

## UMDF UNVEILS MITOCHONDRIAL MEDICINE 2011: CHICAGO

The United Mitochondrial Disease Foundation (UMDF) is ready to launch, *Mitochondrial Medicine 2011: Chicago*. The annual, international symposium begins on June 15-16, 2011 for the scientific and medical community. It will continue on June 17-18, 2011 for the scientific and medical community, as well as patients and families. This is the 13th year for the UMDf symposium, which attracts hundreds of medical and scientific experts from around the world. It will also be the first time that the UMDf is offering something different --- a session that will be attended by both the scientific community and patients/families.

Medical and Scientific experts have been working for the past year to create the Friday afternoon session and it will deal specifically with clinical trials. "The idea to bring together our scientific community and our patient and family members came from Dr. Peter Stacpoole," said Charles A. Mohan, Jr., UMDf CEO and Executive Director. "Dr. Stacpoole has conducted a number of clinical trials from his base at the University of Florida in Gainesville. Dr. Stacpoole thought it would be a great educational opportunity for our members to hear about the process, as well as current trials underway. We are delighted that this session will happen in Chicago," Mohan said.

The sessions will begin with an overview of working with the Federal Drug Administration (FDA) in developing new therapies. Other topics will include the development of new therapies, translating discoveries to patients, an explanation of the North American Mitochondrial Disease Consortium (NAMDC), a look at anecdotal studies to randomized clinical trials, the makings of a good, randomized

clinical trial, a family perspective on clinical trials, and an overview on how the entire mitochondrial disease community can join together to advance clinical trials. "The final session will be a panel discussion that will provide information that will be very important to our patient community and those interested in attending this session in Chicago," Mohan added.

Saturday's symposium topics will include sessions specifically designed for adults, young adults (18-35), and a separate session for the affected teenage community. Topics this year for the Saturday session will include, "Ask the Mito Doc" and sessions on speech and swallowing issues, exercise, dealing with loss, and Munchausen Syndrome by Proxy, otherwise known as Medical Child Abuse.

During the symposium, the UMDf will award \$500,000 in research grants for projects selected by the Grant Review Committee. The grant awards will be presented at the UMDf Banquet on Friday evening. The UMDf will also announce the 2011 winners of the LEAP and Heartstrings Awards. The LEAP Award will be given to one of the numerous nominees who live positively with mitochondrial disease through accomplishments and volunteer service. The Heartstrings Award will be presented to a nominee who is 18 years of age and under who has demonstrated talent, effectiveness, and generosity in raising funds that enable the UMDf to continue its mission. The UMDf will also select from a pool of nominees the 2011 winner of the Stanley A. Davis Leadership Award, which is given to individuals who exemplify the UMDf mission and

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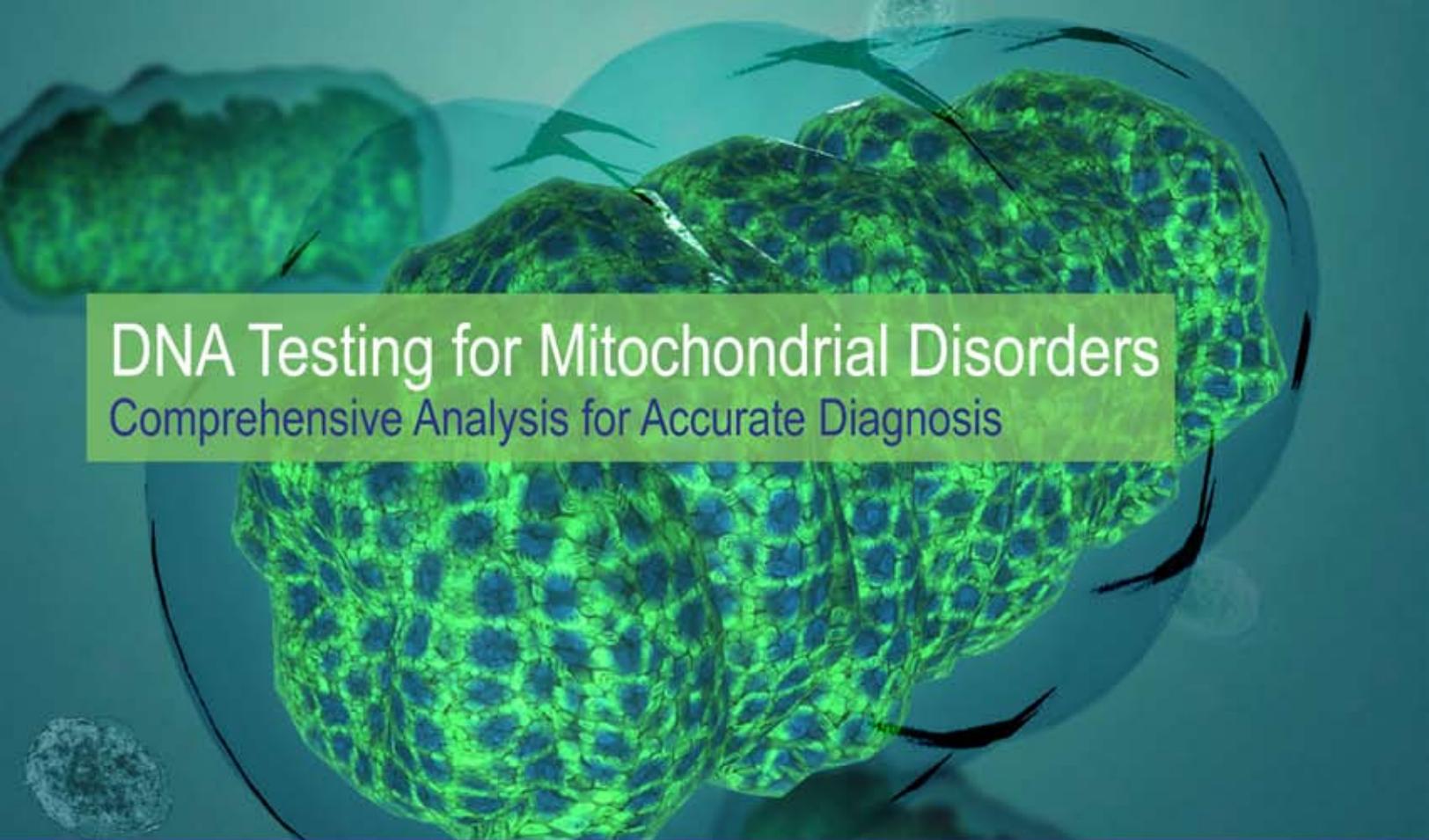
*Jack Arnold in San Diego, CA during his "Pedal from the Pacific" bike tour. See page 10 for details.*



*(Left) Branden Smith and Mighty Mito at the Energy for Life Walkathon: St. Louis. (Above) David Porter with Georgia Tech Cheerleaders at the Energy for Life All Aboard for a Cure Walkathon. See page 12 for more Energy for Life Walkathons.*



**Volume 16, Issue 2**  
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One of the tools that will help move us closer to a cure for mitochondrial disease is clinical trials. Without the participation and support of the affected community we will never know if current, promising ideas will lead to a breakthrough in effective treatments and a cure. This issue is so important, that we have dedicated an entire session at our symposium to clinical trials. We want our membership to have the facts about clinical trials, how they are put together, and how they lead to drug development.



fund \$500,000 in research. The projects selected are chosen by the Grant Review Committee by using the same criteria used to award grants at the National Institutes of Health (NIH). We had 119 scientists submit 'Letters of Intent' this year. The Grant Review Committee invited 31 scientists to submit a full proposal for consideration. We will announce, at the symposium, the five grants that have been selected for an award this year. The 2011 awards, added to the nearly 80 projects funded since we began the program, represent nearly \$8 million in research funded to date. None of this could have been done without your support, your fundraising efforts, your participation in our advocacy efforts, and your willingness to spread awareness. Thank you for your continued support of our mission!

Over the next few months, you will be hearing more and more about clinical trials that are currently underway or will be underway soon. As an affected individual or as the parent of an affected child, you must have the best information to make an intelligent and important decision about participation. As we move forward, the UMDF will continue to provide you information about current and new clinical trials and how you may participate.

Speaking of research, I write this column in advance of Mitochondrial Medicine 2011: Chicago. As you well know, the world of mitochondrial medicine converges with patients and families in an exchange of information and ideas. The annual symposium is a great way to end our fiscal year because it is at our annual banquet that we display the fruits of our hard work as volunteers in the announcement of our 'Research Grant Recipients. This year, UMDF will

Energy to All,

W. Dan Wright, UMDF Chairman

**Thank You  
UMDF Members!**

**We appreciate you  
and your support!**

## UMDF UNVEILS MITOCHONDRIAL MEDICINE 2011: CHICAGO

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goals. Those who receive these awards will be announced on the UMDF website and in our fall newsletter.

Mitochondrial Medicine 2011: Chicago has also secured two large scale donations. Both Akron Children's Hospital and Tischcon have each provided \$15,000 in under writing for our annual symposium. The Burroughs Wellcome Fund has also provided travel scholarships to

qualifying researchers who are new to the field of mitochondrial research.

Look for more details about this year's symposium in the next UMDF newsletter and at [www.umdf.org](http://www.umdf.org). If you aren't able to be with us this year in Chicago, make plans to be with us in June 2012 as we head back to Washington, DC with plans for another "Day on the Hill" event.



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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 DOC<sup>SM</sup>

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 Doc<sup>SM</sup>* at UMDF.org. Please note that information contained in *Ask the Mito Doc<sup>SM</sup>* 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: Mary Kay Koenig, MD of Children's Memorial Hermann Hospital, Houston, TX; Mark Tarnopolsky, MD, PhD, FRCP(C) of McMaster University School of Medicine, Ontario, Canada; and Russell P. Saneto, DO, PhD of Seattle Children's Hospital/University of Washington, Seattle, WA.

