

# Mitochondrial News

United Mitochondrial Disease Foundation

## Cyclic Vomiting in Mitochondrial Disease

By Richard G. Boles, M.D., Division of Medical Genetics,  
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**G**astrointestinal (GI) symptoms are commonly encountered in patients with mitochondrial disease. Most often, symptoms are episodic in that they come and go, and are related to 'functional' problems of the bowel. In particular, vomiting is common among sufferers of many different mitochondrial disorders, and among these individuals, vomiting itself has many different causes. Occasional bouts of vomiting is common, especially in infants, and is often found to be caused by gastroesophageal reflux. This article discusses one particular type of vomiting disorder, called 'cyclic vomiting'.

Cyclic vomiting is not new as it was first described in the eighteenth century, although even today very few physicians or other clinical care providers have heard of it. Cyclic vomiting refers to discrete and severe episodes of vomiting, nausea and lethargy (severe tiredness). Episodes are discrete in that the sufferer is free of nausea and vomiting between episodes. Episodes are severe in that the sufferer almost always feels quite ill, preferring to lie down in a dark and/or quiet place, and not interested in any of the activities of life. Vomiting and loss of appetite can be severe enough to necessitate hospitalization for intravenous (IV) fluids with each episode. In other cases, nausea and lethargy may be much more troublesome than vomiting. Episodes can occur on a routine schedule (such as once a week or once a month), be triggered by physical or psychological stress, or appear to come at random. Each episode can last for hours to many days, but usually there is a characteristic duration in each



Dr. Richard G. Boles, M.D.

individual patient. In some cases, an episode may be stopped if the child sleeps. Some sufferers have additional symptoms during episodes such as loose stools, drooling or headache. There may or may not be an 'aura', or symptoms which occur before vomiting begins. In most cases, cyclic vomiting starts in children ranging from about age 3 to 8 years, although the disorder can start at any age including in infants and adults. Cyclic vomiting can run its course and resolve, continue indefinitely, or change into migraine headaches. Most sufferers have normal intelligence and are generally healthy between episodes, however, many of them have various degrees of developmental delay and/or additional problems such as epilepsy.

Cyclic vomiting has many known causes, including intestinal blockage, brain disorders, kidney disease, and several different metabolic disorders. Many of these causes are treatable, and a careful diagnostic work-up is important. However, in the vast majority of cases, none of the above causes can be found, and these individuals are given the diagnosis of 'cyclic vomiting syndrome' or 'CVS'. Migraine headaches and episodic severe abdominal pain (abdominal migraine) are very common in CVS sufferers and their family members alike (usually in the maternal relatives!). At present, migraine headaches, abdominal migraine and CVS are considered to be related, and possibly are different manifestations of the same disorder. Cyclic vomiting has

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## Astropower President & CEO and UMDF Trustee Receives UMDF Humanitarian Award



Marsha and Dr. Allen Barnett

During the Mitochondrial Medicine 2001 conference's Saturday night banquet in San Diego, Dr. Allen and Marsha Barnett were awarded the first national UMDF Humanitarian Award. The Barnetts have been committed to finding a cure for Mitochondrial disease, and have consistently been compassionate, generous, and dedicated in their efforts. The award recognizes their continuing financial support.

Dr. Barnett has been involved with energy-related technologies, issues, and conservation programs for more than 30 years. In 1983, he founded AstroPower, Inc. (NASDAQ: APWR), a Newark, DE-based manufacturer of solar electric power products, in hopes of building a better solar cell. He has done exactly that. He and his company are recognized as leaders in the solar electric power industry. In fact, Dr. Barnett was recently awarded the Karl W. Böer Solar Energy Medal of Merit by the University of Delaware for his pioneering research, commercial successes, and outstanding service to the solar electric power industry. Dr. Barnett is the fifth hon-

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## Chairman's Report

During the UMDF Board meeting at the San Diego symposium we presented to our Trustees the approved UMDF Business Plan for 2001. A review and inventory of the "wagon" that we have been pulling reveals some astonishing facts:

- ❖ Since 1999 the revenues of our business have increased 104%
- ❖ Revenues generated from established fundraisers have increased 125%
- ❖ Net income rose 134%
- ❖ Our capital rose to over 1 million dollars, up 88% from 1999 and 196% over 1998
- ❖ Investment Income grew by 184%
- ❖ Support services (Research, awareness, membership support and education) account for over 75% of spending.
- ❖ Overhead spending was reduced
- ❖ Eight additional units (chapters) have been established with over 1000 customers - I like to tell my friends who are multi-unit operators in the restaurant business that even though my restaurant is still a single unit I have taken my other business into multi-unit function with international interest. That gets their attention while I pull out the donation envelope!
- ❖ Awareness is very hard to measure but our data reveals over 800 new customer contacts were made in the year 2000. Our donor base grew substantially in 2000, with over 22% being multi-year donors.

