Epilepsy, Abnormal Movements, and Mitochondrial Cytopathies

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INTRODUCTION
Many patients with a mitochondrial cytopathy also have epilepsy. In addition, many have abnormal movements that are not epileptic in etiology. Unfortunately, most families learn about epilepsy from painful and emotionally stressful experiences during the initial seizure episodes. Further frustration often arises in defining what movements are epileptic seizures and what are just abnormal movements.

There is little published information concerning mitochondrial disease and epilepsy when they co-exist. Although many publications have described non-epileptic movements in mitochondrial disease, little awareness of these movements exists in emergency departments and physicians' offices. In the quest to arrive at a medical diagnosis, many parents and/or caregivers go from physician to physician. I have seen many caregivers labeled (at least suggested in conversations between health care providers) as having a psychiatric disorder (histrionic personality disorder) or worse as deliberately injuring their children (Munchausen-by-proxy syndrome) for this behavior.

In this article, I hope to provide some enlightenment on epilepsy, seizures and abnormal movements as they relate to one another in the context of a mitochondrial cytopathy. I will try and give some definitions of terms, understanding of procedures used to diagnosis epilepsy, practical hints on how to approach therapy, and tips on what you as parents or patients can do to allow physicians to take better medical care of seizure activity.

EPILEPSY VERSUS SEIZURE
Epilepsy, as defined by those people taking anti-convulsant drugs or who have had two or more seizures in the past 5 years, ranges from 4-10 per 10,000 people in industrial countries and up to 57 per 10,000 people in developing third world countries (Trescher and Lesser, 2000). Studies have estimated that 1.5-5.0 % of any population will have a seizure at some time in their lives. These data suggest that many more people have seizures than epilepsy. In addition, UMDF International Conference on Mitochondrial Disease
Visit the website at www.umdf.org for updates on future symposia.
More info to follow via upcoming newsletters and mailings

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Ask the Mito Docs and They Will Respond

In the Spring of 2001, UMDF introduced a new look for its web site and added a feature called Ask the Mito Doc. Members ask questions regarding mitochondrial diseases and they are forwarded to a mitochondrial specialist to respond. The questions and answers have been very informative and UMDF felt compelled to share some responses with all its members (especially for those who do not have internet access).

Please note that information contained in "Ask the Mito Doc" is for informational and educational purposes only. Such information is not intended to replace, and should not be interpreted or relied upon, as professional advice, whether medical or otherwise.

Responders for this issue: Bruce H. Cohen, M.D., The Cleveland Clinic Foundation, OH and Richard G. Boles, M.D., Children's Hospital of Los Angeles, CA.

THE QUESTION IS:
I have heard that Depakote is not "mito" friendly, but what exactly does that mean? Is this a theoretical conclusion, or is this an observed pattern? What have been some of the complications with other mito patients?

RESPONSE FROM: BRUCE COHEN, M.D.

There is a great deal of debate about the use of valproate in those with mitochondrial disease. This was discussed in a lively debate at the 2000 UMDF meeting in Cleveland. The transcript of this is available on audio tape through the UMDF office. Comments ranged from "I would never place a mitochondrial patient on valproate" to "Mitochondrial diseases are hundreds of different unique diseases and some patients can be safely treated."

Conflicting thoughts by experts Continued on page 3
Chairman’s Report

As I review the contents of this year’s Annual report I am reassured and confident that UMDF, in its 7th year toward a cure, continues on the correct path. The UMDF Trustees continue their focus on maximizing the efforts and results of the UMDF membership. The hard work of many volunteers is reaping tremendous benefits that continue to position UMDF strategically in its “quest” toward a cure.

The 5th annual UMDF symposium was held this past June in Dallas, Texas and is getting enthusiastic reviews. Feedback from the professionals as well as the parents has been positive and supportive. While many of us are settled back to our routines, after returning home from the symposium, the UMDF staff is already in the process of finalizing negotiations with supporting hospitals, hotels, universities, exhibitors and presenters for the next UMDF symposium.

UMDF’s greatest achievement this year was meeting its commitment by presenting research grants totaling $250,000. The grants were awarded to 4 different researchers all recommended by the UMDF Scientific Advisory Board as qualified recipients with realistic projects having the greatest impact on mitochondrial disease. This is our first installment of the $5,250,000 fundraising campaign. All funds were generated from cash flow representing all the hard work and fundraising efforts of the members. The UMDF Trustees work diligently to ensure that the results of your efforts and hard work are being spent in the most productive and prudent manner. The next installment “toward a cure” will be $500,000, which will be presented next year in June at the UMDF Symposium in Pittsburgh.

Please review the UMDF Annual Report to see how many accomplishments have taken place this past year. The successes experienced can in no way balance the continued effects of mitochondrial disease but they are the building blocks necessary to achieve our ultimate goal- a cure!

There is no secret recipe responsible for the positive growth of the UMDF. The success of UMDF is simply the strong focus and commitment of our Trustees to the UMDF mission, their guidance and perseverance and the continued support and hard work of the members. Simply stated by Anna Pavlova; “To follow, without halt, one aim: There’s the secret of success.”

Even though we are experiencing tremendous growth, the reality of the “cure” rests far beyond the “quest.” Should we get discouraged? Absolutely! Should we give up ... ?

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

— Jacob A. Riis

I won’t give up, will you?

Yours toward a cure

[Signature]

Chairman, UMDF
Ask the Mito Docs
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include the following:
1) Many patients come to diagnosis of a mitochondrial disease because they develop life-threatening complications (liver failure requiring liver transplant) when they are treated with this medication.
2) The fatal/life threatening hepatoxicity is similar to other mitochondrial processes
3) Many patients with mitochondrial diseases are on Depakote and have no problems.
My own personal practice includes a number of patients on Depakote (valproate) without a problem and a handful that have suffered near-fatal events. The risk seems to be clearly increased in young children previously treated with inducing anticonvulsants (ask your doctor which are and are not inducing drugs), and those on more than one anticonvulsant. It is not clear if close monitoring of liver function can really prevent the liver problem..... the issue of stopping the medicine if liver problems arise is one of “too little too late.”

THE QUESTION IS:
Can Mitochondrial Cytopathy be aggravated by Chiropractic treatment? or can Mitochondrial Cytopathy affect chiropractic results?