### THE QUESTION IS...

I was diagnosed with mitochondrial myopathy in 2003, at the age of 50, although I have had symptoms for years. I recently developed a new problem of oxygen desaturation at night and with exertion, requiring supplemental oxygen. My pulmonary function tests are normal, and I have no cardiac issues. Could this be a complication of mitochondrial myopathy? If so, what is the prognosis and treatment?

### RESPONSE FROM MARY KAY KOENIG, M.D.:

We see quite a bit of sleep desaturations in our patient population. Most of these patients have normal cardiac and pulmonary function. Sleep studies are consistent with a picture of central hypoventilation, in other words, the brain doesn't remind the body to breathe. Several of our patients have been placed on oxygen, either at night or throughout day. The patients using oxygen tell us they have improved energy and sleep better. Some patients have had decreases in their lactic acid values and all have described an improvement in their quality of life. None have had worsening of their symptoms since starting the oxygen. I would recommend evaluation by a local pulmonologist and possible use of supplemental oxygen during sleep (depending on the recommendations of your pulmonologist).

### THE QUESTION IS...

Since most mitochondrial disorders are characterized by reduced amounts of specific enzymes in the mitochondrial respiratory chain, is there potential to use enzyme replacement therapy to treat mitochondrial disease in the future? Is there anyone currently looking into this or is there a reason this won't work in mitochondrial disease?

### RESPONSE FROM MARK TARNOPOLSKY, MD, PHD, FRCP(C)

Excellent question. We have ERT for some disorders such as Pompe disease (lysosomal storage disease affecting muscle) but in those disorders there is a known transport protein (mannose-6-P receptor) on the muscle membrane and the lysosome that allows it to get from the blood to the muscle and on to the lysosome. Mitochondrial proteins are MUCH more complex in that many of the subunits are nuclear DNA encoded (~ 38 for complex I) and some are mitochondrial DNA encoded (7 for complex I) and the ones made in the cytosol (nuclear DNA encoded) must be targeted and transported into the mitochondria (MTS) via an elaborate transport mechanism – once inside the mitochondria they are assembled into the final enzyme with assembly factors (also from the nuclear DNA) and embedded specifically into the inner mitochondrial membrane. ERT is very inefficient in lysosomal disorders and the biology is very much more simple than the simplified version of the mitochondrial assembly I gave above.

### THE QUESTION IS...

My 11 year old son who has muscle CoQ10 deficiency has periodic uncontrollable and so far unpredictable verbal tics. The tics seem to get worse after he consumes products containing Nutrasweet. Could Nutrasweet be contributing to these tics? Is Nutrasweet dangerous for those with mitochondrial disease in general? The reason I'm asking is that it is in so many products such as toothpaste, medicines etc. Is it worth the extra cost/trouble to avoid products containing Nutrasweet?

### RESPONSE FROM RUSSELL P. SANETO, DO, PHD

I am sorry to hear about your son. I am assuming that he has no motor tics, just vocal tics? Tics are very common in the general population and in my population of children/adolescents with mitochondrial disease; the frequency of tics matches the figures for the general population. My assumption is that mitochon-

drial disease does not increase the likelihood of having tics over the general population. I am not aware of a correlation between Nutrasweet and tics. However, in any particular patient we sometimes see strange things correlated together. So, although I can not tell you for sure, it seems unlikely that NutraSweet is inducing tics in your son.

Tics wax and wane in frequency over time. They increase during times of stress and fatigue. They are somewhat suppressible so at times the patient can keep them from happening for a very short time, but they will eventually be expressed. There seems to be a "gratification" of some sort from doing them. When I ask my patients about them, they tell me that they have "almost an urge" to have them. When the tic occurs they "feel relief." Tics will often change in type over time. In those patients with mitochondrial disease and tics, I have used the usual medication when warranted, and have had no "unique" side effects because the patient has mitochondrial disease.

### DID YOU KNOW?

You can quickly and easily find "Ask the Mito Doc" Q/As on topics of your choice by doing the following: Place your mouse arrow on the gray Resources for Life box near the top of the UMDF home page at [www.umdf.org](http://www.umdf.org). A drop-down box will appear with various resources in it. Click on the "Ask the Mito Doc" link, which will take you to the Mito Doc main page. Scroll down the page and click on the orange Search "Ask the Mito Doc" link; this will pull up a search box. Type in a keyword or phrase you are interested in and click "Go." It will pull up every Q/A that mentions your word or phrase. If you are not satisfied with the results, try variations or synonyms of your word/phrase.

Submitting questions to *Ask the Mito Doc<sup>SM</sup>* is a benefit of the UMDF "Energy" membership. If you are a member and would like to submit a question, log in to the UMDF website using your user ID and password. If you would like more information on becoming a member of the UMDF, email [info@umdf.org](mailto:info@umdf.org).

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**WE WANT YOUR STORIES!**

Please consider submitting an article on your experiences with a specific topic that would be of interest to others with mitochondrial disease.

Contact Alison Cooley at [alison.cooley@umdf.org](mailto:alison.cooley@umdf.org) with your story or story idea!

**Enjoying Life to the Fullest**

*By Alison Cooley, National Office and Jennifer Schwartzott of North Tonawanda, NY*

Jennifer Schwartzott has Mitochondrial Disease, but she isn't letting that hold her back in living her life to the fullest. She had minor health problems her entire childhood and bad eyesight, but first started getting sick at age 13 and began to have stroke-like episodes at age 17. Her droopy eyes are what led a neurologist to do a muscle biopsy to test Jennifer to see if she had Mitochondrial Disease. She was initially seen by local doctors and then in 1994 by Drs. Salvatore DiMauro and Michio Hirano of Columbia Presbyterian Hospital where she is still a patient today. She was one of the first people in her area to be diagnosed with Mitochondrial Disease in 1990, which was a very rare diagnosis at that time.

Jennifer said that before her diagnosis, "Doctors could not find a reason [for my health problems] and some said it was all in my head. It was a relief to finally get a diagnosis." Today Jennifer is legally blind and uses only one eye. She worries that she will lose her eyesight in her other eye so she is trying to see and do everything she can in the world and enjoy life to the fullest. In fact, she has a bucket list of things she wants to do in life and recommends that everyone – whether they have Mitochondrial Disease or not – do the same. She has accomplished some of her goals on her bucket list already. She went snorkeling in the Bahamas, camped in Bryce Canyon and hopes to go to Paris to see Chartres Cathedral. She also hopes to stay healthy.



Jennifer Schwartzott

Jennifer helped to start the Western New York Mito Group in 2010, and she is currently the co-leader of the group and the co-chair for their Energy for Life Walkathon scheduled on September 25, 2011. She has found that being a part of a support group is good therapy for her. She enjoys sharing her knowledge and experiences of what she has learned about living with Mitochondrial Disease. Jennifer said, "I feel that maybe there is a purpose for me having this awful disease: helping others live with it."

She would like to offer a few words of advice to those who have Mitochondrial Disease. "Don't give up. Find something that makes you happy. Yes, you may feel like garbage and have little energy but you need to find happiness and positive energy in something. Listen to your body and rest when it's telling you to. I took on too much in the '90s with school, family, and work. It almost killed me. When I

slowed things down, went part-time to college and took care of myself, I started to get better. It took me longer to accomplish things, but they got accomplished if they were important enough to me. I am fully affected, 29 years after first getting sick, and things can get really rough. I don't remember a life without pain and discomfort, but I have found a way to live with it and still enjoy life. I do physical therapy daily, take good care of myself, and laugh often."

Jennifer has developed many close friendships with other people who have Mitochondrial Disease or Muscular Dystrophy. She enjoys getting together with them for "Girls Day Out" adventures and even creates beaded jewelry with them – with the use of only one of her eyes, and hands that don't always work right. "It is important to have support and friendship and to laugh," she said. "When one of us is having a bad day, we know we can count on the others to let us vent and offer support. We celebrate even little accomplishments like making champion on the Wii Fit in Physical Therapy. Little things do matter and friendship is important."

Mitochondrial Disease has changed the vision of how Jennifer thought her life would be. She has a Master's Degree in Multi-disciplinary Studies that she worked very hard to obtain while she was sick, but now Jennifer cannot use it because the disease has impacted her ability to work. She has had to give up things she once enjoyed doing, such as skiing, dancing, and reading. However, she doesn't dwell on the negative things that have happened in

her life as a result of the disease. "I have just had to redefine what accomplishment is and find new hobbies and activities that make me happy. I have learned that you don't have to give up everything even though things might be difficult. There are days when I can't do anything, but I know that I can rest and eventually get back to doing things I love," she said.

Jennifer lives near Niagara Falls in North Tonawanda, NY. She does a lot of volunteer work. She has been an Auto Racing Official at professional and amateur road racing events for 23 years. In fact, she has worked at Nascar and Indycar events. She also helps promote professional auto racers by providing them with public relations support, writing press releases and managing websites. Jennifer also enjoys spending time with her daughter, Emily, and her granddaughter, Amara who is a source of new hope and light and can make her smile on the worst of days.

## THOUGHTS BY A MITO PARENT

### WHY I CHOOSE TO EDUCATE OUR SON AT HOME

By Susie Leach MD, MPA

Most of us have heard that it is good for our children to get sick. I always listened in disbelief as numerous doctors told me that it does not matter if my 8-year-old son with a life-threatening illness and deficient in the IgA antibody gets sick. After all, I was told, he needs to boost his immune system. Nine to 11 infections a year are a “natural” part of childhood. Going to school and getting exposed to many germs would be good for him. Besides, how can he learn if he is not at school?

But the idea that getting sick is actually good for you – is wrong. The notion that sickness is good actually stems from a theory called the “hygiene hypothesis.” A study in 1989 revealed that babies born into households with more siblings were less likely to develop asthma and allergies. The investigator concluded that the modern epidemic of allergies and asthma is a direct consequence from a decrease in the number of infections of childhood (1).

