism symptoms have multiple causes. Most of the causes of primary autism and PDD are likely various DNA typos, which alter brain development and function. That means there is no single cause of autism/PDD but many different DNA mishaps that may all lead to these similar symptoms. Due to limitations in genetic testing, we are still far from perfect in finding all DNA typos and can only find DNA causes of developmental delay and autism a small percentage of the time. Thus many patients with autism still do not have a genetic etiology identified even though there is likely one to find.

We also know that a single DNA typo may affect more than one body function. So there are DNA typos that affect both brain development and mitochondrial function at the same time. So autism/PDD and mitochondrial disease can and do coexist. We do not know if there is a direct cause and effect. If not directly linked, it is possible that unhealthy mitochondria may amplify the underlying autism symptoms. Thus, a child with underlying (potentially undiagnosed) mitochondrial disease may have their mitochondrial and autism symptoms brought out by a physiologic stressor such as illness, prolonged fasting or certain medication.

We do not know if autism symptoms in mitochondrial disease patients are different than 'typical' autism. We know that mitochondrial patients can have mild, moderate or severe autism or PDD.

THE QUESTION IS...

I have an 18 year old son who has been diagnosed with mitochondrial encephalomyopathy, complex 1. School is a major challenge for him as he experiences severe learning and behavioral disabilities and extreme fatigue. I'd like some help explaining his condition to his teachers. Two questions:

1. Could you explain the biology of the chronic fatigue associated with mitochondrial disease in a way that I could explain to educators?

2. Along the same lines, why do kids with mito suffer fatigue in the classroom but can perk up at lunch time or recess?

RESPONSE FROM RUSSELL P. SANETO, DO, PhD:

I am sorry to hear about your son. The mitochondria are the source for almost all of our energy production. The body needs a certain amount of energy to function properly. Within the various organs in the body, different organs need different levels of energy. For instance, the brain needs the most energy to function well as do muscle cells. When there isn't enough energy available, the organ starts to become dysfunctional. An analogy would be the electrical needs for a large city. When everything is going well and there is enough electrical energy available, then there are no problems with lights, heat, and other electrical utilities. However, as demand increases and the energy stores of the city cannot meet this need, there are "brown outs" where certain utilities begin to fail. For instance, to save energy, they may tell people not to run their appliances or turn up their air conditioner's temperature settings. This actually happened in New York City. When it happens at the gas station (gas prices increasing), we buy less gas and go to fewer places. When there are demands at school (that require neuronal function) such as learning and memory work, or a lot of muscle work such as writing papers or test questions in a short amount of time, then learning becomes compromised, memory becomes faulty, handwriting becomes messy, etc.

Sometimes the patient may perk up, but other times, quick recovery may not happen unless we help the patient receive more carbohydrates (energy). So, I often have my patients take sports drinks into class, or allow them to take sports bars into the classroom or have them available for such occurrences. However, if it is a true brown out, then just going to recess would not alter the problem; physical activity would just compound the problem. I hope this helps you.

Submitting questions to *Ask the Mito DocSM* is a benefit of UMDF membership. If you are a member and would like to submit a question, please log in to the UMDF website using your user ID and password. If you would like more information on becoming a member of the UMDF, please e-mail us at info@umdf.org.

CHAPTER ACTIVITIES

CHAPTER NOTES

ARIZONA CHAPTER

- **September 1, 2008.** A Mochas for Mito event was held at Leap's Frozen Custard in Avondale, AZ. A portion of sales were donated to the UMDF totaling \$100. Thank you to Leap's Frozen Custard for your support!
- **September 20, 2008.** Derek's Challenge was held at Christ Presbyterian Church in Goodyear, AZ. The event included a vendor fair and silent auction. Thanks for all of the hard work from those involved; over \$2,000 was raised in honor of Derek Swanson!
- **October 25, 2008.** The Arizona Chapter worked with the Southern California Chapter to ensure a large delegation of mito supporters attended the LOVE RIDE. Participants rode from Phoenix, AZ to Glendale, CA, raising money and awareness for mitochondrial disease along the way!

ATLANTA CHAPTER

- **September 27, 2008.** The second annual Music for Megan Charity Benefit Concert was held at Wills Equestrian Park in Alpharetta, GA. Over \$32,000 was donated to the UMDF in honor of Megan Sheridan. Thanks to Laura Sheridan and her fantastic crew for hosting another great event!



Megan Sheridan at Music for Megan

- **October 6, 2008.** This year's fifth annual Fore-a-Cure Golf Tournament enjoyed the best weather to date. It was once again held at The Standard Club in Duluth, GA. During the 165 yard "Shot for \$1,000,000," one of the participants got within a few feet. The Atlanta Chapter raised over \$16,000. It was another successful event made possible thanks to the many volunteers.
- **October 23, 2008.** The Ravina Club Silent Auction event was held at the Ravina Club in Atlanta, GA. Proceeds totaling more than \$2,300 were donated to the UMDF in honor of Morgan Gassel.

CALIFORNIA CHAPTER

- **October 25, 2008.** The Pre-Party LOVE RIDE Fundraiser was held at the Anaheim Hills Golf Course in Anaheim Hills, CA. The event

was sponsored by Smith-Cooper International and included classic rock music, great barbecued food, a screening of "Easy Rider," silent auction, raffles, and original artwork from renowned artist, Nancy Ostrovsky. The event raised more than \$23,000 for the UMDF in honor of Chad Cooper. Special guests of the event included Chuck Mohan, Executive Director of the UMDF and Sharon Shaw, Vice Chairman of the Board of Trustees.



Jay Leno, EJ & Taryn Fogel and Sharon Shaw at the LOVE RIDE

- **October 26, 2008.** The LOVE RIDE weekend continued with the Taryn's Hope 4 Life event which began at Francie's Pub in Corona and traveled to Glendale, CA. Thanks to the hard work of EJ and Debbie Fogel, for the first time in the event's 25 year history, the UMDF was named a beneficiary of the LOVE RIDE. Over 25,000 motorcycles were present, and all those who participated in the event had a great time!

CAROLINA FOOTHILLS CHAPTER

- **August 21, 2008.** The annual Goober Golf event was held in Clemson, SC. The outing organized by Danny Nichols raised more than \$3,000 in honor of Alex Newton.
- **September 12-13, 2008.** Blue Knights motorcycle club of Rocky Mount, NC hosted a 24-hour, 1,000-mile "Iron Butt Ride" in honor of Connor Armstrong. The Blue Knights also sponsored a poker run leaving from Rocky Mount Harley Davidson, which was followed by a Family Fun Day. This family event featured food, games, a dunking booth, bouncy houses, pony rides, a live DJ and more! Thank you to Tammy Armstrong and her great team for the great awareness and generous donation!
- **September 23, 2008.** The Carolina Foothills Chapter held a restaurant night fundraiser at Nothing But Noodles in Charlotte, NC. A portion of the restaurant's sales were donated to the UMDF.
- **November 1, 2008.** A Halloween-themed day of fun was held at the Sea Pines Resort in Hilton Head, SC. The Harbour Town Happenings event included a day of activities, games and food. Proceeds were donated to the UMDF in honor of Olivia Custer. A special thank you to the chapter for all of your hard work!