RESPONSE FROM: BRUCE COHEN, M.D.
I would not imagine that most mitochondrial symptoms would be aggravated by chiropractic treatment. However, mitochondrial disorders are highly variable and although I assume that chiropractic treatment includes manipulation and massage; there may be other treatments I am not aware of. Likewise, Chiropractic treatments may result in improvement of some symptoms of mitochondrial disorders, such as pain or stiffness. Unfortunately, the field of chiropractic medicine is still a “black box” to most of us allopathic doctors (M.D.s) and osteopathic doctors (D.O.s). I have had patients with pain, headaches, backaches and so forth benefit from chiropractic treatment. Many chiropractic doctors focus on nutrition and exercise, which is very reasonable as long as it does not involve therapies such as chelation. (However, many mito doctors are criticized for using supplements such as carnitine and CoQ10). Like any medical care, you need to choose your doctor with care. If a patient wishes to use chiropractic treatments, I do pick up the phone and speak with the other doctor to make sure we are on the same page.

THE QUESTION IS:
How does mitochondrial disease affect the brain, and cognitive function? How common is it to see a child with mitochondrial disease that is quite bright?

RESPONSE FROM: RICHARD BOLES, M.D.
As all cells and organs require energy, mitochondrial disease can affect almost any part of the body. However, because of their very high energy requirements, nerve and muscle, and especially brain, are affected more often than other parts of the body. Mitochondrial disease can affect any part of the brain, resulting in many possible problems that can occur in any combination, including mental retardation, learning disabilities, autistic features, depression, attention deficit, seizures, loss of balance (ataxia), floppy muscles (hypotonia), tremor, and many others. Many physicians have the opinion that all individuals with mitochondrial disease are mentally retarded. Many are, but many are not. The truth is that any level of intelligence is possible ranging from profoundly mentally retarded to profoundly gifted to quite bright. How common is it to see a child with mitochondrial disease that is quite bright?
the data show that both are common medical problems. So what is the difference between epilepsy and seizures? Epilepsy is a condition in which multiple seizures occur as a result of persistent abnormal brain function, whereas seizures may only happen once during a person's lifetime. The latter person would not be considered as having epilepsy. Having only a single seizure might be due to trauma, medications, illness, etc and therefore not the result of persistent abnormal brain function. This is an important point to remember when filling out health-related documents.

What about convulsions with a fever? Are these seizures considered epilepsy? The clinical events are actual seizures but the condition is not epilepsy in many cases. The National Institutes of Health consensus statement defines a febrile seizure as “an event in infancy or childhood, usually occurring between 3 months and 5 years of age, associated with fever but without evidence of intracranial infection or defined cause” (Consensus Development Conference on Febrile Seizures, 1981). Thus, both age and absence of underlying brain abnormalities are emphasized. The consensus statement also implies the reason for not calling this condition "epilepsy" as affected individuals are not predisposed to recurrent afebrile (without fever) episodes. The occurrence in the mitochondrial population remains to be elucidated. Anecdotally, both Dr. Bruce Cohen of the Cleveland Clinic Foundation (personal communication) and I (unpublished data) believe that a higher percentage of children with a mitochondrial disease have febrile seizures compared to their counterparts without the disease. This may be because children with a mitochondrial cytopathy may have an underlying neuronal function abnormality.

**TYPES OF EPILEPSY**

There are a variety of epilepsy types. Epileptologists try and group common signs and symptoms of patients into syndromes. A syndrome would include seizure symptomatology, electroencephalography (EEG) findings, medical history, neurologic and physical findings, neuroimaging, and metabolic and genetic testing. There is currently much debate concerning redefining the classification of the epilepsy types. The important parameter for you to know, and one that will likely not change, is that the basic classification stratification is based on the definition of electroclinical syndromes: localization-related or focal epilepsies, and generalized epilepsies. Focal epilepsy would be characterized by seizures where the first clinical and EEG changes indicate the initial involvement of one hemisphere or region. Generalized epilepsy would be characterized by seizures having the first clinical and EEG pattern changes involving both hemispheres (Commission on Classification and Terminology of the International League Against Epilepsy, 1989).

Both focal or localization-related epilepsies and generalized epilepsies are further divided into the classifications of idiopathic, symptomatic, or cryptogenic. Idiopathic is defined as those epilepsies that occur in the setting of normal neurological status, with seizures that begin in childhood or adolescence and lack any clear cause. Symptomatic epilepsies are those that involve abnormal neurologic or psychological findings and diffuse or multifocal brain lesions. The term cryptogenic refers to those epilepsies presumed to be symptomatic but have unknown cause. Most patients with a mitochondrial cytopathy and epilepsy would fall into the symptomatic epilepsy classification.

The group of mitochondrial patients with epilepsy that Dr. Bruce Cohen and I follow would be classified as focal or localization-related epilepsy. We have over 70 patients with epilepsy and only approximately 30% had generalized epilepsy, with 10% of these patients having infantile spasms. This latter epilepsy type is a very special type of infant epilepsy syndrome. Based on this data, I believe that the majority of mitochondrial cytopathy patients with epilepsy may have focal, symptomatic epilepsy. Most of the remainder of mitochondrial patients with epilepsy would be classified as having generalized, symptomatic epilepsy. The above data was presented at the UMDF-Dallas Symposium 2002.

**TYPES OF SEIZURES**

Seizures can be thought of as the clinical manifestation of an electrical storm in the brain. Because seizures are one of the major defining parameters of epilepsy classification, it follows that they are also classified as being partial (focal or localization-related) or generalized. Partial seizures are those where the first clinical and EEG changes indicate initial activation of a system of neurons limited to part of one cerebral hemisphere. One group of partial seizures is defined by the event occurring without loss of consciousness. This is called a simple partial seizure. A second group of partial seizures is defined by consciousness impairment during the seizure. When consciousness is impaired, the seizure is called a complex partial seizure. The impairment of consciousness may be the first clinical sign or a simple partial seizure may evolve into a complex partial seizure. A third group of partial seizures is defined by a partial seizure, either simple or complex, evolving into a generalized tonic-clonic convolution.

Generalized seizures are events in which the first clinical changes indicate initial involvement of both hemispheres. Consciousness may
be impaired and this impairment may be the initial manifestation of the seizure. The EEG findings are initially bilateral (both hemispheres) and are thought to reflect widespread neuronal discharges in both hemispheres. If there are abnormal body movements involved, then these are usually bilateral.

In small children, it is difficult to fully assess if the child has an impairment of consciousness during a seizure. This is especially true in a child with cognitive disabilities. As you can understand, the formalities of seizure classification breaks down when young children and infants are taken into account. There is a movement underway to try and develop more meaningful seizure classifications for infants and young children.

There is also a type of seizure that cannot be classified. This is not selective hearing loss by teenagers or husbands. We place seizures in this group when inadequate or incomplete data concerning the seizure event occurs. Also included in this group are some neonatal seizures that defy classification, such as infant chewing or jittering movements.