Furthermore, a study in The New England Journal of Medicine followed over a thousand children from birth to age thirteen. The results confirmed protection against allergy and asthma with early exposure to many children – either as siblings or as daycare classmates. Many in the medical community attributed the protective effect to the abundance of colds and other respiratory infections that children normally spread amongst each other. Children born on farms and in areas without public sanitation also experienced lower rates of allergy and asthma (1).

Less publicized were numerous follow-up studies that disproved the cause-and-effect relationship between getting sick and subsequent protection from inflammatory disorders like allergies and asthma (1,2).

The link between allergy/asthma and the number of siblings and/or children in daycare is not the disease-causing germs. Rather, it is the lack of exposure to harmless bacteria, especially those living around livestock and other children, which results in a rise in these other conditions. It is critical to distinguish between microbes that cause disease and those that are harmless. The latter group of benign germs comprises our body’s normal microflora and others that simply pass through our body in food and water. Presumably, the disease-causing germs and the harmless germs exist side by side, and if children are not exposed to the ‘bad’ germs, they are also not exposed to the ‘good’ germs. These ‘good,’ beneficial germs appear to exert a calming effect on the immune system, and without them, the net result is a rise in allergy and asthma as well as a rise

in other immune-related diseases, (such as Diabetes type I, Multiple Sclerosis, lupus, rheumatoid arthritis, Myasthenia Gravis, Addison’s disease and Hashimoto’s disease) (1).

Contrary to what we often hear, there is nothing “natural” about our children’s 9 - 11 infections a year. For almost a quarter million years, the human species was free from contagious diseases. It was only the past five thousand years that colds and other contagious illnesses became a part of everyday life - after we and our domestic animals began crowding together in settlements. It was the development of civilization that fostered the rise of microbes which led to infections and contagious diseases (1,2).

In “contrast, the mycobacteria of untreated water and mud” as well as “lactobacilli and other organisms” “have been with us throughout our evolution.” The latest thinking is that our immune system evolved within the setting of these harmless bacteria. Without this normal level of bacteria in our environment, our immune system could over-respond to everything – resulting in rises of allergies and asthma and other autoimmune diseases (1).

Not only is it untrue that infections will “boost” one’s immune system, but the greater number of infections during childhood, the greater the chance of dying prematurely due to heart disease and cancer (1,3). Recent scientific evidence shows that the more infections a person has, the greater the likelihood of arthritis, heart disease, stroke and even cancer by middle age (4,5) The reason is that inflammation remains long after the infection is gone, and prolonged exposure to inflammation can lead to premature development of these aforementioned illnesses. Over time, with repeated infections, inflammatory cells may have the tendency to attack not only the bugs, but also surrounding healthy tissue such as blood vessels, resulting in atherosclerosis (1,6,7).

Infectious disease is a number one killer worldwide. The development of vaccines and antibiotics has relegated infectious disease to third place in the US and other developed countries, following cancer and heart disease (3).

Dr. Philip Tierno, director of clinical microbiology and immunology at NYU Medical Center describes how we can protect ourselves against germs in his book, “The Secret Life of Germs.” He shares protective response strategies to keep the reader healthy and to minimize the extent to which we can make others sick. For example, he recommends that the reader avoid crowded public areas. Additionally, “real heroes stay home in bed when sick” instead of going to work and infecting colleagues (3). Once again, the message is clear - It is NOT good to get sick.

But germs are actually vital to humanity and are in fact the seeds of life (1,3). A fossilized germ cell discovered in a rock from Australia dates back 3.5 billion years ago and is the oldest known sign of life on earth. Since then, thousands upon thousands of species of germs have evolved and colonized every inch of our planet and our bodies. They are in the air we breathe, the water we drink, the food we eat and the surfaces we touch. “There are more germs in our intestines than there are stars in the sky, some thousand billion germs per gram of matter.” In fact, “the combined weight of microscopic germs exceeds the combined weight of all living animals and plants (3).”

“No living creature could survive for long in an entirely germ-free environment.” Some exposure is fundamental to human health and immunity. The tremendous number of microorganisms living in and on our bodies protects us against infectious agents. Without germs, animals “could not develop mature immune systems or even digest their food (3).”

We also depend on germs to decompose dead animals and plants and recycle life’s nutrients. Current research even includes using germs to clean up toxic wastes and to produce biofuel.

Germs are extraordinarily durable and resilient - some “can survive and even thrive at radiation counts a thousand times higher than the level that would kill a human.” “They have been recovered alive, from the petrified gut of a forty million year old bee and from a 250 million year old piece of frozen brine.” Dr. Tierno did a study on washers and dryers and found many bacteria emerged from the wash unscathed (3).

Bugs today are particularly virulent. The threats from infectious diseases have become especially overwhelming in recent years because of antibiotic resistance. Our war on germs since the discovery of the first antibiotic paved the way for multi-drug resistance in every known kind of disease-causing germ. Some of these new superbugs combine drug resistance with extreme virulence. Over the past fifty years, “the typical human body has become a vast reservoir of drug-resistant bacteria.” Bacteria can mutate itself and avoid capture by antibiotics which in turn paves the way for more drug resistance (1).

We have heard an increasing number of reports for instance about otherwise young healthy individuals falling victim to methicillin-resistant Staphylococcus aureus (MRSA). Contracting a deadly pneumonia is a very real risk for a compromised individual with the flu.

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Only a fraction of the germs that exist are disease-causing, but that fraction includes a number of bugs that we normally encounter during our daily activities. Household toys are likely to harbor their own set of germs and those of playmates. Dr. Tierno found that a steering wheel of a child's ride, a shopping cart handle and an infant's walker all bore numerous fecal and skin germs such as *E. coli* and *Staph aureus*. The wheel was also covered in beta hemolytic group A strep which can cause strep throat or flesh-eating disease. It would be perfectly normal for these toys to be covered in cold, flu and stomach viruses as well (3).

At schools, countless fomites, (objects and surfaces that harbor infectious germs and that many different people touch), are contaminated by children and teachers. Amongst other things, Dr. Tierno recommends that sick children should stay home from school until they are fully recovered (3).

We all know that sick children are frequently present at schools. Furthermore, there is the incubation period when a child may be contagious before exhibiting symptoms. Even if every sick child remains home, there will always be contagious children at school who unknowingly are in the incubation period for a particular pathogen.

Eighty percent of all infectious illnesses, from the common cold to flesh-eating bacteria and lethal viruses like Ebola are transmitted by touch. This happens either directly by contact with the infected person or indirectly by contact with something that person has touched. The common cold, flu, and stomach viruses can live on fingertips for hours, and they can survive on the surfaces of objects for days (3). Imagine what is breeding in our schools.

Furthermore, hospitals are very dangerous places. Nosocomial infections (infections contracted while in the hospital) "kill more people every year than pancreatic cancer, leukemia, multiple sclerosis, Parkinson's disease and Alzheimer's combined" (3). (Our son contracted influenza A, the more virulent flu strain, during one hospitalization, after being given a roommate with a non-stop cough.)

What causes an illness to take hold is not just contact with an infectious microbe, but it is also dependent upon the kind and quantity of germs, the frequency or length of exposure and the health of the individual (3). If the dangerous world of germs poses a threat to the general population, imagine the implications for our children with mitochondrial disease.

We know that here are no known effective treatments for mitochondrial disease, and it is often progressive. But we do know that

metabolic stress is bad for patients with mitochondrial disease. Infection is a major cause of metabolic stress and all the mitochondrial experts agree that people with mitochondrial diseases should try to avoid illnesses. In fact, at one of the UMDF conferences, one of the doctors told families that while there may not be any pharmacological treatments currently available, prevention is still a treatment. That is, preventing infection is in fact a wonderful therapy for mitochondrial disease.

In our 'welcome-to-mitochondrial-disease packet' from our doctor when we received our son's diagnosis, PREVENTION OF INFECTIONS was one of the key topics. "Because the metabolic stress of infection causes increased problems to those with mitochondrial disorders, precautions should be taken to help reduce exposure to infection and therefore the number of infections sustained"(8).

As is often the case, our son seems to be hit particularly hard even by a simple cold. "It takes longer for a mitochondrial patient to recover from an illness, and sometimes the illness is far more severe than if the same illness happened to someone with normal mitochondrial function" (9). Simple infections can be life-threatening for patients with mitochondrial disease and can result in irreversible progression (10). I learned at one of the UMDF conferences that it is the back-to-back infections that pose a serious threat, just like the ones my son experienced the one year he attended school.

ATP is the fuel that powers most cellular reactions and is necessary to sustain life. It is produced through multiple reactions along the electron chain transport within the mitochondria. Free radicals (also known as reactive oxygen species) are produced as byproducts of these reactions and can act as a poison to the cell by damaging the mitochondrial DNA. Unlike nuclear DNA, the mitochondrial DNA's proximity to the site of production of these oxygen radicals makes it uniquely susceptible to damage.

Patients with mitochondrial disease have a defect in the production of ATP; the flow of electrons down the chain and accompanying chemical reactions do not occur normally; as a result, people with mitochondrial defects presumably produce more of these free radicals



*Rick, Brandon, and Susie Leach  
at the White House Basketball Court*

than do those with normal mitochondrial function.

In fact, one of the research grants funded by UMDF in 2008 was entitled, "Cerium oxide nanoparticles in the treatment of mitochondrial disease." This research will investigate the potential for a new free-radical scavenging therapy to reduce oxidative stress on mitochondria. This has implications for potential treatment modalities.

In situations of metabolic stress, there is a greater demand for energy. For patients with mitochondrial disease, metabolic stress is accompanied by an even greater production of reactive oxygen species, (as compared with times of no metabolic stress.) When there are more of these free radicals, there is a greater chance of injuring the mitochondrial DNA even further. The damage may be cumulative, such that the more the mitochondrial DNA is injured over time, the greater the likelihood of causing harm clinically (worsening symptoms). In other words, the more the mitochondrial DNA is injured, the greater the likelihood of resulting in disease progression.