CHAPTER ACTIVITIES

CENTRAL OHIO CHAPTER

- **September 22, 2008.** The third annual Kovalcik & Geraghty Wealth Partners (KGWP) Charity Golf Outing was held at Worthington Hills Country Club in Columbus, OH. The annual event raised more than \$6,000 to date for the UMDF in honor of Ellie Kovalcik
- **October 4, 2008.** The eighth annual Olivia Steele Memorial Golf Outing was held at Kyber Run Golf Course in Johnston, OH. The outing was sponsored by Performance Site Co., Shelly Material and the Steele Family. The event has raised more than \$1,700 to date for the UMDF in memory of Olivia Steele.

CHICAGO CHAPTER

- **September 14, 2008.** The second annual UMDF Chicago Area Chapter 5K Walk & Family Fun Day was to be held along scenic Lake Michigan in Lincoln Park. Even though the event was cancelled due to rainfall from Hurricane Ike, more than \$90,000 was raised for the UMDF. Great work!
- **November 3-5, 2008.** The Mario Trococi Salon and Day Spa participated in a Spa and Share event with the Chicago Chapter. All 20 locations were involved, and 10% of sales were donated to the UMDF. Thank you to Mario Trococi Salon for your support!

DELAWARE VALLEY CHAPTER

- **September 13, 2008.** The ninth annual Go for Mito! 5K Run and 1 Mile Walk was held at the Philadelphia Museum of Art in Philadelphia, PA. The event raised more than \$10,000 to date for the UMDF. A special thank you to all the participants and volunteers who made this event a success!



Members of Team JuJu Bug at Go for Mito! 5K Run 1 Mile Walk

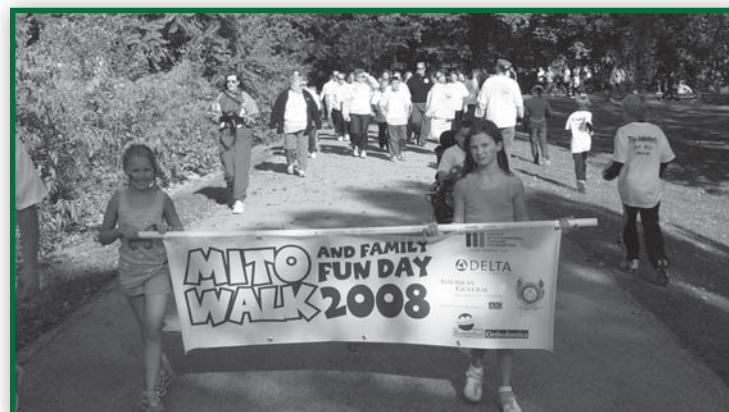
- **September 20, 2008.** The Agar-Lawrence Fundraiser raised nearly \$4,000 for the UMDF. The event, held during Mitochondrial Disease Awareness Week, included a picnic and other family activities.
- **September 27, 2008.** In conjunction with New Jersey's Mitochondrial Disease Awareness Week, Jamming with Jamie was held at the Ramblewood Country Club in Mount Laurel, NJ. The event was held in honor of Jamieson Smith, a UMDF Youth Ambassador and board member of the Delaware Valley Chapter.

- **October 4, 2008.** The Communities Care Funday was held in Philadelphia, PA and raised \$2,600 for the UMDF. The event featured children's activities and rides as well as live entertainment, including the Journey tribute band "Separate Ways." The event also featured a performance from Ben Singleton. Thank you to the Donnelly family for your hard work!

- **October 4, 2008.** A bingo night was held at Central Bucks East High School in honor of Ryan Thomas. A big thanks to all those who participated and organized this fun event!

INDIANA CHAPTER

- **October 4, 2008.** The Indiana Mito Walk and Family Fun Day was held at Forest Park in Noblesville, IN. The event had a great turn out, the participants were able to raise more than \$23,000 for the UMDF. Thank you to the walk committee for your hard work!



Indiana Mito Walk and Family Fun Day

NEW ENGLAND CHAPTER

- **September 27, 2008.** The New England Chapter held its annual Mito Walk and Family Fun Day at the LEGO Campus in Enfield, CT. The day included a walk, LEGO building, family activities, and lots of fun! Thanks to Heidi Bailey for organizing this great event, which has raised more than \$20,000 to date!
- **November 10, 2008.** The New England Classics dinner event was held at The Publick House in Sturbridge, MA. The all-you-can-eat buffet included meatloaf, mashed potatoes, corned beef and cabbage, salad, and macaroni and cheese. A portion of the proceeds, totaling \$350, were donated to the UMDF in honor of Jordan Kalick. Thank you to The Publick House for your support!

OHIO CHAPTER

- **September 22, 2008.** A Guest Bartending night was held at the House of Blues Foundation Room in Cleveland, OH. The event, held during Mitochondrial Disease Awareness Week, included great food, drinks, lots of fun, and Monday Night Football. The tips that were collected from the guest bartenders, totaling more than \$900, were donated to the UMDF.

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

MITO FACTS

- Defects in the mitochondria cause the body to be unable to convert food into life sustaining energy.
- There are more than 40 known mitochondrial disorders.
- There are NO cures for mitochondrial diseases.

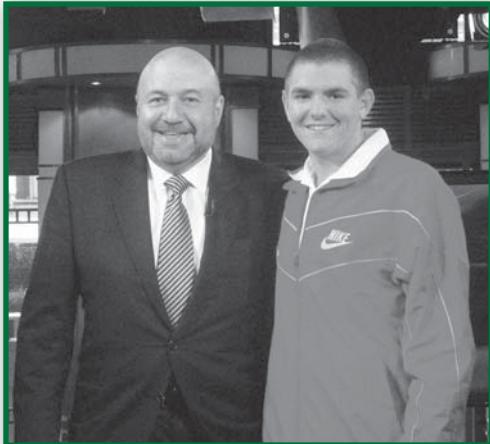


Volume 13
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I AM A PARALYMPIAN

A Day in the Life of Joe Wise

It is a beautiful autumn day in midtown Manhattan. Joe Wise and his mom, Marie, are sitting in a green room deep in the basement of the FOX NEWS building. He is laughing at the prospect of having to get a little bit of makeup on his face. "Just a little bit to take the shine off," encourages the makeup artist, as she quickly whisks Joe into a waiting chair. "The price of fame," shouts Marie from an adjoining room. Joe, 15, from Menlo Park, California, is about to have an opportunity to talk about mitochondrial disease on national television. He is about to be interviewed by Dr. Manny Alvarez, a FOX NEWS medical contributor, about his struggle with mitochondrial myopathy.