The UMDF Trustees approved by motion and majority vote a more aggressive approach to encouraging and supporting research by increasing our annual research grants to:

2002: 250k Awarded at the Dallas symposium  
 2003: 500k Awarded at the next scheduled symposium  
 2004: 1m Awarded at the next scheduled symposium  
 2005: 1.5m Awarded at the next scheduled symposium  
 2006: 2m Awarded at the next scheduled symposium

This is a 5-year total commitment of \$5,250,000.00 towards encouraging and funding research for treatments and ultimately a cure for mitochondrial disease! My only concern is not whether or not we will reach this goal, but by how much we will surpass it!

This is in addition to our 5-year commitment to the Research Expansion Project beginning, hopefully, next year with the epidemiology study.

I have used the terms, business, business plan, strategic plan, investment income, cash flow and customers. We understand and realize that the world we live in demands a business approach for success and the reason for which UMDF was formed certainly deserves success and thus a business approach.

We are a parental founded organization that realized early on that the emotions, memorials, honors and eulogies that initially brought us together had to be placed on the shelf so we could get down to the BUSINESS of finding a cure to mitochondrial disease.

*Our business in life is not to get ahead of others,  
 but to get ahead of ourselves—to break our own records,  
 to outstrip our yesterday by today.*

– Stewart B. Johnson

Charles A. Mohan, Jr.  
 Chairman, UMDF

## United Mitochondrial Disease Foundation

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# Therapist and Parent: Seeing Both Sides of the PT/OT Coin

By Patrick Rodgers, *Free Lance Writer*

The very nature of mitochondrial disorders puts unique burdens on both parents and the physical and occupational therapists working with their children. It can be helpful for each to understand the limitations and perspectives of the person on the other side of the waiting room door.

Leslie McKibben is a Registered Physical Therapist. She opened our discussion by differentiating between the roles of a physical and an occupational therapist. A PT addresses a child's gross motor skills - rolling, sitting, crawling, and walking. They generally work with larger muscle groups. They might also assist the child with mito-specific needs like energy conservation, endurance training, breathing techniques, and balance-training.

Occupational therapists normally specialize in upper extremity and hand/eye coordination skills used in everyday living. These skills include things like dressing, teeth brushing, personal hygiene, and feeding. Oral motor dysfunctions and feeding difficulties are often left to the OT to resolve.

Both PTs and OTs use threshold electrostimulation to treat children with muscle atrophy disorders, including those related to mito. Their combined role is to provide families with a program of activities for use at home to assist child development.

The overall goal? According to McKibben, it is to address the medical issues of each child and their family individually in a non-threatening, non-medical scenario.

Each child's program should be designed to meet their current status and individual goals. McKibben places patients in therapies designed for mild, moderate, or severely affected. The goals of each are vastly different, ranging in mild cases to kicking a ball to more basic breathing and crawling skills for children having more difficulties.

School therapy provided by school systems keeps its aim limited to enhancing a child's school performance. School districts are usually less able to deal with medical issues due to more limited resources, both in time and money.

Both parents and therapists acknowledge that one of the primary difficulties in treating mito patients is the variety of disorders that fall under the penumbra of "mitochondrial dysfunction." Saying that a child has a mitochondrial disorder is non-specific, like the terms "heart ailment" and "mental illness." A prolapsed mitral valve is not a heart attack, and depression is not schizophrenia. Consequently, using one child's case as a reference to help another is often times impossible. McKibben commented: "One child may be progressing while another child will regress very fast. It's hard to keep a good plan of action when you're unsure of how they'll respond." It's important to inform a PT or OT the precise details of your child's particular mitochondrial disorder, and the ramifications of that diagnosis for physical therapy short- and long-term.

Another issue that both parents and PT/OTs are mutually aware of is the need for energy conservation. Staying attuned to a child's energy level is one of the particular challenges McKibben faces with mito patient therapy. The energy level of any given child can change drastically from one day to the next. Parents know their children best; a therapist should consult parents to find out how a

child has been feeling since the last session.