Additionally, with mitochondrial disease, food may be incompletely burned in attempts to produce ATP. At times of high energy demand, as in metabolic stress, there would be a greater chance that the chemical reactions do not run perfectly. The resulting incompletely burned

*(Continued on page 8)*

## THOUGHTS BY A MITO PARENT

(Continued from page 7)

food could generate toxic by-products that can interfere with other critical chemical reactions. This unburned food can also increase free radical production which can damage the mitochondria and mitochondrial DNA over time, resulting in irreversible damage (10,11).

Perhaps there is a certain threshold by which irreversible damage occurs in the mitochondrial DNA. Perhaps when that threshold is reached, there is a corresponding worsening of symptoms and disease progression. I believe one treatment could be to decrease the amount of free radical production – reduce metabolic stress and reduce production of these cellular poisons. Infection is a major cause of metabolic stress. A tremendous way to decrease infection rates among our children is to remove them from school.

Parents are increasingly homeschooling their children in the United States and throughout the world. There are roughly two million children in the U.S. who are educated at home. There is a common misconception about families who choose to educate at home - the majority of these parents are in fact not religious zealots. The most frequently cited reasons for homeschooling include: customizing the curriculum and learning environment; enhancing family relationships, controlling social interactions and achieving high level academics (12).

In addition to avoiding germs, a homeschool education offers other benefits as well to children with mitochondrial disease. First, there are the issues of stamina and fatigability. Most affected children fatigue more easily than their peers; many are already in wheelchairs. For us, the option of half days and/or naps during classroom hours for grade school would be too disruptive. I believe my son would spend most of his time either at school, or recovering from school – either from exhaustion or from illness, or catching up from the days he missed. After homework, there would be no time, or energy, left for extra-curricular activities and play dates. Furthermore, being a “part-time” student could make him stand out, and not necessarily in a positive light among his classmates.

Second, I do not believe that a school teacher or a shadow could possibly know our son as well as I do and pick up on the “little” symptoms, which actually are not so little. Third, I am concerned about cruelty and teasing. Our son has some manifestations of mitochondrial disease that could very easily be a target for meanness. I have already heard comments.

For those who believe children can only learn in the classroom settings – a common criticism I have heard – the data suggests otherwise: “children educated at home typically score 15 to 30 percentile points above public-school stu-

dents on standardized academic achievement tests.” Further, homeschool students are actively recruited by colleges (12,13). They have won spelling bees and other awards, such as when Cheyenne Kimball won NBC’s America’s Most Talented Kid at age 12 (13).

Further, many children with mitochondrial disease require many accommodations. Not all schools are so understanding or accommodating. For us, there came a point where it was just easier and better to teach our son ourselves.

Another frequently cited concern is ‘lack of socialization,’ but information garnered from numerous studies should ameliorate this worry. Dr. Taylor was the first to study the topic of “socialization” in the home educated. He showed that those educated at home have a positive self-concept that is stronger than that of the conventionally schooled, and concluded that the home educated are not socially deprived (14,15). Dr. Delahooke found that homeschooled children are less peer dependent than are private school students (16).

For those who are apprehensive about what happens to homeschooled children as they enter adulthood - current research indicates that they “participate in local community service more frequently than does the general population; vote and attend public meetings more frequently than the general population; and go to and succeed at college at an equal or higher rate than the general population (12).”

Aside from all the studies, we see that our son is learning and is socializing. We schedule dates when both our son and his friends are well. He participates in small classes/activities that meet either weekly or monthly for just a few hours. He therefore has a social life in a controlled setting, limiting his contact with infectious agents.

Our son’s current extracurricular activities include horseback riding and volunteering to feed the horses; African dance; acting class; Hebrew school and ice skating. He also raises money through a lemonade stand to buy gifts for the service men and women stationed overseas.

Another benefit of homeschooling is being able to take these amazing field trips during the week when most places are not terribly crowded. I do not have to worry as much for example about our son catching a bug from a nearby coughing child. I can greatly control and limit his infection rate. We go to museums, battlefields, nature centers, piano and high tea with live music. In the past, we enjoyed weekly sessions with a park ranger as well as occasional excursions with a paleontologist.

Brandon is a very happy boy. Neither he nor I feel like he is missing out by not being in a formal classroom setting. We do not look at homeschooling as a loss, but rather Brandon is very proud of all his achievements and extracurricular activities. By the age of eight, he visited more civil war battlefields than I ever had in my 47 years of life. He has had the time to foster

(Continued on page 9)



*Brandon Leach sitting in the sidecar of a secret service agent’s motorcycle*

## DR. COHEN HONORED AS A HEALTH CARE HERO

**B**ruce Cohen, MD, was recently honored as a "Health Care Hero" for northeast Ohio. Dr. Cohen, who is a member of the UMDF Board of Trustees, was selected for the honor by a panel of judges who based their selection on the nominee's leadership, approach to healthcare and philanthropy, and community service. The awards were presented by Crain's Cleveland Business newspaper at a ceremony on May 18, 2011. Dr. Cohen was honored in the category of 'physician.'

"There are very few doctors in the world with as much clinical expertise and leadership in the field of mitochondrial disease as Cleveland's own Dr. Bruce H. Cohen — and even fewer are as tireless and caring," wrote Darcy Zehe, president of the Northeast Ohio Chapter of the United Mitochondrial Disease Foundation, in nominating Dr. Cohen.

Ms. Zehe, who also is a partner in the Breehl, Traynor & Zehe marketing firm, said it was Dr. Cohen who first diagnosed her son, Nicholas, with mitochondrial disease.

In April, Dr. Cohen joined the medical staff at Akron Children's Hospital as Director of the Department of Pediatric Neurology. He joined the Akron Hospital from the Cleveland Clinic, where he held appointments in Neurosurgery and Pediatrics and was Chief of Pediatric Surgery.

Dr. Cohen is a graduate of the Albert Einstein College of Medicine of Yeshiva University, Bronx, N.Y. He also has been elected by his peers into leadership positions, including President of the Mitochondrial Medicine Society and Professor of Child Neurology.

"We are very proud of Dr. Cohen and are thrilled that he continues to be recognized as

being among the best in his field," said Charles A. Mohan, Jr., CEO/Executive Director of the United Mitochondrial Disease Foundation. Mr. Mohan traveled to Cleveland to attend the awards ceremony. "It is always great when 'one of our own' is acknowledged for the excellence that Dr. Cohen not only provides his patients, but the entire mitochondrial disease community."



Dr. Bruce H. Cohen

## THOUGHTS BY A MITO PARENT

(Continued from page 8)

his interest in American military history, as well as the history of Israel. He has developed extremely special friendships with some amazing adults, including our country's service men and women; pilots; FBI and Secret Service agents. This past year, Brandon met President Obama and befriended Secretary Clinton. Had our son been attending school, his entire knowledge base and life experience would be virtually void of everything he currently knows and loves.

We are told by many to prevent illness and avoid metabolic stress, yet encouraged to go to school. Some doctors appear to reserve the recommendation to educate at home for those children who are more severely affected by mitochondrial disease. We do not want to wait for our son's underlying disease to progress before we consider homeschooling. I realize he will still get sick, but once in a while is probably a lot better to his system than the 16 infections he experienced during his one year at school. (He missed nearly half the year.)

In a world where there are no pharmacological treatments that have been proven to be effective against mitochondrial disease, we want to treat our son the best and most aggressively way possible. For us, this includes avoiding metabolic stress and avoiding infection.

We were told that we can do everything 'right' yet still, the disease may just progress. I believe there must be a chance, if we do everything possible to reduce metabolic stress, that our actions will have beneficial consequences. I believe that in the case of mitochondrial disease, an ounce of prevention is worth a ton of cure. If there is a possibility that reducing

metabolic stress may result in adding more years, or a better quality of life, then it is well worth the effort.

I feel that a homeschool education should be an option on par with public school, private school, and special education settings. Ten years from now, if our son's disease progresses, I do not want to be in the position of wondering what his life would have been like had he experienced fewer infections.

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## CHAPTER EVENTS

### CALIFORNIA CHAPTER

- **MARCH 12, 2011.** The sixth annual Brittany Wilkinson Dinner and Silent Auction was held in Fresno, CA. The annual event is held in memory of Brittany Wilkinson to benefit the Brittany Wilkinson Research Fund with the UMDF. A special thank you to Linda and Doug Wilkinson and all that made this event possible.
- **MAY 22, 2011.** The second annual Co-Ed Softball Tournament in memory of Brittany Wilkinson was held at Bicentennial Park in Clovis, CA. The annual event is estimated to raise about \$2,000 for the Brittany Wilkinson Research fund with the UMDF. Thank you to the Wilkinson Family for keeping Brittany's passion going!

### DELAWARE VALLEY CHAPTER

- **March 1, 2011.** The Adam Mamawala's Charity Comedy Show was held at The College of New Jersey. All proceeds from the event went to the UMDF. The event raised \$590. Thank you Adam! And, thank you Amy Burgener, for assisting Adam in this great charity event!

### NEW ENGLAND CHAPTER

- **April 18, 2011.** Marge Olson of Lebanon, NH ran in the Boston Marathon in honor of Rachel Varriano, her 5-year-old niece who suffers from Mitochondrial Disease. More than \$3,000 was raised in honor of Rachel, and money is still coming in. Thank you Marge! Way to go!

*Marge said, "It was an honor and a privilege to run in the 115th running of the Boston Marathon in honor of my niece Rachel. It was a most grueling race for me as it was my first Boston and at times I wanted to quit. It was the image of little Rachel smiling in the arms of her grampa that I received in an e-mail the eve of the race that spurred me on. I told myself, 'I have to keep going for Rachel' and my legs continued to put one foot in front of the other until I crossed that coveted finish line....for Rachel!"*



A group of supporters surround Marge Olson at the Boston Marathon

### OHIO CHAPTER

- **March 4, 2011.** The Ohio Chapter and the Kobunski family hosted the 8th Annual Guest Bartending Night at the 82nd Street Grill & Pub in North Royalton, OH. The event raised \$4,195. Thank you Anita Rippepi and Diane Kobunski for being guest bartenders! And, a big thanks to the Kobunski family and members of the Ohio Chapter for organizing this event.
- **March 12, 2011.** The third annual Elite Fitness Spin-A-Thon was held in honor of Bobby Arnold of Cleveland, OH. Participants received a great workout, food, and music while helping out a great cause. The event raised \$8,750. Thank you Brooke Furino for organizing this event!