Dr. Manny Alvarez and Joe Wise at FOX NEWS studio

For Joe, this television interview caps an exciting couple of months. Less than a day before his interview in New York, Joe and the entire 2008 United States Paralympic Team were in the Oval Office accepting thanks and congratulations from President Bush. For his part, Joe bested his own record by 9 seconds in the Men's 400m Freestyle. Overall, he placed 5th. The U.S. Paralympic Swim Team secured 44 medals.

As Joe and his mom are relaxing in the green room, the door bursts open and into the room bounds Dr. Manny. Joe and Dr. Manny review what they will discuss during the interview and Dr. Manny promises him that they will get underway. "Now don't forget all of the information we want to share about mitochondrial disease," Marie reminds him. Within a few minutes and amid the whirl of robotic cameras, Joe is ushered onto the set and within seconds, the interview is underway.

He tells the national audience how difficult it was to get a diagnosis. He talks about his daily struggles. Most importantly, Joe Wise offers hope to thousands of

(continued on page P6)

LOVE FOR LIFE vs. LOVE OF THE GAME

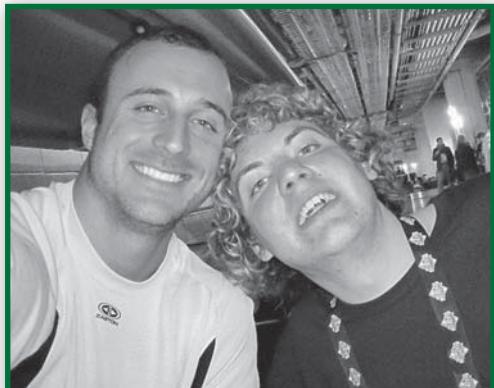
A Day in the Life of Jamieson Smith

It was a dream come true. The Philadelphia Phillies were in the World Series, something my Mom has been waiting 28 years for, and something I have never seen. Baseball is our favorite sport and the Phillies are our team, all year round.

It was a dream come true. Battling mitochondrial disease and trying to raise awareness has been my passion because I know just how blessed I am to be alive. When I learned that Tampa Bay outfielder, Rocco Baldelli, had mitochondrial disease, I began to root for Tampa Bay. Now Rocco was in the World Series too...and we had tickets to game five.

"Who are you going to root for?" I dreaded this question the entire World Series. I did not know how to answer it so that people could understand, especially other people who were not battling this disease, those people who think I look so "normal."

I was conflicted with whom I wanted to win the World Series because I am a diehard Phillies fan. I have sat through good games, bad games, rain delays and rowdy crowds. I so want my team to win it for themselves, the city, and the fans. However, I also have that deeper connection to Rocco.



Tampa Bay Ray's Rocco Baldelli and UMDF Youth Ambassador Jamie Smith

So I came up with a simple answer, I root for Rocco because I know how hard it is to make your legs move when they do not want to. I know how it feels to have your muscles so tired that you do not know if you can even walk another step. Most of all, because he is working so hard to do something he loves, which I believe is the key to living with mitochondrial disease. I want him to play well, to field well, and to hit a home run for all of us affected with mito.

I really was happy that I actually got to meet Rocco at game three of the World Series. He is a true hero

(continued on page P6)

FROM THE CHAIRMAN

Every two years, an exciting process takes place that helps the UMDF direct its future. The process is called Strategic Planning. The two-day meeting takes place in Pittsburgh and brings together board members, staff and Chapter presidents from around the country. We reviewed the current progress of UMDF and looked at what has worked well for the organization, as well as the areas in which we need to improve. The process allowed all of us to offer input as to how we can improve the UMDF and its programs in the years ahead. I thought you might be interested in the five main goals that were developed during our strategic planning session.

Mitochondrial Doctor Recruitment

Doctors Charles Hoppel and Amy Goldstein will spearhead this task force. The goal is for the UMDF to recruit three physicians to practice mitochondrial disease medicine by June 30, 2011. They will try to accomplish this goal by creating a Request for Application (RFA). By the end of 2010, they hope to have reviewed all applications, secured funding, and have mitochondrial medicine added to the curriculum at key medical schools. By June of 2011, they hope to have the three candidates who will begin their education in mitochondrial medicine.

Develop a Speakers Bureau

The UMDF Communications Department will lead this goal. We will identify medical and non-medical community members who can help educate the general public and medical community about mitochondrial disease. Materials such as visual aids and collateral will be created to accompany any scheduled talk. The goal is to identify and train potential members of the speakers bureau by August, 2009.



Physician Education

This goal will be developed by the UMDF's Scientific and Medical Advisory Board. The objective of this goal is for the SMAB to develop problem solving and educational tools for mitochondrial diseases and disorders for physicians across the nation. The goal is to develop these tools by June, 2010.

Membership

A task force has been formed that will review and make a recommendation to the board about UMDF membership levels. They will investigate several different types of membership levels and benefits. The ideas generated by this task force will be forwarded to the board of trustees for action by February, 2009.

Signature Event

I am sure you have heard about the Susan G. Komen Race for the Cure or similar events that are held on the same day in cities across the nation. The 'Race for the Cure' is an example of a 'signature event'. It was recommended at our strategic planning session that UMDF consider developing a singular, branded event that can be carried out in multiple cities and towns across the nation. The Executive Committee is investigating this issue and will report their findings and ideas by March, 2009.

As you can tell, we made tremendous progress over the two day session. The free flow of ideas from trustees, staff and chapter leaders was exceptional and informational. It is our hope that we can continue to work towards implementing these goals. It will not be easy given the economic situation we are all facing. I hope to be able to report to you on the progress we are making in the near future.

Energy to all,

A handwritten signature in black ink, appearing to read "W. Dan Wright".

W. Dan Wright, UMDF Chairman

SUPPORTING OUR CAUSE

LOOKING FOR SPONSORS

It's not too early to be thinking of the UMDF's annual symposium! The symposium will be held June 24-27, 2009 at the Sheraton Premiere Hotel in Tysons Corner, VA, just outside of Washington, D.C. In addition to the scientific and family sessions, the symposium will feature a 'Day on the Hill' for participants to meet with their representatives and senators in order to promote the need for increased funding of mitochondrial research.