Unfortunately, there can come a point when ceasing therapy is advisable, McKibben said. If therapy becomes too stressful or if families are not willing to work at home with their child, treatment may be discontinued. Like all things children learn, what is reinforced at home has the most staying power.

And, of course, issues with insurance companies plague many mito patients' treatments. From her vantage point, McKibben said that things like vitamin supplements are generally not covered by insurance companies, as well as entire therapy courses themselves. She remembers cases where insurance carriers' unwillingness to cover ongoing therapy has cut children off from necessary treatment.

Between dealing with insurance companies, finding the right therapist, and making the schedule changes needed to transport the child to and from therapy, the journey from diagnosis to proper treatment is often times a frustrating odyssey for parents.

Sandi Anderson fights those battles every day. Her daughter, Ashley, receives treatment at The Gregory Kistler Treatment Center in Arkansas. In choosing that site, she judged by some invaluable criteria for any parent of a mito child to consider.

- Environment and equipment available
- Therapist education
- The degree to which a therapist seems to enjoy his or her work
- Willingness to let parents observe and talk to other parents before signup
- The therapist's ability to make the therapy seem like play, not therapy
- A willingness to explain what is being done and why
- Level of respect shown to patient and family; lack of condescension
- Flexibility; a willingness to rethink a treatment plan
- Allowing the young patient some choice in activities
- Willingness to adjust to good and bad days for both patient and family

The Kistler Center raises its own funds and does not charge families for therapy. Insurance companies tend to view any "therapy" as a short-term program, as it would be for a knee injury or a stroke, rather than a lifetime commitment for a child. Anderson said that applying for Medicaid through the Katie Beckett waiver (also called TEFRA) has given her family much more freedom to pursue the most helpful therapy.

Beth and James DeArce have two children, 14-month old Juliana and 6 1/2 year-old Erik. Both children have mitochondrial disorders. In addition to helping to maintain the physical condition of the children, James DeArce also noted that succeeding in therapy adds to Erik's self-confidence, perhaps in and of itself a reason to have mito kids enter PT/OT. You may have to lobby your insurance company and the government to get what you need, but it may be the most important things you do from a treatment standpoint to facilitate the best quality of life for your child.

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# UMDF Expands Funding for Research

*By Mark Fleming, UMDF Grant Research Coordinator and REP Committee Chair*

The UMDF is in the midst of an ambitious program to expand mitochondrial disease research, both in funding and in scope. During the March 2001 meeting of the UMDF board of trustees in San Diego, the board approved \$250,000 in funding for UMDF research grants in 2002. As stated in the chairman's report, the board also approved the following additional research funding goals:

2003: \$500,000

2004: \$1 Million

2005: \$1.5 Million

2006: \$2 Million

The national office solicits Letters of Intent in July and the purpose of the Letter of Intent phase of the grant process is to pre-qualify researchers and to assess the conformance of projects with one or more of the following grant categories: 1) Seed money for new researchers, 2) Clinical research, 3) Post-doctoral fellowship and 4) Established investigators proposing new mitochondrial research. To obtain a complete Grant Information Packet, contact the office at 412-793-8077 or via email at [info@umdf.org](mailto:info@umdf.org).

The UMDF has also expanded its scope of research by initiating the Research Expansion Project (REP). The goal of the REP is to revolutionize mitochondrial disease research over the next five years. At the end of that time, we expect to have an Office of Mitochondrial Medicine at the NIH, improve patient care by defining and initiating Mitochondrial Research Centers, and identify promising new drugs by establishing Mitochondrial Research Units consisting of centers working together on clinical trials.

This year the UMDF's REP has several important activities:

- Researching and creating a report which defines the extent of government and private mitochondrial disease research in all aspects of society
- Initiating an epidemiology study to define the prevalence of mitochondrial disease in America (see Request for Proposals on this page)
- Creating a national campaign to solve the "Coding Problem" in mitochondrial disease by identifying how each state identifies mitochondrial disease (see MICAR Project on the facing page)
- Co-sponsoring and participating in the Clinical Trials Task Force and Laboratory Methods Committees of the Mitochondrial Medicine Society (see Christini Uridine Trial on page 8)

Your participation in the REP is key. This effort will require membership participation to succeed. There are many ways to get involved. Call the UMDF office for more information. I look forward to what we will accomplish as we work together toward a common goal. See you on the front lines.