In my experience, patients with mitochondrial cytopathies fall into all three types of seizure classification groups: partial, generalized, and unclassified. Although I have not calculated exact numbers yet, I think the most common seizure type is generalized, myoclonic seizures. This type of seizure is defined as a sudden, brief (<1 sec), shock-like contraction, which may be generalized (whole body) or confined to the face and trunk or to one or more extremities, or even individual muscles or groups of muscles. I have seen seizure types from simply the loss of consciousness to generalized tonic-clonic seizures. There have been several patients who have only tremulousness or jittering movements. It is important to note that each seizure event is correlated with an abnormal EEG finding.

PAROXYSMAL NON-EPILEPTIC EVENTS

When abnormal movements occur without EEG or abnormal brain electrical events inducing them, we call these movements paroxysmal non-epileptic events (paroxysmal=spontaneous; non-epileptic=not induced by abnormal EEG activity). These events are very troubling to emergency room physicians, epileptologists, caregivers and families. This is especially true for patients with a mitochondrial cytopathy. Why do I say this?

Mitochondrial disease can produce abnormal movements. These can be both epileptic seizures and non-epileptic movements. Let’s initially talk about epileptic seizures. Seizures are repetitive abnormal movements that recur over time. They are unpredictable and their frequency can vary over a given time. Seizures usually occur without warning, unless a preceding aura occurs before loss of consciousness. By definition, aura occurs before loss of consciousness and for which memory is retained afterwards. For the most part, within a given patient the types of seizures remain constant in their expression. So, in a patient having a stable seizure type, it would be uncommon for a change in seizure type to occur. However, we know that occasionally seizures change and a patient develops a new seizure type. When the latter event has occurred, the physician would characterize the new seizure, hopefully with an EEG, and either change the dosage or the type of medication, or both. When a known seizure type begins to recur, we will often check medication levels to note if changes in the level of medication(s) are allowing breakthrough seizure activity.

Patients with a mitochondrial cytopathy can have abnormal movements that are not seizures. Examples would be tremor, body jitteriness, chorea, athetosis, and hemiballismus. These movements do not have an EEG correlation, in other words, they are not caused by detectable EEG abnormality. All these types of abnormal movements can occur repetitively, which can look like a seizure event. Generally, physicians do not treat these movements with anti-seizure medications. In fact, paroxysmal non-epileptic movements can occur with epileptic seizures in the same patient.

The dilemma occurs when a mitochondrial cytopathy patient develops a new repetitive movement. Is this an epileptic seizure? I can tell you that I have gone to the emergency room many times during the middle of the night to see a mitochondrial patient with a seizure or what is thought to be a new seizure type. I would call the EEG technician to come into the hospital, perform an EEG, and discover that the event was not a seizure but only a new abnormal movement. However, what happens when the physician is not familiar with your child or does not understand mitochondrial disease or epilepsy? I have seen too many patients being started on new (additional) seizure medication, or even worse-the patient is sedated, paralyzed, intubated, and life-flighted to the nearest major hospital without a medical investigation. Seizures can be life-threatening and many emergency physicians do not have the capability of arranging an EEG in the middle of the night and having a trained epileptologist read the EEG. So, the intensity of medical management is understandable.

What can you as the caregiver do to encourage proper investigations, to ensure proper medical treatment? The first thing is to have a good working relationship with the primary health provider of your child. Hopefully, it is a physician knowledgeable in the medical management of seizures and mitochondrial disease. A quick phone call can forestall a major medical procedure. You should maintain a written description of all the known seizures, a list of all seizure medica-
Epilepsy, Abnormal Movements

Continued from page 5

tions (the doses and the most current drug levels), and past seizure medications that your child has taken. This will help prevent treating a non-epileptic movement, over-dosing on medications and using previously failed medications. You should have a medical emergency plan that has been set up with your physician for the possibility of a new seizure or breakthrough seizure. This should include criteria for using rectal valium, calling 911, and the names to be called in case of an emergency.

Most of you know that many physicians do not know about or understand mitochondrial disease. The initial diagnosis has been made only through your hard work and persistence. I congratulate you on how well you have overcome stiff obstacles. However, the same traits that finally resulted in your son, daughter, or loved one to be diagnosed with a mitochondrial cytopathy are the same traits that many emergency room staff and some physicians might consider histrionic or “Munchausen”. In other words, you are trying to get attention or seeking medical care that is not needed, usually for your own benefit. Most of us who have taken care of mitochondrial cytopathy patients understand your travails and do not think twice about the persistence needed to adequately care for your child or loved one. However, this heartfelt concern is not widespread in the medical community. So, your understanding and teaching about mitochondrial disease needs to be tempered in knowing that you probably know more about mitochondrial disease than the physician and staff who is treating your son or daughter.

CONCLUSION

Many patients with a mitochondrial cytopathy have epilepsy. Our data suggests that about 30-40% of the mitochondrial cytopathy population have epilepsy (unpublished data). I am not aware of any publication demonstrating co-existent data on paroxysmal non-epileptic events or abnormal repetitive movements. My opinion is somewhat biased as I am a pediatric epileptologist. However, I think that seizures need to be characterized by EEG and video, if possible. [If you have a video recorder, it is great to have video of abnormal movements or seizures for us to review]. By knowing what is an epileptic seizure and what is not, we can be certain that we are treating seizures and not just events. Also, we can adjust medications appropriately. As many of you already know, the process of diagnosing what is an epileptic seizure and what is not can be a frustrating experience. It is very important that you as a caregiver know how the seizures look, the medications, doses and serum levels of medications, and what medications have failed in the past. This information is needed for us to give your son or daughter optimal medical care. This is a lot of work, however, the gain in quality of life is well worth it.

References


United Way and You

Many companies require United Way giving - why not take this as an opportunity to support UMDF and its new 5 year grant initiative. Start off by asking the employees you work closely with and maybe they’ll help spread the word.

How to Make it Work . . .

The United Way campaign in your local area is designed to meet a diversity of health and human care needs. You may give an unrestricted gift and, in some areas, you may designate UMDF as the recipient of your gift to United Way. Contact your local United Way office to find out if there is a DONOR CHOICE program in your area. We have received funds from a variety of communities through the Donor Choice program and appreciate being included in this effort.

We will acknowledge each gift received unless otherwise indicated or if no address is provided.

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

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

Matching Gifts . . .

Your gift could be doubled! Does your employer participate in a Corporate Matching Gift Program? If so, your gift could be doubled. Please obtain the appropriate form from your comptroller or personnel office using the same contact information as you would for a United Way designation.
Pittsburgh Golf Outing Raises over $40,000 and Roasts UMDF Chairman, Chuck Mohan

The Fifth Annual Golf Outing raised over $39,000 on June 22 - taking the annual event’s total to over $163,000 since its beginning in 1998. The 2002 event also scored its first Hole In One winner - Mr. Art Schake walked away with a 2002 Buick Rendezvous, courtesy of Hamilton Buick, GMC, Mazda & Subaru of Irwin, PA.