- **April 25, 2011.** Jack Arnold of Montville, OH began his bike tour to raise money for the UMDF. He started his tour in San Diego, CA and planned to finish in St. Augustine Beach, FL. Jack shortened his bike tour due to the death of his granddaughter, Sadie May. Jack made it home to see her before she passed. Jack was riding his bike for his two granddaughters, Sadie May and Maiya Jean, who both died from mitochondrial disease. For more information about Jack and his bike tour, please visit: [www.pedalfromthepacific.com](http://www.pedalfromthepacific.com).
- **May 7, 2011.** The Wild for a Cure Walk was held at the Cleveland Metroparks Zoo. The event included a one mile walk through the zoo. The event raised more than \$76,000. Thank you to the amazing walk committee for coordinating this event!

### MEMPHIS AREA MITO GROUP

- **March 26, 2011.** The Second Annual Jackson Culley Mito – What? 5K was held at USA Stadium in Millington, Tennessee. The event drew over 250 people and raised over \$20,000 for the UMDF in honor of Jackson Culley. Thanks to the hard work of Angie Hayes, event chair, the race went off without a hitch! Many will be returning for the third annual event next spring.



Angie Hayes handing a race participant a ribbon at the Second Annual Jackson Culley Mito - What? 5K

### WESTERN PA MITO GROUP

- **April 10, 2011.** Bruster's of Ingomar hosted an Easter egg hunt, collected donations, and donated 10% of all food sales to the UMDF. A total of nearly \$400 was raised for the UMDF! Thank you Bruster's of Ingomar for your continued support.
- **May 14, 2011.** The first annual Fighting for a Cure for Anthony was held at the Keecksburg Volunteer Fire Department Social Hall in Mt. Pleasant, PA. The event was held in honor of 9-month-old Anthony Maccarelli and included an all-you-can-eat spaghetti dinner and music by TJ's Music Express. The event raised \$1,700. Thank you Crystal Maccarelli for organizing this event!

- **May 22, 2011.** The third annual Mitochondrial Disease Awareness Day was held at PNC Park in Pittsburgh, PA when the Pittsburgh Pirates took on the Detroit Tigers. The event raised \$250.

### AROUND THE COUNTRY

- **March 19 – 20, 2011.** Preston's March for Energy was held in Virginia Beach, VA. The event was held in conjunction with the Shamrock Sports-fest. The proceeds from this year's event were donated to the UMDF in honor of Preston Buenaga. The event raised over \$33,000. Thank you Deb Buenaga for organizing the event!



Preston Buenaga with his teachers at Preston's March for Energy

- **March 27, 2011.** The Kindbom family held a wine tasting event, "Cheers to you, Hope for Others" at Lakeside at the Medford Clubhouse in Medford, NJ in honor of their daughter, Rachel. The event raised more than \$23,000. A big round of applause to the Kindbom family for coordinating this event!
- **April 2, 2011.** The seventh annual Bet on Baylee Casino Day & Night Auction to benefit the UMDF was held at the Roseville Community Center in Roseville, OH. Three bands played after the auction: Vision, Familiar Stranger, and Fast Freddy. Fast Freddy sang a special song, entitled "Baylee's Eyes" at the event that was dedicated to Baylee Thompson and others affected with mitochondrial disease. The event raised \$8,875. Thank you Jody Thompson for organizing this event!

*"I am Jade Thompson and I am the sister of Baylee Thompson who has mitochondrial disease. As my family geared up for our annual Bet on Baylee event, I wanted to do something to raise awareness and money too. I went to my school's principal and asked permission to do a spirit week. Each day, a student gave a donation to wear something for each day of the week, such as crazy socks, a hat, or school pride. Also, the teachers paid \$10 to wear jeans for the week. Crooksville Middle School raised over \$600 and we are proudly giving it to the UMDF in honor of Baylee to help "fund a cure" for her and all people that are affected. A big thanks to my besties who helped me plan and watch over our project and to Mrs. Caton for allowing me to do this."*

- **April 16, 2011.** The Andrew Radney Research Fund participated in the Belk Department Store Charity Sale in McDonough, GA. Thank you to Angie Radney for your support of the UMDF!
- **May 1, 2011.** A cut-a-thon was held at Clyde St. Amand's Hair Salon in Avon, CT in honor of Evan St. Amand. Thank you to the St. Amand family for your support!
- **May 8, 2011.** A Benefit Concert for Mito was held in Manhattan, NY in honor of Ted Tiller. The one night acoustic rock cabaret benefiting the United Mitochondrial Disease Foundation featured some of Broadway's up and coming talent. Thank you to Ted and his family for their continued support of the UMDF!



Baylee and Jade Thompson

- **May 15, 2011.** A Stamp Out Mito fundraiser was held in Kernersville, NC. Participants were able to make two hand stamped cards or two 12x12 scrapbook pages - all for only \$15! All proceeds from sales were donated to the UMDF. The event raised \$80. Thank you to Pattie Curran for organizing this great event!

## GIFTS FROM THE HEART

- The teachers of the Grace Hill Elementary School in AR participated in a fundraiser for the UMDF. Each week during the month of May, the school offered a day where the money from the lunches would go to the UMDF. The event raised \$300. Thank you to the Grace Hill Elementary School for your support!
- The employees at Ackerman, Link & Sartory in West Palm Beach, FL participated in their weekly "Dress Down for Charity Day" and raised \$98 for the UMDF. They chose the UMDF as their charity for the week in honor of Michael Link and Christopher Link of Palm Beach Gardens, FL. Thank you for supporting the UMDF and the Links!
- The Second Grade Class in Jackson Elementary in Jonesboro, GA made rice crispy treats to sell for the UMDF. After a lesson taught by their teacher Mrs. Jessica Mercado about economics and philanthropy, the class decided to donate the proceeds to the UMDF in honor of Katie Rachau (whose mom works at the school). They were able to raise more than \$200 for the UMDF! Thank you Mrs. Mercado and your wonderful Second Graders!
- Ava Caroline Wilson of GA celebrated her 4th Birthday in February and donations were made in her honor. The family donated \$90 to the UMDF. Thank you to her family and friends for sending in donations to celebrate her birthday!
- Jon Axness of Williston, ND donated loose change that he collected over the past year to UMDF in honor of Logan Palmer. Jon's loose change totalled more than \$200! Thank you Jon for your donation to fund research!
- The employees at PG&E Corporation in New Jersey hold a "Campaign for the Community" fundraiser each year. They chose the UMDF for one of their events and raised more than \$630! Thank you to the PG&E employees for your generous donation!

- A Ninth grade Biology class in Chelmsford High School in North Chelmsford, MA donated money for bonus points while learning about cells, their parts, and their functions. Joseph Landry who takes the Biology class, asked if he could give a Microsoft Power Point presentation to the class on mitochondrial disease. Joseph knows all about mitochondrial disease from his friend, Jordan Kalick, who suffers from a mitochondrial disorder. Joseph and his class raised \$162. Thank you Joseph and your entire Ninth Grade Biology Class!
- Diana Nieves of Glen Oaks, NY hosted a Lia Sophia Jewelry fundraiser in honor of her daughter, Nicole. She was able to raise \$300 for research! Thank you Diana!
- Jennifer Cook and the JC Penney Salon Stylists in WY along with Store Manager, Kathy Paull and the JC Penney employees participated in several fundraisers, including two jeans days, coin boxes, and a bake sale for the UMDF. The fundraisers were held in honor of Logan Palmer of North Dakota. The fundraisers raised \$335. Thank you JC Penney for your generous donations!
- The Syosset Central School District of Long Island, NY has held some fundraisers in honor of Ted Tiller, a 2009 graduate of the school district. Ted has written a book titled, "The Bullies Learn Their Lesson" and is donating \$1 for each book sold. So far, \$2,400 has been raised. Thank you to the Ted and the Syosset Central School District for your generous donations!
- The Minnechaug Regional High School National Honor Society in Wilbraham, MA donated over \$3,500 to the UMDF by holding a basket raffle. Thank you to the Minnechaug Regional High School National Honor Society for your donation!
- Crop For A Cure..."to cut out mito" scrapbooking event was held in Cumming, GA. The event raised \$721 for the UMDF. Thank you Robyn Gravittl for your support.

# ENERGY FOR LIFE WALKATHONS



Participants in the Energy for Life Walkathon: Middle Tennessee

• **April 2, 2011.** The first annual Energy for Life Walkathon: Middle Tennessee was held at The Nashville Zoo at Grassmere in Nashville, TN. With over 500 walkers, they raised more than \$77,000! A big thank you to Sonya Murray, Event Co-Chair and the entire committee for all your hard work!



Members of Team Emma at the Energy for Life Walkathon: St. Louis.  
(Photo by: Lappin-Vogler Photography)

• **April 2, 2011.** The St. Louis Metro Area Mito Group held an Energy for Life Walkathon at Forest Park - Upper Munny in St. Louis, MO. With about 230 walkers, they raised more than \$18,000. Thank you Hope Grover, Group Leader and Victoria Helms, Logistics Coordinator, for all of your support!



Pictured above are members of Team Tara at the Energy for Life Walkathon: Indiana. Tara McCrary is in the wheelchair. She is 19 years old, and her mom, Kim was the Team Leader. Team Tara raised more than \$1,000 for the UMDF! Way to go!

• **April 30, 2011.** The Indiana Chapter held their first annual Energy for Life Walkathon at the IUPUI Campus in Indianapolis, IN. With more than 400 walkers, the event raised almost \$47,000. Thank you Amanda Whitfield, John Goerges, and the entire walk committee for organizing the event!