## Request for Proposals

### Defining the Epidemiology of Mitochondrial Disease in the United States

The United Mitochondrial Disease Foundation is pleased to announce an innovative, new grant program designed to result in the first rigorously designed and conducted epidemiology study of mitochondrial disease in the United States. This program will provide money for salary for up to 6 months for two principal investigators (a mitochondrial specialist and an epidemiologist) during the time required to write a grant proposal to the National Institutes of Health, and other potential federal and private funding agencies, for a 5-year epidemiology study. The objectives of the study shall be to define the age-specific incidence, prevalence, morbidity, and mortality imposed mitochondrial disease in the US by coordinating the efforts of 3-5 mitochondrial centers serving well-defined populations, and to develop a durable infrastructure for the efficient implementation of prospective studies.

#### Eligibility

Both US and International investigators are encouraged to apply. While the study must be conducted in the US, there is no restriction on the country of origin for the principal investigators.

#### Deadline

Additional information regarding the UMDF grant program is available immediately upon request. Letters of Intent are due July 1, 2001.

#### Contact Information

UMDF Epidemiology Grant Program  
8085 Saltsburg Rd, Suite 201  
Pittsburgh, PA 15239 USA  
Tel: (412) 793-8077  
Fax: (412) 793-6477  
Email: [info@umdf.org](mailto:info@umdf.org)

## The MICAR Query Project

Every year, it is estimated that thousands of children and adults fall ill to mitochondrial disease in the United States. Unfortunately, the true burden of these illnesses is never recorded at the National level, because our current health care system has no way of tracking mitochondrial disease. When a person gets sick or dies in the United States, the reason for illness or death is given a numerical code from a large listing in the "International Classification of Diseases, 9th revision, Clinical Modification" (ICD-9-CM). Unfortunately, there are no specific, numerical codes for mitochondrial disease. Therefore, all illnesses or deaths resulting from mitochondrial disease are necessarily miscoded, or given more general codes that make it impossible to track key facts about mitochondrial disorders. Also, the lack of codes makes it more difficult for families affected by mitochondrial disorders to receive approval from their health care insurance providers for necessary tests and medical care. This is called "The Coding Problem".

You can help take an important step toward solving this problem by volunteering to be your state representative in a national campaign called, "The MICAR Query Project". Volunteers will be asked to go to their state capitol and talk with officials at your State Health Department to get their help in gathering important information on mitochondrial disease.

If you would like to be a volunteer, please contact the UMDF as soon as possible for additional information. You will need to have this information before contacting your state health department. We are working against the clock. The results of the MICAR Query Project must be completed before June 1, 2001. Thank you for your help.

## Clinical Trials

*Reprinted with kind permission of the Niemann Pick Disease Group (UK) and CLIMB (UK), Vol. 1, No. 4, October 2000*

**C**linical trials are used to determine whether new drugs or treatments are both safe and effective. Carefully conducted clinical trials are the fastest and safest way to find treatments that work. Many new medicines and treatments are found to be helpful and safe in test tubes and in animals. They must also prove safe and effective in humans before doctors can prescribe them.

Ideas for clinical trials usually come from researchers. Once researchers test new therapies or procedures in the laboratory and get promising results, they begin planning Phase I clinical trials. New therapies are tested on people only after laboratory and animal studies show promising results.

*What are clinical trial phases?*

Clinical trials of experimental drugs proceed through four phases:

In Phase I clinical trials, researchers test a new drug or treatment in a small group of people for the first time to evaluate its safety, determine a safe dosage range, and identify common side effects.

In Phase II clinical trials, the study drug or treatment is given to a larger group of people to see if it is effective and to further evaluate its safety.

In Phase III studies, the study drug or treatment is given to large groups of people to confirm its effectiveness, monitor side effects, compare it to commonly issued treatments, or placebo and collect information that will allow the drug or treatment to be used safely.

In Phase IV studies are done after the drug or treatment has been marketed. These studies continue testing the study drug or treatment to collect information about their effect in various populations and any side effects associated with long-term use.

*What is a protocol?*

All clinical trials are based on a set of rules called a protocol. A protocol describes what types of people may participate in the trial; the schedule of tests, procedures, medications, and dosages; and the length of the study. While in a clinical trial, participants are seen regularly by the research staff to monitor their health and to determine the safety and effectiveness of their treatment.