During the evening dinner, a special “Roast” was initiated through one of the golf event coordinators. Special guests, Dr. Bruce Cohen and long time friend, Jim Antis, "educated" the attendees on the life of Mr. Charles A. Mohan, Jr. and his continued dedication to the UMDF Mission.

2nd Annual Kites for Kristen Raises over $5,700

The week of May 13-17, children at St. Daniel the Prophet School in Chicago, IL, were asked to make a donation to the UMDF and in return they were given a paper kite to decorate. According to Pat Charleston, Kristen’s mother, some children were real good artists while others wrote inspirational messages for Kristen. Anyone who donated were allowed to “dress down” on Friday in colorful clothing. One of the fifth grade classes won the grand prize for donating the most money and enjoyed a hot dog lunch.

In her letter to the home office, Pat noted that “I don’t consider myself an outgoing person but after the San Diego conference in 2001, I felt that it is my mission in life to help my daughter and all others afflicted with Mito disease so I gave fundraising a try and yes, I’m proud. Knowing that I’m doing all humanly possible makes this disease a little easier to deal with." She’s already got the okay for the 3rd Annual Kites for Kristen. We’re proud of you too Pat!

2nd Annual Tierney Holiday Golf Tournament

On December 20th, 2001, Tierney Communications of Philadelphia, Pennsylvania, raised $1,081 during their 2nd annual office golf tournament. Each hole was developed with a distinctive theme. For example, our Yellow Pages group set up a hole called “Let Your Putter Do the Walking” where the entire hole was outlined in phone directories. Creativity and difficulty was the common theme of all the holes and less than 5% of the participants scored under par.

The donation of $1,081 was realized via greens fees and hole sponsorships. Each participant was required to pay a minimum greens fee of $5 prior to playing the course. Sponsors included, but not limited to, WPVI-TV (ABC), Clear Channel Outdoor and Traffic Pulse Radio.

Festival Booth

Hope and Keith Barnhill, of the South Carolina Support Group (which is led by Karis Mott), raised awareness and over $200 at an information/donation booth during a local festival in honor of their son Joshua as well as all the other families affected by mito.
Fundraisers

4-H Club Freedom Farmers

The Freedom Farmers 4-H Club bagged groceries on July 6th at the Pick-n-Save grocery store in Ironton, Ohio. The club raised over $750 for UMDF and raised awareness of the disease by passing out over 400 UMDF pamphlets. The club donated the money in honor of Jordan Gresham and made him an honorary 4-H member. Keep up the great work Freedom Farmers!

Sweet Tomatoes Restaurant Fundraiser Brings in over $2,600

Due to personal injury, Lori Camaiani took the year off from her annual Megan E. Camaiani 5K Mito What? Walk/Run. However, through the efforts of Julie Clare, an energetic 17 year old friend of the family, over $2,600 was raised on June 5, 2002 at a Sweet Tomatoes Restaurant in Coral Springs, Florida. Julie wanted to do something to continue the Camaiani’s fundraising endeavors for the year 2002 and contacted the restaurant to get the ball rolling.

Heidi’s Wine Tasting Another Success

After last year’s wine tasting event, Norma Gibson said that her daughter Heidi would be looking over her shoulder counting every penny in 2002 and we’re sure that Heidi has a smile on her face — the Wine Tasting raised $6,244 this past June and she was probably counting those pennies! To all of Heidi’s family and friends — thanks for keeping her memory alive through this very special event!

Raffle Benefit for Little Emily

Debi Plesko and her friend Jodi organized a Raffle Benefit for Little Emily (Plesko) and as a result of this benefit, $1,500 was donated to UMDF in honor of Debi’s 4 year old daughter, Emily. Thank you so much Pleskos and to Grandma Evelyn Perry!

Hearts Full of Hope Cookbook Sales Continue

This is a special cookbook with 602 recipes submitted by our very own mito families, friends and relatives across the states. Some recipes are in honor or memory of loved ones. The spiral bound, laminated hard cover book includes over 100 inspirational sayings, information about mito disease, and each category divider has a special poem. Again, we thank Tishcon Corporation for generously funding one half the cost to reprint 1,500 more books which means more profit to support the UMDF mission! Get your orders in now for Fall and Winter holidays and any special birthdays that you have coming up!

To order your cookbook(s), please contact the chapter nearest you or the national office at 412-793-8077. The cost is $15.00 plus $2 shipping and handling (Shipping will be higher for orders taken outside the US/Canada). Order forms are available via the UMDF web site or the national office.
Fundraisers

For her 8th birthday, Grace Thomas asked her friends and family to donate to UMDF in honor of her brother, Gabe Thomas. Grace is center holding UMDF sign - Happy Belated Birthday. Grace and please thank all your friends and family for the $675!

Thank You ...

to the Individuals and Organizations who helped make the UMDF Mito-Dallas 2002 Symposium possible

The Dallas 2002 Mito-What? Party!

A combination of efforts and generosity from many individuals and the following major contributors to the Mito-What? Party! provided the majority of the funding for the UMDF Mito-Dallas 2002 symposium:

- Pat and W. Dan Wright, TXU Communications
- Joy and Craig Lentzsch
- Lester Levy, NCH Corp.
- Risa and Jay Bender, M.D.
- The Hoglund Foundation
- Marsha and Dale Clark
- Sally and Forrest Hoglund
- Jane and Jerry McManus
- Karen and Les Alberthal
- The Mike A. Myers Foundation
- Kay and Elliot Cattarulla

Many thanks to these underwriters of the 2002 UMDF Symposium:

- The Hoglund Foundation
- The Eugene McDermott Foundation
- Medical City and the North Texas Hospital for Children

Exhibitors:

- Advanced Technology Program, NIST
- Exceptional Parent
- MegaEasy Computer
- Sigma Tau Pharmaceuticals
- Texas Talking Books Program

And to all of the Speakers, Professionals and Volunteers who donated countless hours: Many, many thanks!

Letter of Love

As you can see I have donated $10. This $10 is for my little cousin Ryan (Meade). He died at age 4 because of this disease. This money is in memory of my smiley little cousin. I will try and send at least $10 a month. Thank you for your attention. Have a good day.