Hudson Sundgren at the Energy for Life: All Aboard for a Cure Walkathon

**UNITED MITOCHONDRIAL DISEASE FOUNDATION**  
**energy for life**  
**walkathon**

• **April 30, 2011.** The Energy for Life: All Aboard for a Cure Walkathon was held at Thrasher Park in Norcross, GA. The event raised nearly \$110,000. Thank you Lisa Higgins and the entire walk committee for coordinating the event!

[www.energyforlifewalk.org](http://www.energyforlifewalk.org)

## UPCOMING EVENTS

### ATLANTA CHAPTER

• **June 24 - 26, 2011.** Rich Sheinis is planning the Ride the Ridge for Mito, a three-day bicycling event along the Blue Ridge Parkway. Enjoy 150 miles of gorgeous sights while raising funds for the UMDF. More information can be found at: [www.umdf.org/ridetheridge](http://www.umdf.org/ridetheridge).

### CAROLINA Foothills CHAPTER

• **October 15, 2011.** The Carolina Foothills Chapter has planned an Energy for Life Walkathon in Freedom Park in Charlotte, NC. The day will include an opening ceremony and post-walk program. For more information, go to: [www.energyforlifewalk.org/carolinafoothills](http://www.energyforlifewalk.org/carolinafoothills).

### CENTRAL OHIO CHAPTER

• **August 5, 2011.** The Third Annual Baylee's Ball Bash will be held at Cannelville Softball Field in Cannelville, OH. The Annual Softball Tournament is held in honor of Baylee Thompson. For more information, please contact Jody Thompson at: [buff2506@hotmail.com](mailto:buff2506@hotmail.com).

### CHICAGO CHAPTER

• **July 16, 2011.** A Ralph's World Charity Concert will be held at the College of Dupage in Glen Ellyn, IL. All proceeds from the event will benefit the UMDF! To purchase tickets, make a donation, or for information, please visit the event calendar on the UMDF website, [www.umdf.org](http://www.umdf.org).

• **September 11, 2011.** The Chicago Chapter will be holding an Energy for Life Walkathon in Busse Woods Forest Preserve in Elk Grove Village, IL. A picnic has been planned after the walk. For more details, visit: [www.energyforlifewalk.org/chicago](http://www.energyforlifewalk.org/chicago).

• **October 9, 2011.** The Chicago Chapter is encouraging anyone who will be participating in the Chicago Marathon to join their team, Hope, Energy, Life! If you are registered for the marathon, or would like to donate to a runner, please visit, [www.umdf.org/chicagomarathon!](http://www.umdf.org/chicagomarathon!)

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## **DELAWARE VALLEY CHAPTER**

- **August 23, 2011.** The annual Mitochondrial Disease Awareness night at the Camden Riversharks game will be held at Campbell's Field in Camden, NJ. A portion of the ticket sales will be donated to the UMDF. Come out to the game, enjoy \$1 concession night and see where the Energy for Life: Delaware Valley will be held! Check the UMDF website for more information!
- **September 17, 2011.** The Delaware Valley Chapter has planned an Energy for Life Walkathon at Campbell's Field in Camden, New Jersey. The event features a beautiful walk along the Delaware River and a spectacular view of the Philadelphia Skyline. For more details, go to: [www.energyforlifewalk.org/delval](http://www.energyforlifewalk.org/delval).

## **MINNEAPOLIS/ST. PAUL CHAPTER**

- **September 10, 2011.** The Minneapolis/St. Paul Chapter has planned their Second Annual Energy for Life Walkathon at the Normandale Lake Bandshell in Bloomington, MN. For more information, go to: [www.energyforlifewalk.org/minnesota](http://www.energyforlifewalk.org/minnesota).

## **OHIO CHAPTER**

- **August 1, 2011.** Owen's Homerun Heroes Night - Purchase a ticket to Owen's Homerun Heroes Night at Chillicothe Paints stadium and \$1.00 from every ticket purchased with flyer will be donated to the UMDF. To obtain a flyer please contact [am\\_birk@yahoo.com](mailto:am_birk@yahoo.com).

## **CENTRAL FLORIDA MITO GROUP**

- **August 14, 2011.** The Central Florida Mito Group will be hosting its Third Annual "Bowling for Mito" event at Colonial Lanes in Orlando, FL from 1:00 pm to 4:00 pm. For more information, e-mail Jennifer Slauter at [jslauter@yahoo.com](mailto:jslauter@yahoo.com).

## **ERIE MITO GROUP**

- **September 18, 2011.** The Northwestern PA Group has scheduled an Energy for Life Walkathon at the Sugar Grove Amvets Post 50 in Sugar Grove, PA. A barbeque is planned immediately after the walk. Go to: [www.energyforlifewalk.org/northwesternpa](http://www.energyforlifewalk.org/northwesternpa) for details.

## **IOWA MITO GROUP**

- **June 11, 2011.** The Iowa Mito Group will host an Energy for Life Walkathon at Zsavooz Sports Lounge & Grill in Cedar Falls, IA. For more information, visit: [www.energyforlifewalk.org/iowa](http://www.energyforlifewalk.org/iowa).

## **KANSAS CITY MITO GROUP**

- **September 17, 2011.** The Energy for Life Walkathon: Kansas City will be held at the Community America Ballpark (Kansas City T- Bones Stadium) in Kansas City, KS. For more information, please visit: [www.energyforlifewalk.org/kansascity](http://www.energyforlifewalk.org/kansascity).

## **PACIFIC NORTHWEST GROUP**

- **July 4, 2011.** The Fourth of July 5k/10k Run will be held in Kelso, WA in honor of Joshua Chilson. For more information or to register, please visit: [www.cowlitzvalleyrunners.org](http://www.cowlitzvalleyrunners.org).

## **UTAH MITO GROUP**

- **September 10, 2011.** The Utah Mito Group has planned an Energy for Life Walkathon at Murray City Park in Murray City, UT. For more information, visit: [www.energyforlifewalk.org/utah](http://www.energyforlifewalk.org/utah).

## **WESTERN NEW YORK MITO GROUP**

- **September 25, 2011.** The Western New York Mito Group has coordinated an Energy for Life Walkathon in Island Park in Williamsville, NY. A picnic is scheduled after the walk. For more information, please view: [www.energyforlifewalk.org/westernnewyork](http://www.energyforlifewalk.org/westernnewyork).

## **WESTERN PA MITO GROUP**

- **June 28, 2011.** California Pizza Kitchen in Pittsburgh, PA will be donating a portion of its sales on Tuesday, June 28th to the UMDF. For more information, please call the UMDF National office at 888-317-8633.

## **AROUND THE COUNTRY**

- **June 11, 2011.** The Second Annual Mason's Mountain Run will be held at Lions Camp, south of Red Lodge, Montana. The day includes a 10k trail run, a family fun trail walk, a treasure hunt, barbeque lunch, live music, inflatable rides, and face painting. The event is being held in memory of Mason Shuck, who loved to go on trails in the woods. For more information, visit: [www.umdf.org/masonsmountainrun](http://www.umdf.org/masonsmountainrun).
- **June 25, 2011.** Lizzy's Walk for Kearns Sayre Syndrome will be held at Norwalk Park in Norwalk, CT in honor of Elizabeth Piro. All proceeds from the walk will benefit the Elizabeth Piro Research Fund with the UMDF. For more information or to register, please visit the following website at: [www.umdf.org/Lizzyswalk](http://www.umdf.org/Lizzyswalk).
- **June 25, 2011.** The annual Lavallette 8K, formerly Save Barnegat Bay, will be held in Lavallette, NJ in honor of Lauryn & Owen Boyle. For details, please contact Kirk Tilton at: [lavallette8k@gmail.com](mailto:lavallette8k@gmail.com).
- **August 6, 2011.** The annual Run 4 Raley event will be held at the Philo Ball Park in Philo, IL. The annual event is held in honor of Raley Kirby and features a 5K run, 1 mile walk and a kids fun run! For more information, please visit [www.umdf.org/run4ralely](http://www.umdf.org/run4ralely).
- **August 27, 2011.** Support the UMDF by purchasing a \$5.00 coupon to Macy's Shop for a Cause. By purchasing a shopping pass, you support the UMDF while enjoying a day of spectacular discounts. Shopping passes will be available for sale starting July 1, 2011 at: [www.umdf.org/shopforacause](http://www.umdf.org/shopforacause).
- **September 17, 2011.** The Fourth Annual Savannah's Hope Mito Walk will be held at Adventure Life Reformed Church in Altoona, Iowa. The event will include family-friendly activities and much more! For more information, please visit: [www.savannahshope.com](http://www.savannahshope.com).
- **September 18, 2011.** The Second Annual Mito is a Mess event will be held at the Haven Restaurant in Houston, TX. For additional information view: [www.umdf.org/mitoisamess](http://www.umdf.org/mitoisamess).
- **September 23, 2011.** The Show of Hope Benefit Concert in support of the UMDF will be held at Lowell Memorial Auditorium in Lowell, MA. The concert will feature performances by Air Traffic Controllers, Liz Longley and Stefani Bush. To purchase your tickets, make a donation, or for information please visit: [www.showofhope.org](http://www.showofhope.org).

*If you are having or have held a fundraising event, or are in need of assistance, we want to talk to you!*

*Contact the Special Events Department via e-mail at: [events@umdf.org](mailto:events@umdf.org) or call them, toll free, at: 1-888-317-UMDF.*

## LIFE AS A MITO SIBLING - TURNING A NEGATIVE INTO A POSITIVE

By Alison Cooley, National Office

**K**yle Schindler, who is 27, lost his little brother, Christopher, to mitochondrial disease on October 29, 2004. Christopher was 11 years old, and Kyle was 20. Kyle described his brother, Chris, as having a dynamite personality. "Chris had more personality than anyone I've ever met. When he walked into a room, even at 11, he owned it," Kyle said. "People gravitated towards him: so warm, so loving."