The UMDF development team is soliciting sponsorships for this year's symposium. We remind our local Chapters, Mito Groups and Ambassadors to consider companies and foundations in your areas that might be able to support our symposium or help provide travel scholarships to the symposium for families. Grant writer Don Gielas is available to work with you to complete any application. Contact Don at don@umdf.org or toll free at 888-317-UMDF.

2009 ENTERTAINMENT BOOKS

The UMDF is offering the 2009 Entertainment Books for sale, and now is the time to buy! Save money on things you do every day, and support the

UMDF at the same time. Dine, shop, travel and SAVE!

Buy Entertainment Books for yourself or as gifts. Entertainment Books are available throughout the country in more than 150 editions. Be sure to pick the edition that is close to your home. Entertainment Books will be shipped directly to your house at no additional cost and the UMDF will receive a percentage of each book purchased!

To purchase an Entertainment Book and have the proceeds go to the UMDF, go to www.umdf.org/entertainmentbook.

IBM DONATES LAPTOP TO ATLANTA CHAPTER

IBM Corporation has presented the Atlanta chapter with an IBM Think Pad laptop computer through its Community Equipment Grant Program. The computer was given on behalf of IBM employee Joanna Erion to honor her hours of volunteer work. Ms. Erion chose the UMDF's Atlanta chapter as the beneficiary of the gift.

The UMDF expresses its thanks to IBM and Ms. Erion for their generosity. The computer will be used to help the chapter in its ongoing work to disseminate information to doctors and health professionals about mitochondrial disease and to raise funds for medical research.

VOLUNTEER SPOTLIGHT

UNITED MITOCHONDRIAL DISEASE FOUNDATION

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Linda Cooper wakes each morning to her 13 year old son, Chad, saying "Where da fun?" with a huge smile on his face and a giant hug to follow. He is not looking for anything in particular, just fun, any fun, he's ready! Chad has a mitochondrial disease, Creatine Transport Deficiency, which causes him to have speech, language and developmental delays.



Linda, Chad and Bob Cooper with a \$23,000 check for the UMDF.

Chad received his diagnosis in 1998 when he was two and a half years old, and that is when Linda first contacted the UMDF. She was looking for guidance and advice; what she found was the love and support of the Southern California support group. "I met some wonderful families, the cutest little babies and children, all dealing with this unknown disease," Linda says recalling her first support group meeting. "My heart was heavy and sad for all of us." It was at that moment that Linda realized the only way she knew how to deal with Chad's illness was to get involved and to help in any way she could. She attended every support group meeting and would do simple things like bringing donuts, making coffee, scheduling speakers or just lending an ear to listen.

In a very short time, the Southern California support group was ready for growth. Linda, along with other volunteers in her area, helped to launch the UMDF Southern California Chapter. In the first five years of the Chapter's existence, Linda held the positions of Secretary, Vice President and President, as well as helping with 10 UMDF fundraisers and countless awareness activities.

Linda's most recent volunteer activity was an idea suggested by her husband, Bob. The UMDF was chosen as one of the beneficiaries

of the world renowned LOVE RIDE. The LOVE RIDE is the largest one-day motorcycle fundraiser in the country. When Linda and Bob heard that UMDF Board of Trustee Sharon Shaw and UMDF CEO Chuck Mohan were coming to Southern California to represent UMDF at the event, the Coopers brainstormed until they developed an idea that would become a fund-and-awareness-raiser. That is when the Pre-Party LOVE RIDE was suggested. The event quickly went from a suggestion to a full-fledged fundraiser, with Smith-Cooper International as the event sponsor.

In a short amount of time, Linda was able to collect enough donated items for 16 raffle baskets, had the barbecue lunch donated, and had six Harley Davidson motorcycles on site



Chuck, Bob, Chad, Linda and Sharon at the Pre-Party LOVE RIDE Fundraiser

for photos and rides. The event attracted 100 people and raised an outstanding \$23,000 for mitochondrial disease research! "Bob and I were honored to host the Pre-Party LOVE RIDE Fundraiser," Linda said, "it was a great way to celebrate the UMDF being added as a LOVE RIDE charity."

As a reward for Linda's hard work, she was able to attend the LOVE RIDE the next day with Sharon and Chuck. "It was a wonderful experience," Linda said of the LOVE RIDE, "How much fun can you have in one weekend?" Linda and Bob have already begun to think about their Pre-Party LOVE RIDE Fundraiser for 2009!



Youth Ambassador Brittany Wilkinson featured on 10 buses in Fresno and Clovis, CA.

IF YOU KNOW OF A VOLUNTEER IN YOUR AREA THAT YOU WOULD LIKE TO SEE FEATURED IN OUR NEWSLETTER, CONTACT THE UMDF AT NEWS@UMDF.ORG.

DONORS - THANK YOU!

APPRECIATING THOSE WHO HAVE HELPED ALONG THE WAY!

While we would like to list ALL of our donors individually, please understand that it would be very difficult to do so with 7,557 donors of \$1-\$99 (*THANK YOU!*), 1,826 donors of \$100-\$249 (*THANK YOU!*) and 541 donors of \$250-\$499 (*THANK YOU!*).

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

The following acknowledgements include donations of \$500 or more entered into the system between January 1, 2008, and June 30, 2008. If your name or company's name is incorrect or not listed, please contact info@umdf.org.

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DAY IN THE LIFE (con't)

I AM A PARALYMPIAN

teenagers and adults who face a similar struggle with mitochondrial disease.

To the naked eye, Joe looks like a normal high school kid. There is no outward sign that anything is wrong. He received his diagnosis at the age of nine. After playing on a youth football team, Joe started to have muscular issues and fatigue. His parents initially thought the symptoms were the result of a football injury. After a muscle biopsy, doctors determined that Joe was suffering from a mitochondrial myopathy. Despite initially hating swimming, he credits his mom with making him stick with the sport that has become a family tradition. Joe's brother Jack, 13, is also a swimmer, and he too is affected with a mitochondrial disorder.



Joe swimming in the 2008 Paralympics in Beijing, China

"My life as an athlete is busy enough. Add in battling mitochondrial disease, and it takes on a whole new dimension," Joe says. On days that he has swim practice, he gets up at 4:40 am and has a Power Bar. Practice begins at 5:15 am. There are days that he has double swim practices. "I swim until 7:00 am, then I eat breakfast in the car and it is off to school. My school schedule has been put together to accommodate my fatigue and need for time on my Bipap ventilator."