Sincerely,
Megan Talley

Charity Softball Tournament

With the leadership involvement of UMDF member, Jody Czako, the Columbus office of BISYS Fund Services in Ohio selected UMDF for their June Jeans Day Charity. Each month, one Friday is chosen when associates can wear jeans in exchange for a donation to a variety of charitable organizations that are recommended by associates. The “Jeans Day” raised $650 to benefit UMDF.

Jeans Day Charity

Through the leadership involvement of UMDF member, Jody Czako, the Columbus office of BISYS Fund Services in Ohio selected UMDF for their June Jeans Day Charity. Each month, one Friday is chosen when associates can wear jeans in exchange for a donation to a variety of charitable organizations that are recommended by associates. The “Jeans Day” raised $650 to benefit UMDF.
Individuals, families, caregivers, researchers and physicians helped "Turn Up the Power" this past June by attending the 5th International Symposium on Mitochondrial Disease. In one weekend, over 30 speakers caught the attention of eager attendees seeking new information and all walked away with just a little more - whether it was new information, a new network of support (new friends), resources, or maybe just the feeling that they are not alone in their battle against Mitochondrial Disease.

The Scientific Meetings attracted doctors from all over the world and topics seemed to be well received by those in attendance. One doctor emailed the home office and stated that "The symposium is a powerful stimulant; I came home with a ton of new ideas!" If every researcher walked away from the meeting with such a feeling, imagine the progress that can be made in the upcoming years.

The Family Meeting attendees gave the symposium an overall "thumbs up." Those new to the conference scene and our veteran attendees enjoyed the many opportunities to network with physicians and other families. Most were very receptive to the new meeting format - offering two separate tracks - and hope to see this continued in the future.

The biggest hit, as a new addition, was the "Doctor is In." During the session breaks, doctors were stationed at a booth to answer questions from individuals and families and the line was constant for these wonderful physicians! Special thanks to all the doctors who shared their expertise with the families at the "Doctor is In" booth.

Audio Tapes are available for each session, including the Scientific Meetings. Video Tapes are available for a select few of the sessions.

For order information please contact:
Strong AV Productions, Inc.
417 Vista Noche Dr.
Lewisville, Texas 75067
Ph/Fax (972) 316-0678

Order forms are also available at the UMDF office and website at www.umdf.org.

If you were unable to attend the Mito-Dallas 2002, we encourage you to purchase your tapes today. The home office also has a limited supply of syllabi from both the scientific meetings and the family meetings. Contact us at 412-793-8077 for order information.
Future UMDF Symposia
We Want to Hear From You!

Your life has been severely compromised by Mitochondrial Disease and you want to better arm yourself to provide the best care possible for yourself and/or your loved ones. The UMDF Board of Trustees has approved the continuance of symposia because it is one of the single most important venues to educate families and physicians as well as provide a strong atmosphere for networking and support. To better serve you, we would like your feedback on topics of interest as we plan for future conferences.

Please indicate ideas for future session topics:

Please suggest names of doctors or other medical professionals to invite to future symposia as a speaker and kindly include contact information for the suggested speaker(s):

How have you heard about the past meetings?

Mailed brochure _____ Newsletter _____ Internet _____
From a friend _____ From your physician _____
Other (Please specify):_________________________________________

Please complete this form and send it to UMDF, 8085 Saltsburg Road, Suite 201, Pittsburgh, PA 15239. Or fax it to us at 412-793-6477. An online form is also available via the website at www.umdf.org.
Thanks To Our Contributors

The United Mitochondrial Disease Foundation wants to thank the many people who have made contributions that will support our initiatives. 2-26-02 to 7-8-02

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In Support of the Mito Dallas 2002 Conference
- Medical City Dallas Hospital
- The Eugene McDermott Foundation
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GUARDIANS $1,000 - 4,999
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- In Honor of Hannah & Emma Bruder and Jordan & Arielle Cohen
- Dr. Martin & Norma Markowitz
- In Memory of Linda M. Rice
- Joe & Patricia Rice
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Dealing with Emergency Treatment

Many adult patients with Mitochondrial Cytopathy are hesitant to go to the emergency room for acute problems associated with mitochondrial disease because of negative, even damaging, experiences. Mitochondrial Cytopathy symptoms often do not quite fit the classic models for typical emergency room problems.

Chest pain does not test like either a classic heart attack or the usual alternative of uncomplicated gastric reflux. A request for specific pain relief medication for intense headache instead of medications usually helpful for migraine can be seen as an attempt to obtain controlled drugs illegally. A busy physician may interpret extreme weakness as a psychiatric problem and pass the patient on to a social worker rather than ordering screening tests. Change in consciousness may be seen as probable drug abuse. Movement disorders may be treated as seizures leading to inappropriate prescriptions and in some parts of the USA mandated Department of Motor Vehicle notification and loss of driving privileges.

Russell P. Saneto, DO, PhD and Bruce H. Cohen, MD in Management Strategy for Acute Illness in Patients with Mitochondrial Cytopathy, list the following indications to seek emergency medical attention:

- Unexplained or excessive fever
- Alteration of usual level of cognitive function
- Confusion, excessive sleepiness, excessive crying
- Vomiting
- Loss of appetite
- Rapid breathing
- Abdominal pain

Even for more typical Emergency Room visits involving injuries or acute infection, differences in metabolism can require modifications in treatment. The patient or caregiver, along with the primary care physician, should develop a plan for how these illnesses will be approached ahead of time.

In addition to their own health concerns, many adult Mitochondrial Cytopathy patients are caregivers for family members with mitochondrial disease and need to be prepared to help them get appropriate and timely medical attention too.

The Mitochondrial adult group submitted the suggestions described below. Because of the nature of mitochondrial disease, not all suggestions will fit everyone, so please work with your own physician, specialists, and caregivers to help make preparations that are appropriate; then hope and pray that they are not needed.

There can be positive outcomes from emergency room visits. This may be the first opportunity for your physician or other qualified medical personnel to examine you during a "bad spell" or crash. This may help to manage your disease better or lead to a better diagnosis.

EMERGENCY PROTOCOL LETTER

The patient and the primary care physician, in coordination with consulting specialists, can prepare an emergency protocol letter much like the examples on the Fatty Oxidation Disorders website (http://www.fodsupport.org/child_sick.htm links in the lower right column). Print one and take it with you for your next appointment and ask your physician to develop one for you.

WALLET CARD

Sandra Sirrs, MD, FRCPC, Adult Metabolic Diseases Clinic, Vancouver General Hospital, British Columbia recommended preparing a card containing the following information:

- Name
- Diagnosis
- Address
- Phone
- Emergency contact
- Family doctor and phone
- Medications and daily dosage

AN EXPLANATION OF MITOCHONDRIAL DISEASE

"Mitochondrial Disease is a genetic disorder involving areas of the body with high energy requirements (CNS, skeletal musculature and cardiac muscle). Mitochondrial disease can affect all body systems and can lead to acute symptoms such as seizures, early stroke, peripheral neu-
ropathy, cardiomyopathy (heart failure and conduction block), Fanconi syndrome, intestinal obstruction and diabetes. These problems can be worsened by general anaesthetic or surgical stress."