"With mourning, I feel there are two ways to go. Find reason for your loss and make the world a better place because of what you went through, or the other direction," Kyle explained. "I went the other direction and life got dark for me. It was selfish and my poor mother was once again told by doctors that another one of her sons was going to die." At age 20, he fell 30 feet head first onto concrete. He had severe amnesia and was paralyzed on the right side of his body. His mom, Debra wondered if she would lose another son. Thankfully, he recovered from his fall and was given a second chance at life. He has to wear a patch over his right eye, but it serves as a constant reminder to never take life for granted.

Kyle then had to pick himself up and start his life over. He had to find reasons to live and that's when he started to go move in a positive direction in the mourning process. Kyle goes on to say, "I found a reason why Chris left us when I met Andrea, a beautiful girl that had Mito." Kyle felt that he helped Andrea simply by being a good friend and being there for her when she felt completely alone. Mitochondrial disease ended up taking Andrea's life but Kyle is not bitter about it; he is thankful that she experienced so much happiness her final week on Earth and he knew he was a factor.

Kyle has turned his life around and has made a difference in the lives of many people, including people who have mitochondrial disease and their families. Kyle began to realize that there is a plan for all of us. He learned how to turn a bad situation into a good one. He said that through the sacrifice of his brother, he has met many wonderful people. As the coordinator of a sibling support group that he started in Houston, TX, Kyle enjoys helping siblings

of mitochondrial patients, and he is making the difference in the lives of many. "A lot of children who have siblings who suffer from mitochondrial disease love their siblings so much, yet they get angry because their sibling gets more attention than they do, and then they become angry at themselves for feeling that way," he said.



*Christopher and Kyle Schindler*

A bonding moment happened to Kyle recently when he was talking to a little girl named Lauren Knight who lost her brother, Samuel, to the disease. Lauren looked up at Kyle and said, "My brother's in Heaven." Kyle looked down at her and said, "Mine is too." This is not the only bonding moment that has occurred at support group meetings in Houston. While Kyle runs the sibling support group, Debra runs the family support group. Kyle said that these support group meetings have brought many mothers together who share a special bond of raising children with mitochondrial disease. He has watched them share stories and names of doctors. "What started out as a mourning tool for our family has become something very special," Kyle said.

Kyle and Debra also started the Houston Chapter and the Christopher's Heart Energy for Life Walkathon in Houston, TX. This past year, Kyle was the Co-Chair for the Walkathon and handled all of the logistics for it. "Every year, the walk is an emotional journey, and every year, I feel Chris' presence," he said. He feels that Chris is bringing families together through all of the activities at the Houston Chapter. This year, the walk that was planned on February 5, 2011 was cancelled due to the severe ice in the Houston area. However, many families who signed up for the walk still wanted to walk for their loved ones in their own neighborhoods. The event raised more than \$161,000 for the United Mitochondrial Disease Foundation and more donations are still coming in.

Today, Kyle is facing life with purpose. He is driven. Kyle works as a Technology Sales Consultant for his mother's business, Genesis BCS, which is 27 years old. Prior to working there, Kyle owned a web design firm.

He looks forward to making a difference in the world and hopes to be able to help others who have mitochondrial disease or are affected by it through a family member. He is thankful that he was given a second chance, not just for himself, but also for the sake of his mother, Debra, and sister, Katherine, age 19. He doesn't know how they would have handled his death, along with the death of his brother. "It took me a little while but all of a sudden I could see why Chris left us; there is in fact a plan," Kyle explained. "Chris was still working through me. I realized that I never would have met all these special people if it weren't for his sacrifice. That's why it happened, so I could be there for so many. I find myself filled with love for all of mankind, and I look forward to making a difference for whoever I am meant to help."

Kyle has not only found a new life for himself, but he has also found that there is something extra special about individuals that have mitochondrial disease. "They have a radiance about them that you and I don't possess," he said. "I can't put my finger on it, but their personalities all seem to shine with a different light."

## FINDING SUPPORT AND BUILDING FRIENDSHIPS...

By Darla Cohen, Indiana Chapter; Melinda O'Toole, National Office; and Jennifer Schwartzott, Western New York Mito Group



Some members of the Western New York Mito Group

Facing the challenges of life with mitochondrial disease can often leave you feeling confused, powerless, and frustrated. There is comfort in knowing that you are not alone; and sharing your thoughts, fears, and hopes with someone that is a little further down the path of life with mitochondrial disease can ease the burden. This is where the UMDF Mito Groups come in. Mito Groups are as unique and diverse as the people that participate in them. What they have in common is compassion and a desire to improve the lives of those involved in the group. Sharing tips, enjoying a picnic or party, inviting health professionals to share their knowledge, planning a fundraiser, or providing a listening ear are just some of the ways our groups offer support. We asked a few of our UMDF support groups to offer their perspective on their group. If you feel inspired to join an existing group or start your own group, please contact UMDF Member Services Department via e-mail at: [info@umdf.org](mailto:info@umdf.org). They would be happy to assist you.

Support. Understanding. Friendship. Hope. These are words that could be used to describe the Western New York UMDF Group. Our group started in March of 2010 and quickly grew and flourished, and today has about 260 members. We meet on the third Thursday of every month and alternate with guest speakers and general support meetings. Our group is unusual in that it is mostly comprised of affected adults, although we do include and welcome parents of affected children. Since our beginning, we have shared our stories, information, and support. Strong friendships have grown and members have found a new purpose and place in the organiza-

tion. Although our energy and health is limited and life is not the way we would choose it to be, it has been fun and inspiring to watch the quiet ones turn into spitfires and the tears turn into laughter. It is a relief to not be alone and to have a new circle of friends that understand. Hope is empowering.

One member of our group said it best: "I was feeling devastated after being told that I was diagnosed with mitochondrial disease. Then I found the WNY Mito Support Meetings. I remember after the very first meeting thinking, "Thank You God. After all these years and all the illnesses I have been through, I am not alone anymore." This member is now a leader in the group and has been hard at work raising funds and awareness.

In September of 2010, we held our first Energy For Life Walkathon, raising over \$24,000. This year we plan to double that amount at our Energy for Life Walkathon on September 25. We have also held Grand Rounds with Dr. Cohen in March and an "Ask the Doc" session with Dr. Julian Ambrus. Our goal is to raise awareness in our community so that our members have the proper treatment of medical professionals and the understanding of people in their



Those members of the Houston Mito Adult Support Group that could attend the support group meeting on April 18 are pictured above.

neighborhoods. We want to continue to raise money to find treatments and be part of a cure. We are hoping to find every affected person and family in our area so we can offer them the same support, information, and friendship that has become so important to us. What we lack in energy, we make up for in heart.

In Indiana, the UMDF Chapter holds a meeting every month on the second Sunday afternoon. Families come from all over the state to attend the two hour session. By design, very little of the meeting is devoted to business, focusing rather on supporting the families who are there to learn more about mitochondrial disease. Some families received the diagnosis for their children years ago. Others are newly diagnosed and some still have no definitive reason for the symptoms their children have. When they come to the meeting they hope to gain the wisdom of those who have gone before them in parenting children with special health care needs.

There are some basic ground rules. They are announced each meeting in subtle ways by the more veteran parents. For example, a veteran parent may say something like this, "I cannot tell you what will work for you because each child is unique, so what works for one may not work for any other." There is absolutely no medical advice given and no negative comments about any health care provider.

So what are the advantages of talking with other families? According to a long time chapter member Camille Gaughan, it is the opportunity to network with other parents, give and receive advice, and experience the comfort of knowing that others are going through some of the same things. "I always love it when we have new families who join us and we more seasoned Mito parents are able to put our collective arms around them & help them through such a difficult time in their lives. When your kid has Mito, you find yourself asking for help a lot--financial help (via Medicaid and waivers), educational help, therapy help, babysitting help, etc.--and it is nice to be able to help others, even if it's just informing a new Mito mom or dad that an insurance company's "no" doesn't always really mean "no," or encouraging a new member to join us Mito moms out for dinner. It's about empowerment and venting and seeing how other families deal with life with Mito. It just gives me hope, and strengthens me as a parent, citizen, and person." Her fellow chapter members agree. Family support is critical for any number of reasons--not the least of which is everyone's emotional well-being.

# CHAPTERS, MITO GROUPS AND AMBASSADORS

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***How to Stay Positive When You Have Mitochondrial Disease***

*By Karen Wilson of Connellsville, PA*



*Karen Wilson with her husband, Bill*

I first heard about mitochondrial disease over fifteen years ago. I had been to several specialists for migraines, GI problems, chest pain, asthma, RA, and a droopy eye. One of the doctors told me that he suspected that I was dealing with a mitochondrial disorder. At that time, he said we would not do a muscle biopsy since there were no treatments. Since then, I have had three muscle biopsies and a diagnosis of mitochondrial myopathy.

I had many questions and spent hours doing research. I was quite surprised to find the UMDF and couldn't believe it was in Pittsburgh so close to my home. The staff was kind and extremely helpful. A diagnosis or suspicion of a mitochondrial disorder brings with it many questions. Some of the questions have answers and some do not. A basic understanding of the disorder helps explain symptoms and enables the patient to ask better questions.

I began taking the mitochondrial cocktail. It made a huge difference for me. It is not helpful for all patients,

but since it works for me, I am very careful to follow the plan. I do take an array of other medications that, for the most part, keep things under control. I continue to see my PCP and several other specialists on a regular schedule. Following these schedules and taking the medications is what I can do to help myself. My doctors are great and I can trust them.

Fatigue has been a problem. The cocktail certainly helped, but I decided that I had to accept that problem and develop a plan that would work for me. I have been very lucky to work through that issue. I was able to continue teaching and complete the 35 years required for retirement. I plan activities and divide household tasks so that there are not too many for one day. Weakness can also be a problem; I have found that exercise is helpful. I had been walking on the treadmill for 30 minutes and riding the bike for 10 minutes, 5 times per week. After a surgery last August, I had to begin my routine again and am still working to return to my previous level. I actually hate to miss a day of exercise. Again, I feel it is something I can do to help myself.