*Who can participate in a clinical trial?*

All clinical trials have guidelines about who can get into the program. Guidelines are based on such factors as age, type of disease, medical history, and current medical condition. Before you join a clinical trial, you must qualify for the study. Some research studies seek volunteers with illnesses or conditions to be studied in the clinical trial, while others need healthy volunteers.

The factors that allow someone to participate in a clinical trial are called inclusion criteria and the factors that keep them from participating are called exclusion criteria. It is important to note that inclusion and exclusion criteria are not used to reject people personally. Instead, the criteria are used to identify appropriate participants and keep them safe. The criteria help to ensure that researchers will be able to answer the questions they plan to study.

*What is a Placebo?*

A placebo is an inactive pill, liquid, or powder that has no treatment value. In clinical trials experimental treatments are often compared with placebos to assess the treatment's effectiveness. In some studies, the participants in the control group will receive a placebo instead of an active drug treatment.

*Continued on page 8*

## Clinical Trials

*Continued from page 7*

*What is a control or control group?*

A control is the standard by which experimental observations are evaluated. In many clinical trials, one group of patients will be given an experimental drug or treatment, while the control group is given either a standard treatment for the illness or a placebo.

*What is a blinded or masked study?*

A blinded or masked study is one in which participants do not know whether they are in the experimental or control group in a research study. Those in the experimental group get the medications or treatments being tested, while those in the control group get a standard treatment or no treatment.

*What is a double blind or double-masked study?*

A double-blind or double-masked study is one in which neither the participants nor the study staff know which participants are receiving the experimental treatment and which ones are getting either a standard treatment or a placebo. These studies are performed so neither the patients' nor the doctors' expectations about the experimental drug can influence the outcome.

*What protections are there for people who participate in clinical trials?*

The government has strict guidelines and safeguards to protect people who choose to participate in clinical trials. Every clinical trial must be approved and monitored by an Institutional Review Board in the USA to make sure the risks are as low as possible and are worth any potential benefits.

An Institutional Review Board is an independent committee of physicians, and lay people that ensure that a clinical trial is ethical and the rights of participants are protected.

All institutions that conduct or support biomedical research involving people must have an Institutional Review Board that initially approves and periodically reviews the research.

## The Christini Uridine Trial

TRIACETYLRIDINE (TAU) - A POTENTIAL THERAPY FOR MITOCHONDRIAL DISEASE

Triacetyluridine (TAU) has been found to help several symptoms of mitochondrial disease in Phase 1 clinical studies conducted by investigators at the University of California, San Diego (UCSD). Some patients have shown improvements in their neurological, cognitive or muscular function with TAU therapy including increased stamina, muscle strength, reduced frequency of seizures and infections, and improvements in growth and development. Additionally, some patients have shown improvements in kidney function in a condition called Renal Tubular Acidosis (RTA). RTA can lead to severe acidosis (acidification of the blood), susceptibility to infections, malnutrition and failure to thrive. RTA is seen in about 10% of patients with mitochondrial disease.

The Mitochondrial Medicine Society and the United Mitochondrial Disease Foundation are pleased to announce the opening of the recruitment phase of the Christini Trial—a double-blinded, placebo-controlled Phase 2 clinical trial of TAU in approximately 30 - 40 patients with mitochondrial disease and Renal Tubular Acidosis. This patient population has been selected as the best initial way to rapidly assess the therapeutic benefit of TAU. Should the study be successful, it would provide a path for potential treatment of mitochondrial patients with many other disease manifestations. Today there are over 20,000 patients in the United States suffering from some type of mitochondrial disease for which there are currently no FDA-approved therapies.

### WHAT TRIACETYLRIDINE DOES

Triacetyluridine or TAU is rapidly converted to uridine, the active drug compound, when taken orally. Uridine is a natural chemical present in every cell of the body that is essential for normal cellular and tissue function. Mitochondria are essential for many cellular functions including energy production and are needed to make uridine. Patients with mitochondrial disease may not be able to make enough uridine naturally to meet their needs and may develop symptoms related to uridine deficiency. In these cases, uridine therapy may be beneficial when provided in the diet to help overcome any potential deficiency.

### TRIACETYLRIDINE CLINICAL TRIAL

We are currently seeking approximately 30 - 40 patients to participate in this double-blinded placebo-controlled study of TAU therapy in patients with mitochondrial disease and RTA. The study will be conducted at 3-5 participating clinical sites around the US and Canada.