**EMERGENCY ROOM SURVIVAL KIT**

Assemble materials and keep them in a sealable plastic bag in an obvious place (taped to the refrigerator, for example) so that it would be available for paramedics. Think one for your vehicle and a small one for your wallet or purse. Make sure both your major caregiver and a reliable friend have one of your Emergency Room Survival packages.

**KEEP THE INFORMATION CONCISE**

- Emergency Protocol Letter
- Copies of recent laboratory reports
- Up-to-date list of medication and dosages
- Nonprescription medications such as the vitamin "cocktail"
- A listing of next of kin designate and contact information, resuscitation orders
- Money for telephone calls
- Your name, address and telephone number
- Your health insurance information
- Anesthesia chart (see excerpt from Dr. Cohen's article available at the UMDF office)
- MedicAlert card, which will contain Primary Care and Specialist names and contact information
- List of contraindicated medications

**MEDICALERT**

MedicAlert is a multinational organization, which maintains a database of clients' names, addresses, telephone numbers, date of birth, and identifies them by a member number. Members wear a bracelet or necklace and carry a card. Emergency responders are trained to identify the emblems and contact Medic Alert (although patients should be aware that there is no legal obligation for emergency personnel to look at the tag). A collect call to the MedicAlert Emergency Hotline (for emergency personnel only, at 209-634-4917) can provide additional information including:

- Full contact details for primary care and specialist physicians
- Full contact details of emergency contact individuals
- Allergy details
- Any special information, e.g. extreme reactions to specific products or foods or MALIGNANT HYPERTHERMIA hotline and details
- Medication details including dosages
- Health Provider details

You can join on-line at the MedicAlert secure Internet web site http://medicalert.org/ or use their inquiries@medicalert.org e-mail address. MedicAlert forms are also available from doctors' offices, community health agencies, and pharmacies.

**OTHER RECOMMENDATIONS**

Instruct a trusted friend or caregiver who can accompany you to get the emergency room physician's name and telephone number then inform your Mitochondrial Cytopathy specialist of the situation. This person should also have the names and contact information for other members of your care team (neurologist, endocrinologist, physiologist).

Add your current height and weight to the information to help determine dosages. This is important for children, but adults with Mitochondrial Cytopathy can experience extreme weight changes.

Medical directives listing next of kin designates, resuscitation orders, and treatment protocols can be filed with the local hospital and an attorney. Unfortunately, emergency room files are often made up without accessing the main facility's medical record archives, and the attorney may not be in his or her office at the moment the patient arrives in the emergency room. Therefore copies of this information (in your kit) could prove helpful the next time you find yourself visiting an ER.

This Adults Corner was provided courtesy of the collaborative effort of the following individuals: Tara Collyer, Kathy Graff, Denise Gregorich, Pat Kniel, Brenda Shanley and Jean Sheperd.

**UMDF at WORLD CONGRESS ON DISABILITIES**

The UMDF will present a booth at the Third Annual World Congress & Exhibition on Disabilities on October 3-5, 2002 at the Orange County Convention Center in Orlando, Florida.

All UMDF members are welcome to stop by. Look for us at the Non-Profit Exhibitors area in the exhibit hall!
Let the Buyer Beware
By Ken Cooper, M.D., M.P.H.
Founder/CEO, Cooper Clinic,
Dallas, Texas

I know that I am "preaching to the choir" when I speak to UMDF about the importance of vitamin supplementation. Obviously a well-balanced, nutritious diet that includes ample servings of fruits and vegetables is the foundation for optimal health, but I feel that the right combination of vitamins and minerals is also essential to properly maximize what your diet provides.

One of the biggest problems though is being able to trust what you buy. Unfortunately because of DSHEA, the Dietary Supplement Health and Education Act of 1994, it's virtually impossible to know for sure that what it says on the label is what's inside the bottle. Instead of treating nutritional supplements like prescription drugs, they are classified as foods, which means there is little scrutiny, if any, involved before products end up on the shelves. The Food and Drug Administration has minimal resources to counter the incredible lobbying efforts of the nutritional supplement industry.

Here is how Dr. Christine Lewis Taylor, director of the FDA's Office of Nutritional Products Labeling and Dietary Supplements, explains the problem, "We have very few field staff and no budget at all to compile the kind of proof that would stand up in court." That clearly is something that needs to change but I don't foresee any substantial improvements in the near future.

SOME VITAMIN TIPS

Here are some things to keep in mind regarding vitamins. First of all, they work synergistically, not independently. For instance, vitamin E is a very powerful antioxidant but is much more effective when combined with proper amounts of vitamin C. Vitamin C works to "invigorate" vitamin E. If you take E without C you will not get the best "return on your investment."

Mixing and matching your supplements can be counter-productive if you don't know what you are doing. That is why we suggest you find a good multivitamin that already contains the proper levels of the key nutrients you are looking for.

Be sure to take your vitamins with meals. That will ensure the best absorption of the fat-soluble vitamins, which are A, D, E, and K. Those are the vitamins that the body can store, which means you should be careful not to go over the Tolerable Upper Intake Levels, or UL's, established by the National Academy of Sciences. You should not have a problem unless you are "mega dosing."

The water-soluble vitamins, such as vitamin C and the B vitamins, cannot be stored in the body. They will simply pass through the system much like a glass of water. That is why we recommend that you take your vitamins in at least two doses (with breakfast and dinner), to ensure that you maintain the proper levels in your system throughout the day.

Always look for a natural, rather than synthetic, vitamin E. Natural E, which comes primarily from soy, is about sixty percent better absorbed than is synthetic vitamin E, which usually comes from petroleum by-products. How can you tell? Not by the label, but by the fine print on the back. The scientific name for vitamin E is alpha-tocopherol. Natural vitamin E will be listed as d-alpha-tocopherol. Synthetic vitamin E will be listed as dl-alpha-tocopherol. You want the "d," not the "dl." Some people think of it this way, "d" stands for delivers, and "dl" stands for delivers less. Natural vitamin E is more expensive than synthetic but is well worth the investment.

Editor's Note: This article does not constitute the endorsement by the UMDF of Cooper Vitamins or any other vitamin company. Your purchase of any vitamin is at your discretion. Please consult with your physician prior to making any changes to your or your child's vitamin therapy.