Joe's school schedule is set up so that he has three classes in a room with students. Two classes are structured for teachers to meet him in a separate room so that he is taught one-on-one. He also has two classes in which he participates from home. "Sometimes during school, I hang out in the nurse's office and put an hour on my ventilator. After school I try to get as much homework done as I can before I go back to another three-hour swim practice." He does not get special treatment in the pool. "My swim coach expects the same thing out of me as he does from my teammates." Five nights a week, Joe eats dinner in the car on the way home from practice. Once at home, he finishes up homework, takes a hot bath and is in bed by nine o'clock. It would be considered a tough schedule for a healthy person, let alone a person with a mitochondrial disease. "There are days that I am very tired. But I keep swimming because I believe it keeps me going." There is no stopping his momentum. Joe has already outlined his goals for 2009, "I am going to try to make my high school championship swim meet in three events. I want to try and break a few Paralympic American records and most importantly get good grades."

LOVE FOR LIFE vs. LOVE OF THE GAME

and someone that I look up to because he is trying to live every day to the fullest and enjoy it. The funniest thing about Rocco and me is that we have similar stories; we both try to live positively with this disease because we realize how blessed we are as others with mito are more severely affected. He spent months trying to find a diagnosis, and I was the same way. We both have struggled with adversity, take lots of pills every day and pace ourselves. My favorite moment was not when he gave me the bat, like most would expect. My favorite moment was when we just went off by ourselves, two people talking about the things they have in common and how it affects them.

So it all came down to game five of the World Series. On both nights of the rain delayed game we were dressed all in Phillies red with "Root for Rocco" buttons on our coats and a sign for the railing. The first night was pouring down rain and Rocco was in the line up. By the end of the night, the sign was ruined, the game tied and thankfully, Rocco would have two days to rest his body for the remainder of the game.



Jamie with his "ROOT FOR ROCCO" sign

On the second night, we went to hang the new sign and one of the ushers said that I could not put my sign up because it would bother the people in front of us. With that, the people sitting in front not only helped my parents put the sign up, but explained that I had the same disease as Rocco, and didn't he read the Philadelphia Inquirer! When Rocco hit the tying homerun, I was so happy that I felt like I was on a sugar rush. My mom and a friend cried, and the guy in front of me gave us a high five and said that he can hit only one, but no more.

It was paradoxical because I wanted the Phillies to win, but I also felt conflicted because of my illness and caring for Rocco; I wanted both and knew that was impossible.

So fate took it out of my hands, Joe Maddon substituted Eric Heinke for Rocco and Brad Lidge struck him out. The Phillies won the World Series; Rocco won the world's attention in the fight for mitochondrial disease, and it was a dream come true for many.

Note from the Editor: Jamie has been a driving force in the state of New Jersey in advocating for the UMDF and mitochondrial disease research. He has recently sent an email to his friends and family with his most recent goal. Jamie will be celebrating his 18th birthday in December and was diagnosed 10 years ago, so he would like to see 1,800 letters sent to elected officials by April 1, 2009! Good Luck, Jamie! We know you will exceed your goal!

IMPORTANT NOTICE

IMPORTANT – THIS COULD BE YOUR LAST PRINTED NEWSLETTER

For the past 12 years, the UMDF's Mitochondrial News has been an important informational tool for our members and for those who support our organization. Four times a year, we deliver to your mailbox the very latest medical information, information for affected adults and fundraising successes as well as recognition to those who have donated over \$500 to help us fund the research to find a cure. We remain committed to our mission of continuing to provide you with that very important information. But, given turbulence in the economy, the UMDF must do everything possible to reduce expenses in order to keep our focus on funding the research that may lead to a cure. That is why we are asking you to consider helping us reduce expenses by having your newsletter e-mailed directly to your inbox instead of your mailbox. If everyone agreed to have their newsletter e-mailed, the UMDF could save thousands of dollars on paper and postage. In fact, enough money could be saved to fund 1/3 of a typical research grant!

If the UMDF has your e-mail address in our database, we will start e-mailing your newsletter to you starting with the first

issue of 2009. (Note: To ensure your newsletter does not go to your spam box, please add 'news@umdf.org' to your e-mail contact list.) The newsletter will also be available to you on the UMDF website.

If you have changed your e-mail address, do not think we have your current e-mail address, or want the newsletter in printed form because you do not have e-mail access, then we need to hear from you by January 31, 2009. Below you will find a form called "My Mitochondrial News and Partners in Progress." This form will help us to make sure that each member and donor receives their copy of the Mitochondrial News and Partners in Progress. Simply fill out the form and send it back in the enclosed envelope, fax to 412-793-6477, e-mail news@umdf.org with your information, or call 888-317-UMDF. We will send hard copies out only to those who do not have internet access and have contacted us with their preferences.

To ensure that you receive your Spring Issue, you must contact the UMDF.

MY MITOCHONDRIAL NEWS AND PARTNERS IN PROGRESS

Name _____

Address _____

Phone Number _____

E-mail Address _____

_____ UMDF should use the following e-mail address to send my newsletter electronically:

_____ I do not have access to e-mail and would like to continue receiving a printed copy by mail.

Please complete and return to:

United Mitochondrial Disease Foundation
Attn: Newsletter
8085 Saltsburg Road, Suite 201
Pittsburgh, PA 15239

Fax to: 412-793-6477 OR e-mail to: news@umdf.org, please put "UMDF Newsletter" in the subject.

UPCOMING EVENTS

ATLANTA CHAPTER

- **January 11, 2009.** Brian and Lorie Gassel are running in the Disney Marathon at Walt Disney World in Orlando, FL in honor of their daughter Morgan. If you would like to learn more or donate to Marathon for Megan, please visit www.umdf.org/marathonformegan.
- **March 28, 2009.** The second annual All Aboard for a Cure Atlanta 1 Mile Walk and Family Fun Day will be held at Thrasher Park in historic Norcross, GA. Activities include bounce houses, a magician, a DJ, games and prizes for kids, a craft area and a cookie decorating booth. The Music Class will also be on hand to do a live audience participation performance. Please visit www.umdf.org/atlantawalk for more information.

CALIFORNIA CHAPTER

- **March 7, 2009.** The fourth annual dinner and silent auction honoring Brittany Wilkinson will be held at Break the Barriers in Fresno, CA. Proceeds will be donated to the UMDF through the Brittany Wilkinson Research Fund. For more information, please visit www.brittanywilkinson.org.

CAROLINA FOOTHILLS CHAPTER

- **February 21, 2009.** The Hope.Energy. Life. Golf Tournament and Family Fun Day in honor of Olivia Custer will be held at the Island West Golf Course in Bluffton, SC. In addition to golf, the event will also include

live entertainment, a raffle, a silent auction, as well as a Kid Zone area complete with bounce houses, a clown, magicians, cotton candy, tattoos, and balloon animals. For more information, visit www.umdf.org.