Just as there are many similarities among mito patients, there are differences. What helps one may not help another. A positive frame of mind and lots of planning are basic for me. I also have lots of support from my husband, and I am grateful to be doing so well. It is also helpful to focus on something pleasant. I am so happy to have the most pleasant focus object of all... a new grandson. Our wonderful son and beautiful daughter-in-law had a precious baby on December 11. My

husband and I just adore him. As you see, sharing pleasant news makes me positive and happy. Being positive and happy makes me feel wonderful. I hope you have something to make you feel wonderful, too.

**Adult Advisory Council Team (AACT)**

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***PURPOSE OF AACT***

*To represent and serve the unique needs of the affected adult community and to ensure that those needs are adequately represented to UMDF resulting in enhanced services to the affected adult population.*

*AACT is a liaison to the UMDF Board of Trustees and will assess, provide advice and guidance, and make recommendations to UMDF on adult related issues.*

## ADVOCACY UPDATE

### UMDF Prepares for Another “Day on the Hill”



Mark your calendars for June 2012, when the UMDF will hold another “Day on the Hill” in Washington, DC. Once again, the UMDF will schedule appointments for you with your Congressman and U.S. Senator in an effort to help us continue the awareness we began in 2009. Very soon, we will be introducing new versions of our House and Senate bills that will seek research collaboration.

The UMDF continues to hold high level talks with the National Institutes of Health (NIH) to find ways that we can work together to help coordinate the millions of dollars of research that the NIH currently funds in the area of mitochondrial research. Over the next 12 months, UMDF will continue to meet on Capitol Hill on your behalf to make sure that Washington D.C. understands that mitochondrial disease is not as rare as one might think.

#### **How you can be part!**

If you would like to be part of our advocacy grassroots effort and receive periodic updates on our initiatives, including our “Day on the Hill 2012” plans, e-mail your name, address, phone number and your e-mail address to us and we will put you on our advocacy list. Send your information to [news@umdf.org](mailto:news@umdf.org) and put “Advocacy” in the subject line.

## UMDF STRATEGIC PLAN PROGRESS

The UMDF staff continues to work on the process of putting our strategic plan in place. One of the components for the plan is a more regionalized approach to chapters and groups. UMDF will outline a pilot program for this regionalization model that will encompass support, education, development, and awareness. We will have additional details in our fall newsletter and online at: [www.umdf.org](http://www.umdf.org).

## SPECIALTY RESOURCES

### Summer Camps for People with Special Needs

Web: [http://www.amputee-coalition.org/fact\\_sheets/Kidscamps.html](http://www.amputee-coalition.org/fact_sheets/Kidscamps.html) Multiple disability camp listings

#### **Camp Sunshine**

Free camp for children with life-threatening diseases and their families. Their “mission is to address the impact of a life threatening illness on every member of the immediate family.”

35 Acadia Rd.

Casco, ME 01045

Phone: 207-655-3800

Fax: 207-655-3825

E-mail: [info@campsunshine.org](mailto:info@campsunshine.org)

Web: [www.campsunshine.org](http://www.campsunshine.org)

#### **Camp for All**

“Provides weeklong camps, weekend retreats and day programs for more than 55 different special needs groups.” Located in Texas.

Web: [www.campforall.org](http://www.campforall.org)

Mito Camp: <http://mitocamp.org/> (2011 dates: October 28-30, 2011)

#### **Camp Korey at Carnation Farm**

A “Hole in the Wall” medically-supervised camp where kids can go for free. They have a mitochondrial disease camp.

28901 NE Carnation Farm Rd

Carnation, WA 98014

Phone: 425-788-1511

Website: [www.campkorey.org](http://www.campkorey.org)

#### **Dream Street Foundation**

Our purpose is to provide a unique camping program, free of charge, to children with chronic or life-threatening diseases.

433 North Camden Dr.

Suite 600

Beverly Hills, CA 90210

424-248-0696

310-496-0439 (fax)

E-mail: [dreamstreetca@gmail.com](mailto:dreamstreetca@gmail.com)

<http://www.dreamstreetfoundation.org/>

#### **MDA camps**

Web: [www.mda.org/clinics/camp/](http://www.mda.org/clinics/camp/)

#### **Hole in the Wall Camps**

Free camps for seriously ill children

The Association of Hole in the Wall Camps

265 Church Street, Suite # 503

New Haven, Connecticut 06510

Phone: 203.562.1203

Fax: 203.562.1207

[www.holeinthewallcamps.org](http://www.holeinthewallcamps.org)

#### **The Woodlands (PA residents only)**

“Enriching the lives of children and adults with disability and chronic illness.” Weekend retreats, music camp, sports camp (including adaptive golf course) & aquatics program.

134 Shenot Road

Wexford, PA 15090

Phone: 724-935-6533

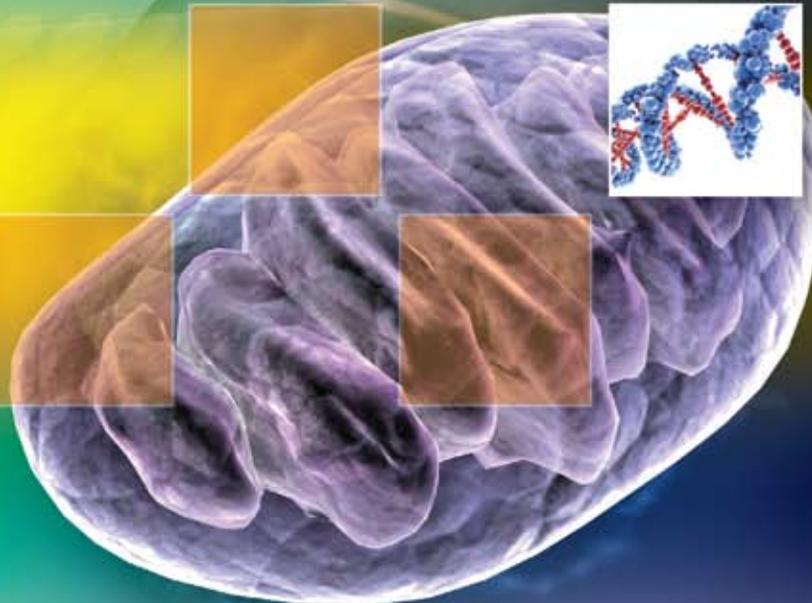
Web: [www.woodlandsfoundation.org](http://www.woodlandsfoundation.org)

If you have a resource you would like to see highlighted, please go to [www.umdf.org/](http://www.umdf.org/) submitaresource and let us know!

# Mito



COX10  
BCS1L  
COO2  
POLG



## Just Got Easier...

## Genetic Testing for Mitochondrial Diseases

### Testing Services:

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

### Patient Benefits:

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

More information: [www.genedx.com/mito](http://www.genedx.com/mito)



KNOWING WHAT TO LOOK FOR

KNOWING WHERE TO LOOK

AND KNOWING WHAT IT MEANS

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# ANNOUNCEMENTS

## UMDF Celebrates 15 Years

In June of 2011, the United Mitochondrial Disease Foundation (UMDF) will celebrate 15 years. The UMDF was started by Chuck A. Mohan, Jr., and his wife, Adrienne in 1996 through the merger of several smaller foundations established by those who lost loved ones to the disease. Started as a volunteer organization based in a basement, the UMDF has grown into a nationally recognized non-profit organization. The UMDF staff responds to hundreds of inquiries a month about mitochondrial diseases and offer affected individuals and families information as well as resources, referrals to experts in the mitochondrial field, and support. The UMDF is represented around the world by more than 60 chapters, groups, and ambassadors.

The UMDF is the leading non-governmental contributor of grants focused on mitochondrial disease research. Since 1996, the UMDF has funded more than \$8 million as part of our Research Grant Program.

## Rachael Pipp Recognized in Wisconsin

Rachael Pipp was one of the 103 people in Ozaukee County, WI recognized for doing positive things. Her positive actions include learning to use a walker instead of a wheelchair, which she has been in for five years. She was also recognized for her fundraising efforts for the UMDF. Some of her efforts include the following: riding a stationary bike for online donations and participating in Coins for a Cure. Coins for a Cure is a fundraiser in which plastic containers are placed on the counters of local businesses or schools with the goal of collecting money in them. If you are interested in doing Coins for a Cure, contact a member of the UMDF Special Events Department at 1-888-317-8633. The Special Events Department includes: Tania Hanscom, Rachel Mazur, and Nicole Shanter.



Coins for a Cure Container

## Leo's Law Passes in Minnesota

Gov. Mark Dayton signed a bill on Friday, May 27, 2011 that will designate the third full week in September each year as Mitochondrial Disease Awareness Week in Minnesota. Mitochondrial Disease Awareness Week was taken off of the calendar on Sunday, May 22, 2011. Anne Simonsen and members of the Minneapolis/St. Paul Chapter sent e-mails and made calls to appropriate government personnel to get the week back on the calendar. Rep. Rod Hamilton, R-Mountain Lake also helped with the effort. The bill passed in the Minnesota Senate, 129-1, and it was back on the calendar on Monday, May 23, 2011. To read an article about it, go to: <http://www.dglobe.com/event/article/id/48906/>. Another article was published about a variety of bills that were signed by Gov. Mark Dayton. To view that story, go to the following website: <http://www.dl-online.com/event/article/id/60739/group/homepage/>. Thanks to Anne Simonsen, Leo's Lions, and the Minneapolis/St. Paul Chapter who did an amazing job. Way to go!



Leo James Chapman-Nesseth

The bill was called Leo's Law and was named after Leo James Chapman-Nesseth who died shortly after his first birthday of Alpers disease, a rare genetic disorder of the mitochondria.



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**What's new in my area?**  
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**The Benefit of Support Groups**  
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**Specialty Resources**  
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