Chapter
Activities

WISCONSIN CHAPTER
Rock-A-Thon

Students at Ripon College Alpha Delta Pi Sorority and Theta Chi Fraternity decided to help us find a cure through a fund raising effort they conceived. The students collected pledges to sit in rocking chairs in front of a local store in the small town of Ripon, Wisconsin. While there, signs were made and additional pledges were collected to also raise awareness totaling over $800.00. This gesture endured the hurdles associated with most fundraising efforts and then some.... the weather did not cooperate and the students braved wind rain, sleet and snow to "redefine hope". Their determination to help promote our mission was a resounding statement of their character. We are thankful for their friendship and support and look forward to our future together.

Cajun Fest

BRIGGS & STRATTON "Blues Busters" Provided Power to help us find Energy for a cure

Our good friends and family served UMDF and Beer in exchange for a financial contribution

Cajun Fest is a celebration based on the Louisiana bayou tradition of family and community gathering for a good time. Our families, friends, the Metropolitan Milwaukee Nights
Kiwanis, and Briggs and Stratton Employees rallied together in the same spirit to staff this year’s event on behalf of UMDF Wisconsin Chapter. In exchange for our labor a contribution based on a portion of the profits will be directed to UMDF. The Briggs and Stratton Corporate band “Briggs Blues Busters” played an energetic set, as did Harley Davidson’s “Parts Rock & Accessories Roll” donating their time and talents Friday night on behalf of UMDF to help Redefine Hope. This event not only helped to raise money but also raise awareness and created inroads within our community for our foundation. All of our volunteers wore distinctive t-shirts with the UMDF logo to identify our concern. An estimated crowd of over 20,000 was on hand throughout the weekend and many questions were asked regarding the disease and the foundation. Thanks again for the commitment and united effort to help the foundation further our mission and help those we love.

NEW YORK METRO CHAPTER

Tickets for the "Vacation Toward a Cure" raffle went on sale June 1st and will continue through October 27th when the drawing will be held. The grand prize is a five-night vacation in Florida for a family of four. American Airlines donated roundtrip airfare from any airport they serve in the continental USA. Walt Disney Co. has donated passes to their parks for three days. Accommodations in a condominium are being donated by the O’Hara family (friends of the Rices). Raffle tickets cost $5 each or a book of 6 tickets for $25. Anyone interested in purchasing tickets or in helping with the sale of this event, please email us at NYMetroChapter@umdf.org or call us 631-862-8975.

The drawing for this event will be held at the Wine-Tasting Dinner scheduled for October 27, 2002 at Café Testarossa in Syosset, NY. Tickets for the wine-tasting dinner will be on sale in August. We have acquired additional space for this year’s dinner so we can, hopefully, accommodate all who would like to attend. Since this was a sold-out affair last year, we recommend making your reservations early. We will take names on a reservation list and forward your tickets as soon as they become available. The price is $75 per person.

On October 6, 2002, we will have an informational booth at St. James Day on Lake Avenue in St. James, NY. Raffle tickets and wine-tasting dinner tickets will be on sale there for anyone who has not purchased them yet. Cookbooks and Mito-bears will be on display and orders will be taken. Stock is available; orders will be filled immediately. Informational booklets and pamphlets about mitochondrial diseases will be available. Please stop by the booth and say "hello".

Our next meeting is scheduled for August 24th at The Manhattan Club, 200 W. 57th Street, New York City. Please email or call us if you are able to attend so appropriate meeting space will be available. The chapter meets six times yearly. Please visit the web site or watch your mail for chapter updates. If you have not received our questionnaire and would like to keep receiving updates form our chapter, please email, phone or write us at NYMetroChapter@umdf.org, 631-862-8975 or UMDF NY Metro Chapter, 1 The Hunt, St. James, NY 11780. We are also in need of volunteers to help with some of these projects.
**SOUTHERN CALIFORNIA CHAPTER**

On Saturday, March 30th, the Southern California Chapter held their first golf outing in Long Beach. It was a beautiful sunny day with over 80 people in attendance. The day included 18 holes of golf, an all you can eat lunch buffet and terrific raffle and tournament prizes. The event was such a great success, it raised over $17,000! Everyone had so much fun, they are looking forward to next year's golf outing. The chapter would like to thank everyone who attended and a special thank you to the Bickerstaff Family, Keno’s Restaurant, the Cooper Family, Smith-Cooper International and First Team Real Estate in Yorba Linda for their extra help in making this event such a success.

The chapter’s next fundraiser is a huge family garage sale, scheduled for the last Saturday in June. Last year the chapter raised over $1,600! This year’s goal is to double that amount. If you live in So. California and would like to donate slightly used items, please contact the chapter at 562-634-1557. Chapter collects and stores donated items all year round.

UMDF Ribbon Awareness Pins have been designed by the chapter for the UMDF National office for distribution. These one inch, die struck flat pins (dark green and silver) include a printed information card about mitochondrial diseases. They are great conversation pieces! If you would like to order your pin, please call UMDF direct at 412-793-8077 or contact your local chapter.

The chapter continues to have “on-going” fundraisers - MRM Vitamins, North Bath and Body Shop, Albertsons Community Partners Cards and the United Way.

**NEW ENGLAND CHAPTER**

The chapter raised over $9,400 during three Boston Bruins games by selling 50/50 raffle tickets this past spring. Special thanks to all the volunteers who gave their time to sell tickets.

Chapter member, Mary Ryan, held an Evening of Jewelry to benefit UMDF in honor of her son, William Ryan. The party, featuring the works of Jennifer Tuton, was a great success and raised $8,000! Thank you Mary and Tim Ryan!

**ARIZONA CHAPTER**

Meet "RADIANCE" the UMDF "ENERGY BEAR"

The Arizona Chapter is proud to announce the development of the "Energy Bears"! The name of this year's bear is "Radiance". The bears will sell for $10 each plus $2.50 for shipping and handling (shipping will vary for orders outside of the US/Canada).

"Radiance" is a long-furred classic brown bear with an iridescent bow around its neck. "UMDF" is embroidered on its chest and "Redefining Hope" is embroidered above the bear’s bottom. Two bears were designed for this year. The first one is "Radiance" as just described and the other is the same bear, but with iridescent wings.

Each bear has a hangtag on its paw and the poem inside reads:

Trials and mishaps may come our way, For our cells lack energy everyday. Through support we will endure, As we work to find a cure. Funding research is our plan, To take us from where we began.

If the bears prove to be successful, the Arizona Chapter plans to design and name a UMDF collector bear each year. “Radiance”, the “Energy Bear”, will make a great gift for birthdays, celebrations, get-well gifts and for the holidays.