This study is designed to evaluate the safety and efficacy of TAU in mitochondrial patients with RTA. In addition to measuring the effects of TAU on RTA, the trial will collect information on the effectiveness of TAU in stimulating growth and development, and reducing seizures, infections, hearing impairments, and GI problems associated with mitochondrial disease.

To be eligible for this study, patients must be more than 1 year of age with a diagnosis of mitochondrial disease and a kidney condition called Renal Tubular Acidosis (RTA), or Renal Fanconi Syndrome. The kidney problems associated with mitochondrial disease can be suspect-

ed if the patient: 1) is currently taking sodium bicarbonate, Polycitra, or Bictra, or has a serum bicarbonate of 18 mEq/L or lower, and 2) has a urine pH of 5.3 or higher. The study will take approximately 6 months to complete.

If you, a family member, or someone you know appears to be eligible for the Christini Trial, and would like to participate, please contact the UMDF at:

United Mitochondrial  
Disease Foundation  
P.O. Box 1151  
Monroeville, PA 15146-1151  
Tel: 412-793-8077  
Fax: 412-793-6477

You will be contacted by a participating mitochondrial center near you.

#### ANTICIPATED BENEFITS

If TAU is shown to be safe and effective, then it will be approved by the FDA for the treatment of RTA associated with mitochondrial disease. In the process of developing TAU for this indication, we will learn a great deal more about the effects of TAU on several other important symptoms of mitochondrial disease. The Christini Trial will also have a long-term benefit that extends far beyond the discovery of an effective new drug. The infrastructure required to conduct the Christini Trial will create a network of experienced mitochondrial centers around North America with a proven track record of collaboration. This network will dramatically accelerate future drug discovery for mitochondrial disease by providing a national resource that is skilled in the systematic and efficient conduct of mitochondrial disease clinical trials. With this resource, several mitochondrial disease treatment trials could be conducted on an international scale, as funding for the trials becomes available, and as new drugs are discovered and older drugs are studied in greater detail.

## UMDF Launches New Web Site

Have you visited [www.umdf.org](http://www.umdf.org) lately? If you haven't, get ready to be launched into a new and exciting cyber source on mitochondrial disease. With the help of some incredible volunteers, the UMDF web site committee redesigned the entire site. Please drop by and take a glance at these new features:

- ✦ A section devoted to explaining "Mitochondrial Disease" in layman's terms - including symptoms, treatments and genetics.
- ✦ The new "Support" section features a clickable map of the world, which searches our online database for a list of helpful resources in your area.
- ✦ "Personal Journeys" shares stories and pictures from patients and families.
- ✦ The UMDF "Patient Registry" is now online. In addition to editing your own entry, UMDF members can also search the entire database.
- ✦ UMDF members can pose questions to physicians in the "Ask The Mitodoc" section.

The Patient Registry and Ask the Mitodoc sections require a member ID. If your UMDF membership is current, your ID has been provided on the mailing label of this newsletter. Go to the Patient Registry on the main menu and select Information. Type in your ID in the Account Activation field and follow the instructions. If you cannot find an ID number on your label, please contact the office at 412-793-8077 or via email at [info@umdf.org](mailto:info@umdf.org).

Special thanks goes to the UMDF web site committee volunteers for dedicating their time and effort toward creating a dynamic resource for all those desperately seeking information about mitochondrial disease.

- Terri Mason - Webmaster and Cyberartist
- Karen Lipps - Content Coordinator
- James Heacock (James' Web Design) - Database Programmer
- Mark Fleming, Vice President, UMDF Board - Technical Advisor

*We hope that our members, and those just looking for more information about mitochondrial disorders, will find the site supportive and informative.*



## Humanitarian Award *Continued from page 1*

oree to receive the Böer award, which was first presented to President Jimmy Carter in 1993.

Chuck Mohan recognized Dr. Barnett's accomplishments in the energy-related fields and compared his work at Astropower with Mitochondrial disease - an energy-related disease. In this realm, however, the issue too often carries with it unfortunate harsh reality, as it has in the Barnett family. The Barnett's sons, Michael and Charles, lost their battle with Mitochondrial disease in 1983 and 1981.

"Allen and Marsha Barnett have dealt with life and all that it has to offer, but more importantly, they have dealt with all that it has taken away," said Mohan. "They continue to use their talents to do whatever they can to make life just a little more tolerable for those less fortunate. Their continued support of symposia through financial scholarships, as well as their continued input into the development and inner workings of UMDF, is a great tribute to their sons, Michael and Charles."