- **April 24-25, 2009.** The fourth annual Caroline's on My Mind Weekend will once again feature a golf tournament, a 5K Family Walk/Run and a BBQ/Band Party on Saturday evening. All proceeds will benefit the UMDF through the Caroline Virginia Pulliam Mitochondrial Disease Fund. For more information, please visit www.umdf.org.

HOUSTON CHAPTER

- **February 7, 2009.** The annual Christopher's Heart Fun Run will take place at Sam Houston Park in Houston, TX. This run/walk event is held in memory of Christopher Schindler. For more information, please visit www.christophersheart.com.

OHIO CHAPTER

- **April, 2009.** The fifth annual Guest Bartender Night will be held at the 82nd Street Grill & Pub in North Royalton, OH. In the past four years, this event, organized by John Kobunski, has raised more than \$15,000 for the UMDF.

SOUTHWEST LOUISIANA MITO GROUP

- **March 28, 2009.** Jude's Fais Do-Do for Mito will be held at the American Legion in Sulphur, LA. The event includes dinner,

dancing, a silent auction and raffles. We are honored to have Mary Kay Koenig, MD as the honorary chair for this event. Please visit www.judesmitojourney.com for more information.

ST. LOUIS MITO GROUP

- **April 11, 2009.** The sixth annual Mito-What? Family Fun Day will be held at the Shrine of Our Lady of the Snows in Belleville, IL. Please contact Marsha at marshamarshamarshah@charter.net for more information, or visit the event web page at www.umdf.org/stlouisrace.

AROUND THE COUNTRY

- **January 2009.** St. Bernadette's School in Monroeville, PA will once again be participating in the Coins for a Cure campaign in memory of Gina Mohan.
- **January 26 - February 11, 2009.** The National Honor Society at Minnechaug Regional High School in Wilbraham, MA will have their annual basket raffle to benefit the UMDF.
- **March 20-21, 2009.** Preston's March for Energy will be held in Virginia Beach, VA. The event is held in conjunction with the Shamrock Sportsfest. In 2007, over \$25,000 was raised by the Shamrock Sportsfest Community. The proceeds from this year's event will be donated to the UMDF in honor of Preston Buenaga.



UNITED
MITOCHONDRIAL
DISEASE
FOUNDATION.
HOPE. ENERGY. LIFE.

UMDF MISSION

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

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OTHER NOTABLE EVENTS

- May 2, 2008.** The third annual Josie Mazzo Children's Charities Golf Tournament was held at Greystone Golf Club in Dickson, TN. The event raised over \$47,000, and the UMDF received a portion of the proceeds.
- September 13, 2008.** The Sip and Savor the Moment for a Cure was held in honor of Hannah Pallas. The event took place at La Casa Narcisi Winery in Gibsonia, PA. The event raised more than \$18,000 for the UMDF!



Sip and Savor the Moment for a Cure

- September 20, 2008.** The Savannah's Hope Walk was held in Altoona, IA. The event raised \$550 in memory of Savannah Bagby. Thank you to the Bagby Family for your hard work and dedication to the UMDF.

GIFTS FROM THE HEART

- In lieu of gifts, newlyweds Glenn and Amy Green asked their wedding guests to make contributions to the UMDF. In total, \$375 was donated in honor of Sophie Edwards who was one of the bridesmaids at the August 15, 2008 wedding.
- The Class of 2009 of Shawnee High School in Medford, New Jersey donated \$3,189 to the UMDF in honor of Jamie Smith. Several of his friends attended the Jamming for Jamie event held in his honor.
- The students in Ellington, CT participated in the Windermere School Mileage Club Walk during recess on September 24, 2008 in memory of Matthew Bailey. The students collected money for each lap they completed and donated the funds to the New England Chapter's Mito Walk and Family Fun Day event held in September. A special thank you to all of the students who participated!

- September 20, 2008.** The Mito 5K Walk/Run was held at Thomas Lake Park in Egan, MN. The event has raised more than \$11,000 to date to benefit the UMDF. Thank you to all who helped make the event a success!
- September 20, 2008.** Kicking off the Mitochondrial Disease Awareness Week activities, the Idaho Mito Group hosted an Energy Bowl-A-Thon held at Meridian Bowling Lanes in Boise, ID. All of the bowlers enjoyed a day of bowling fun and raised \$2,000 for the UMDF!
- September 23, 2008.** Instead of charging patients for services at the Spring Hill office of Campbell Station Chiropractic, patients were asked to make a donation to the UMDF. Not only did the event raise awareness for mitochondrial disease, but it also raised \$2,320 in honor of Natasha Milani.
- September 26, 2008.** The Elena's Hope Dinner was held in Kimberly, WI in honor of Elena Welhouse. Proceeds from the event, totaling more than \$6,000 to date, benefited the Elena's Hope Research Fund with the UMDF.
- October 2, 2008.** Friends and classmates of Daniel Heyman enjoyed some sweet treats and supported the UMDF.



Windermere Elementary School Students

- The members of Delta Gamma sorority at the University of Miami held their annual walk/run in honor of Bobby Arnold on September 27, 2008. The event was held on the scenic campus of the University of Miami in Miami, FL. Thank you to the sisters of Delta Gamma for your continued support of the UMDF!

Maggie Moo's Ice Cream and Treatery set aside a large portion of their sales to promote research and awareness in honor of Daniel. An outstanding \$802.20 was donated to the UMDF!

- October 11, 2008.** The second annual Kure for Kat was held at South Lakes Park in Denton, TX, in honor of Katherine Dickens. The event was a huge success, raising \$7,200 for the Katherine Dickens UMDF Research Fund.



The Dickens' Family at Kure for Kat

- October 16, 2008.** The annual Chris Schindler Memorial Celebration was held at The Briscoe Manor in Richmond, TX. More than \$500 to date was donated to the UMDF in memory of Chris Schindler.

- A poetry reading was held on October 29, 2008 at the Cornerstone Restaurant in Genesee Depot, WI. The event was held in memory of Sam and Zach Juhlmann. Thank you Mary Jo Balistreri for organizing this event.
- Southwest Elementary School in Danville, IL participated in Coins for a Cure during Mitochondrial Disease Awareness Week and raised \$651.12 in honor of Christopher Adkins. A story also ran in the Commercial-News, which Stacy Lomax hopes will help raise awareness for mitochondrial disease. Thank you Stacy for all of your hard work!
- Free-will donations at Krave Salon and Allure Salon were accepted for Elena's Hope Cut-a-Thon in honor of Elena Welhouse. The donations benefited the UMDF through the Elena's Hope Research Fund.