To order your "Energy Bear" or if you have questions, please contact your local chapter or if you do not have a chapter near you, contact the Arizona Chapter at 623-853-8533 or the home office at 412-793-8077.
Michael Friedberg, member of the Delaware Valley Chapter and father of Zachary Friedberg, held a fundraiser at his workplace - Liberty Healthcare System's Revenue Management Department. For $1, employees placed guesses on the amount of candy in a jar in honor of Zachary. Thanks Liberty Health employees for raising $145 to benefit UMDF. Another Zachary Friedberg fundraiser was held through the Congregation Kol Ami via bake sales - $1,052 coming to UMDF. Thanks Zachary and Kol Ami!

The 3rd Annual Shelly's Heroes 5K and 1 Mile Run/Walk and Blosky Blast-Off Children's Races was, once again, a great success - raising over $14,000 to benefit UMDF!

Children’s activities were a huge hit - kids enjoyed the Moon Bounce, the Slime experiment, Moon Rock Painting, and the Fizz-Powered Rocket experiment. Special thanks to the Pot o’ Gold Crew for organizing this wonderful event and to John Walsh (overall male winner of the 5K race) who generously donated his prize money back to Shelly's Heroes!

The Haircuttery in Flourtown, PA held a Cut-a-Thon in April and raised $812 to benefit UMDF.

Chapter Activities

OHIO CHAPTER

Chapter Takes Us One Step Closer to a Cure on June 1 Raising over $107,000!

When called upon to help end the devastating effects of mitochondrial disease, families and friends across Ohio came together on June 1st to raise an astounding $102,298 in celebration of the 1st Annual UMDF 5K Run/Walk...One Step Closer to Cure!
Tomato Face Foods

Spaghetti sauce has given Barbara Bruck, founder of Tomato Face Foods, a reason to live. Barbara, diagnosed with Mitochondrial Disease, had to be careful with her diet and medication in order to avoid the fatigue and a myriad of symptoms that could kill her. Her taste for red meat motivated her to create her meatless “meat sauce” and has helped her cope and live with this incurable and degenerative mitochondrial cytopathy. Not only is this no-fat spaghetti sauce saving her life but it is destined to help in the fight to find a cure.

Tomato Face Foods, a Division of A&B Cuisine, LLC was established in 2000 with a goal of creating a great tasting healthy food and to contribute to the fight against Mitochondrial Disease. Ten percent of the proceeds will go to the United Mitochondrial Disease Foundation to support research.

According to Barbara, “we began as a dream, with an unwavering commitment to a cause and I believe that we will continue to grow, bringing hope to those who have been touched by this disease.” The company’s product is now being sold in three Ohio stores. You can find it at all 14 Greater Cleveland Heinens Supermarkets, the West Point Market in Akron, Internationally acclaimed Jungle Jim’s, located just outside of Cincinnati, Ohio. The Original Meatless “Meat” Sauce may also be purchased through Stello Foods by calling 1-800-849-4599 or by Fax 814-938-8769.

This sauce is available in two flavors, ORIGINAL and MUSHROOM and is soy based using the freshest natural ingredients and simmered to perfection. To learn more about The Original Meatless “Meat Sauce” or Tomato Face Foods, visit them at their website: www.tomatofacefoods.com or email info@tomatofacefoods.com or write Tomato Face Foods, P.O. Box 22694, Cleveland, OH 44122.

What a picture perfect day it was—a day many of us will keep etched in our minds. We are gearing up for next year with many new ideas to put together an event even bigger and better. Anyone interested in organizing a run/walk in their state, please contact the national office at 412-793-8077.

Special thanks go to KFC, Pepsi and WOIO/WUAB for making our first annual event such a success.

UPCOMING EVENTS
IN OHIO

September 21, 2002
UMDF Ohio Chapter Family Picnic, Glenn Chamberlin Park, Twinsburg, OH

October 19, 2002
1st Annual “Mitoween” Party

December 14, 2002
3rd Annual Holiday Celebration

The Ohio Chapter on-going activities:
UMDF Cookbook sales
Vacation Towards a Cure raffle (Disney Trip)
Radiance the UMDF Energy Bear sales
UMDF MEMBERSHIP AND DONATION FORM

☐ Enclosed are my $40 Annual Membership Dues (Outside U. S. $50 in U. S. Currency)

☐ Enclosed is my gift of $ ______ to UMDF to help sustain research and family support.

☐ My gift is $40 or more, please send me a complimentary issue of the Mitochondrial News (Dues paying members automatically receive the Mitochondrial News three times a year).

☐ Change of address

MEMBER / DONOR

Name __________________________________________

Address _________________________________________

City __________________________ State ______ Zip ______

Phone: Home __________________ Work ___________ FAX ______

Email Address _______________________________________

PLEASE CHECK

☐ Patient ☐ Spouse

☐ Parent ☐ Relative

☐ Friend / Teacher / Other

☐ Medical Professional

☐ Specialty ________________________

☐ Professional Organization

Name ________________________________

Affected adult(s) / child / children’s name and date of birth:

________________________________________

________________________________________

________________________________________

________________________________________

MAKE CHECKS PAYABLE TO: U.M.D.F.

UMDF is a 501(c)(3) Organization. Gifts are tax-deductible according to IRS regulations.

UMDF accepts MAC, VISA or Mastercard credit card charges for donations and dues.

Fax or mail the following information to UMDF: credit card number, expiration date, names as listed on the card and signature.

Mail membership, donations and address changes to:

UMDF

8085 Saltsburg Road, Suite 201

Pittsburgh, PA 15239

UMDF MEMBERSHIP RELEASE FORM

☐ Yes, I want to Network!

I will complete this form and send to UMDF.

Please give me the appropriate form to receive network information from the UMDF Patient Registry.

GENERAL RELEASE

Please ☐ DO ☐ DO NOT provide my name and address to other members in my area.

☐ DO ☐ DO NOT include my phone number.

☐ DO ☐ DO NOT include my email address.

Signature _______________________________________ Date __________________

By signing the undersigned Release, the signator authorizes the release of name, addresses and/or phone numbers to be provided to other UMDF members.

If a physician or scientist requests names and addresses, the member will be contacted and given the doctor’s name. Under no circumstances will any member’s name be released to anyone but another member, and only if you have approved such release by indicating above. UMDF assumes no responsibility for the protection of the data except as described specifically in this release. At anytime, you may revoke your approval by delivering a written request to UMDF. Confidentiality is of utmost importance to UMDF and is essential to encourage networking among members.
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UMDF MISSION
To promote research for cures and treatments of mitochondrial disorders and to provide support to affected individuals and families.

Deadline for next issue is 10/1/02