ADVOCACY

Capitol Hill Visits

The United Mitochondrial Disease Foundation is planning to hold our first ever 'Day on the Hill' on June 25, 2009. The Day on the Hill is being held in conjunction with our annual symposium to allow you, your family and friends to advocate for federal funding of mitochondrial disease research. Attendees will have the opportunity to meet with their members of the House of Representatives and United States Senators to tell their stories.

The UMDF has created an attendance survey for those planning on coming to Washington D.C. for the Day on the Hill. The purpose of the survey is for us to have an idea how many people are planning to attend, any specific needs that need to be addressed and what type of activities could be offered. To take the survey, visit www.umdf.org/symposium and click on 'Day on the Hill Survey'.

Once you have taken the survey, the UMDF will be in touch with you to set up your appointment with your elected officials. In order to set up your meeting, we need to know months in advance if you are planning to come to Washington, D.C. This is not our requirement, but the rules many Congressional and Senatorial offices impose.

UMDF Action Center

Using the UMDF Action Center is simple. In fact, we have created a tutorial that you can watch on your computer that will show you how to use the Action Center. You can view the tutorial by going to the main page at www.umdf.org and clicking on the link that says 'Learn how to use the Action Center by viewing this tutorial.'

The Action Center is the most important tool we have in helping you in your advocating efforts. Signing up is free, and it does not obligate you, your family members or friends to join the UMDF. Once you are signed up and select a username and password, you will be able to send letters to your U.S. House member and your two U.S. Senators. Click on 'create and send a letter to your elected official,' and a prefilled letter will appear. You will be given an option to email, mail or fax a letter. Choose one that works for you; however, email is the best way to send the letter.

There are items in the letter that will need to be personalized by you. *YOU MUST READ THROUGH THE LETTER AND ADD THOSE PERSONAL DETAILS.* For example, in the body of the letter, you will see [YOUR STATE]; delete that, and add the state in which you live. You will also see [BRIEFLY TELL YOUR PERSONAL STORY]; again, you will want to delete that and provide details about how mitochondrial disease affects you, your loved one or friend. Scroll down through the letter, and you will see a sentence that says, "As a concerned member of the community and as an [AFFECTED ADULT, THE PARENT/GRAND PARENT OF A CHILD]." Delete that, and add information if you are an affected adult, parent of an affected child or grandparent of an affected child. Finally, the letter calls for you to write in your state name again. The Letter to the Editor has the same bracketing information that will need to be changed by you.

You may also delete the entire contents of the pre-filled letter and write your own. Once you are done with either the prefilled letter or your own draft, click 'Preview,' and you can see your letter and which elected officials or newspapers are designated to receive it. If the letter meets your approval, click 'Send,' and it will either email it to the recipient or print you a copy for regular mail or fax. It's that simple.

What if I will have a new U.S. House or Senate Member?

Many of you will have new U.S. House and Senate members in January. For example, with the election of Barack Obama as President of the United

States, Illinois residents will have a new U.S. Senator. We realize that there will be incoming members of the House and Senate, and we will have a new letter ready to be used in early January. The UMDF will let you know when these letters are ready.

I have sent my letters - What should I do next?

According to our advocacy plan for 2009, all members should have sent a letter to their elected official and a letter to the editor. We are trying to reach 1,000 letters by April 1, 2009. As of our newsletter deadline, we have over 500 people who have sent letters. If you've not advocated, you need to do so today. If you have sent a letter, it is now time for you to locate the phone number and address in your local area for your U.S. Congressman and U.S. Senators and make an appointment for a visit to meet them in person. Planning for your visit is simple, and the UMDF has put together a few pointers to help you in our advocacy toolkit. Visit www.umdf.org/advocacytoolkit or contact the UMDF to receive a copy.

You will want to read the following sections in the Advocacy Toolkit:

- Mitochondrial Disease Fact Sheet (you can print this and leave it with your representative or his/her staff member)
- Links to Other Diseases (again, this can be printed and left behind)
- Talking Points (messages you need to use during your meeting)
- Working With Elected Officials (gives you the basics on writing and meeting with your elected officials)

Why is this important?

We want to make a very strong showing on Capitol Hill on June 25, 2009. We need elected officials to be introduced to mitochondrial disease, the links to other diseases, and the importance of allocating more federal dollars that could fund the research for a cure. Our Day on the Hill in June will not be a one time visit, we plan to start the dialogue about mitochondrial diseases on Capitol Hill. We will be back, each time making increasing progress – but we need to start now.

SAVE THE DATE

MITOCHONDRIAL MEDICINE

2009:

CAPITOL HILL

SHERATON PREMIERE AT TYSONS CORNER -
WASHINGTON, DC AREA

SCIENTIFIC MEETINGS: JUNE 24-27, 2009

CAPITOL HILL VISITS: JUNE 25, 2009

FAMILY MEETINGS: JUNE 26-27, 2009

MEET LORA - By: Rose Mary Wasielewski

My daughter Lora was diagnosed with mitochondrial myopathy when she was 20 years old. She was a pharmacy student at the time and brought a disturbing symptom to our attention. She told us that when she missed a meal at school, her muscles ached all over and then she felt weak for about two weeks afterward. Our family doctor sent us to Rush University Medical Center, and that was where we heard the term "mitochondrial myopathy" for the first time.

As a nurse for almost 30 years at the time, I had never heard the term before. I did a literature search, and after reading the papers on mitochondrial diseases, my heart sank. My beautiful "baby" daughter was being given a challenge far worse than anything that most young adults would encounter. The future was uncertain – we didn't know how this strange disease would play out in Lora.

Yet Lora took the diagnosis in stride and was determined to finish pharmacy school. She even finished as an accelerated student.

As we went through testing and visits with various specialists, Lora's childhood challenges began to make more sense. Lora was my third daughter and developed normally as an infant. There was always a pack of kids at our house, and Lora was able to keep up with the pack. She rode a bike, played with Big Wheels and seemed to do what all the other kids were doing.

At age five, she played soccer but always seemed to be at the back of the pack of kids running. She started softball at about age seven and was a star pitcher. But as the other girls got older and stronger, Lora wasn't able to keep up with them. Lora ran bases as if in slow motion and didn't seem to have the reflexes to catch a line drive. I feared for her safety and her psyche, because the girls started to make fun of her when she ran, and she dropped out of softball. When I asked the pediatrician why she couldn't run, he said that she had knock

knee. Later, when I brought up her shortness of breath, he treated her for exercise-induced asthma, but the inhaler didn't seem to help. We all learned to accommodate for Lora – thinking she was just the "lazy one."

When Lora entered high school, she followed two older sisters who were star athletes. She knew that she couldn't play any sports like her sisters did. She could barely make it through gym classes. Thinking that she was a total failure, her studies suffered in her freshman year. To boost her self esteem, her sister got her a job at a drug store. It was there that she discovered a fascination with medicine

and prescriptions and made a complete turn around in her studies.

Lora now works full time as a retail pharmacist. She is 30 years old, and every day is a challenge. She awakens every morning in pain from the lactic acid in

her muscles. She feels tired in spite of a full night's sleep. Stairs are next to impossible because her muscles in her thighs are extremely weak. She can't take a walk around the block or walk her dog – she can't even walk 200 feet without getting exhausted. Opening a jar is impossible, and even bottled water is sometimes a challenge. She has a handicap placard for her car and uses it most of the time.

Yet Lora is my hero. She never misses a day of work even when she has a "brown out" and is feeling especially weak. She loves her work and everyone loves her. She goes out of her way to help her patients. In spite of her pain, weakness and disability, she is focused and



Adult Advisory Council Team (AACT)

Sharon Shaw, AACT Chair, Arizona

Gail Wehling, AACT Co-Chair, Illinois

Bob Brief, New York

Marge Calabrese, Arizona

Linda Cooper, California

Rev. David Hamm, Maryland

Pam Johnson, MD, Kansas City

Cynthia Rosen, New Mexico

Catherine Stefanavage, Georgia

Dan Stout, Kentucky

Gregory Yellen, Maryland

Medical Advisors:

Bruce H. Cohen, MD

Amy Goldstein, MD

AACT MISSION

To ensure equal representation and service of the affected adult community to the affected pediatric community -- and to better represent, serve and assist adults with mitochondrial disease.

committed to helping others and doing what she loves most. She is kind, caring and gentle – a beautiful flower in a fragile and weakened vase.

I look at her with pride but also with lots of pain. I feel helpless watching her get weaker as the months and years go by. I promised that I would take her to the best doctors no matter what the cost – but even the best have no cure. I pray every day for a miracle because I know that it will take a miracle to cure her. I only hope that the miracle or cure happens before my beautiful little flower fades.

CALLING ALL ADULT MITOCHONDRIAL PATIENTS!

Mitochondrial News Needs YOU! Please consider submitting an article on your experiences with a specific topic that would be of interest to other adults with mitochondrial disease. If you want to contribute, please contact UMDF at news@umdf.org or 888-317-UMDF. We look forward to hearing from you!

HEARTSTRINGS AWARD

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 the UMDF, enabling the 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 criteria of age, time invested, talents demonstrated, effectiveness, and generosity. For nominees who implement fundraising projects, the judges will consider the uniqueness and creativity of the project, communication, 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. The 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 donating to the 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, letters sent with the donation, and so forth).

Please type your essay and attach it to the nomination form.

Mail the nomination by April 24, 2009 to:

United Mitochondrial Disease Foundation
Attn: Heartstrings Award
8085 Saltsburg Road, Suite 201
Pittsburgh, PA 15239

Or fax to 412-793-6477 or e-mail the nomination by April 24, 2009 to info@umdf.org.

Person Nominating

Name: _____

Address: _____

Phone: _____

Email: _____

Nominee for the Award

Name: _____

Address: _____

Phone: _____

Diagnosis (if known): _____

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

United Mitochondrial Disease Foundation LEAP Award

Living, Encouraging, Achieving & Persisting

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

Eligibility: Age 14 years or older.

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

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

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

Please type your essay and attach it to the nomination form.

Mail the nomination by April 24, 2009 to:

United Mitochondrial Disease Foundation
 Attn: LEAP Award
 8085 Saltsburg Road, Suite 201
 Pittsburgh, PA 15239

Or fax to 412-793-6477 or e-mail the nomination by April 24, 2009 to info@umdf.org.

Person Nominating

Name: _____

Address: _____

Phone: _____

Email: _____

Nominee for the Award

Name: _____

Address: _____

Phone: _____

Diagnosis (if known): _____

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

ANNOUNCEMENTS

MITOCHONDRIAL NEWS AND PARTNERS IN PROGRESS

The next issue of the Mitochondrial News and Partners in Progress, Volume 14 Issue 1, will be going virtual! What does this mean to you? It means that your copy of the Mitochondrial News could come to your e-mail box instead of your mail box! Please see page P7 of the 'Partners in Progress' for more details!

MITOCHONDRIAL DISEASE AWARENESS WEEK

September 21-27, 2008 was Mitochondrial Disease Awareness Week! This designation has been adopted in 19 states nationwide, five of which have a permanent resolution! UMDF Chapters, Mito Groups, Ambassadors and members held awareness and fundraising events across the country during the amazing week of awareness. The following states have designated the third week of September as Mitochondrial Disease Awareness Week!

Permanent Designation

Alabama
Georgia
Michigan
New Jersey
Wisconsin

One Time Designation in 2008

California	Mississippi
Connecticut	Ohio
Indiana	Pennsylvania
Iowa	Tennessee
Kansas	Texas
Louisiana	Washington
Massachusetts	West Virginia

**SUBMISSION DEADLINE FOR VOLUME 14 ISSUE 1 IS
JANUARY 31, 2009!**



IN THIS ISSUE:

A "Probable" Diagnosis
Read page 1!

Problems explaining extreme fatigue to teachers?
See page 3!

What's new in my area?
Check out pages 4-7!

Heartstrings and LEAP Award Nomination Forms
Find out more on pages 10-11!

UMDF MERCHANDISE

UMDF merchandise is a great way to raise awareness and to support the UMDF and all those affected with mitochondrial diseases. The UMDF's new logoshop opened up over the summer! Check out all the new merchandise and old favorites available at <http://umdf.promoshop.com>.

NEW UMDF STAFF MEMBER

The UMDF would like to introduce the newest member of the Development Department, Kylie Dunmire. Kylie is a 2005 graduate of Allegheny College and received her Masters in Sport Management from Slippery Rock University. Kylie will be taking charge of the Coins for a Cure, Tea for Mito, and Energy for Life campaigns, and assisting those doing Mitochondrial Disease Awareness Week activities. Please join us in welcoming Kylie to the UMDF!

The following Grand Rounds are scheduled for 2009:

- January 27, 2009 in Lexington, Kentucky
- February 3, 2009 in Phoenix, Arizona
- March 3, 2009 in Nashville, Tennessee
- March 6, 2009 in Milwaukee, Wisconsin
- April 1-2, 2009 in Memphis, Tennessee

For more information on the Grand Rounds program, contact Janet at 888-317-UMDF, email janet@umdf.org or visit www.umdf.org

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