There is a beacon of light however. "Through God's maddening mystery of premature death, all of our loved ones have given us a spirit and a strength, which no one can take away," Mohan said. "Allen and Marsha's strength and commitment is a living example for many to follow. Even though their lives were short, Michael and Charles will have a tremendously important impact on many for a long time to come due to their parents' continued involvement."

# Mitochondrial Medicine 2001 Attracts 400!

## SPECIAL THANKS

### FAMILY MEETING PLANNERS

Sharon Shaw, Southern California Chapter, President

Mark Fleming, VP, UMDF Trustee  
Southern California Chapter

### MEDICAL MEETING PLANNERS

Richard H. Haas, MB, BChir, MRCP

Robert K. Naviaux, MD, PhD

### SCHOLARSHIP SPONSORS

Allen and Marsha Barnett

The Markowitz Scholarship Fund

The Tri-State Support Group (DC area)  
Arizona Chapter



*Volunteers for the 2001 Conference (from left to right), Lissa Mirand, Karen Lipps, Laura Owen, Karen Clark, Jeannine Sawyer, Terri Mason, and Kristine Biagiotti*

## 2001 SPONSORSHIPS

CorDax

General Nutrition Centers

J & M Printing

Michael Brewster of Lehman Brothers Inc.

Rexall Sundown

Roche Vitamins

Sigma-Tau Pharmaceuticals

Springs Blessings Fund, St. Mary of the Springs

The Kozuch Memorial Foundation

(proceeds from Kozuch Golf Outing)

Tishcon Corporation

Virginia Friedhofer Charitable Trust

Stan and Carole Davis

Hal and Ronna Uhrman

Encore Audio Taping

The conference began in a “not so sunny” San Diego but delivered in more ways than one. Amanda and Tom Owens, of Aptos, CA, sent a letter to the national office and noted the following:

“Thank you, thank you for hosting such a wonderful event this past weekend in San Diego. This was our first symposium, and we are so grateful we were able to attend. The panel of renowned doctors was fantastic, the subject matter was extremely informational, and the parents and caregivers we met were incredibly wonderful individuals. We couldn’t have hoped for a more perfect event.

Highlights of our weekend included having the opportunity to share our table at lunch on Saturday with Dr. Salvatore DiMauro, speaking with Dr. John Shoffner during one of the breaks, and sharing our table Saturday evening with our son’s neurologist, Dr. Jonathan Strober. We felt incredibly lucky to be in the company of so many well-renowned doctors and to actually be able to personally speak with a few of them as well.”

For those who attended and completed an evaluation form, almost 99% gave the conference a thumbs-up overall. The national office will use the comments from the forms to assist in the final plans for Dallas 2002.

Thank you all for your feedback!

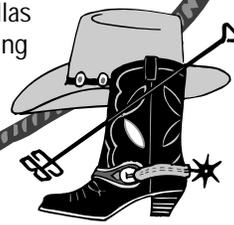


*Coordinators for the Saturday Night Banquet Raffle - Linda and Bob Cooper. In honor of their son, Chad, the Cooper family raised close to \$8,000 to help offset the cost of the conference. Outstanding!*

MARK YOUR CALENDARS FOR THE  
DALLAS SYMPOSIUM, JUNE 6-9, 2002

- Program highlights will be topics and different tracks for newly diagnosed families, as well as returning families.
- There will also be special programs for adult Mito patients. The program will provide ample time to network by location, symptom and diagnosis.
- Event organizers are currently negotiating with the Dallas Galleria Hotel, so all families will find shopping, ice-skating and many restaurants right within walking distance.

**Be ready for the tastes of Texas!**





Mark Fleming, UMDF Trustee/Vice President and Family Meeting Planner for the 2001 conference, relaxes during a break with fellow trustees, Chuck Mohan, Chairman, and John DiCecco, Treasurer



Monica Avila's a winner!



Jane Clarke McManus, UMDF Trustee and Family Meeting Planner for the next UMDF conference, shares her plans for Dallas 2002 with Dr. Richard Haas



Sharon Shaw, Southern California Chapter President and Family Meeting Planner for the 2001 conference, checks out the raffle prizes



Dr. Salvatore DiMauro speaks to a very attentive audience during Saturday's sessions



Renee and Steven Wojciechowski huddle with Chuck while Kristine Biagiotti enjoys herself at the Friday night welcome reception



Saturday Lunch on Mission Bay

## Cyclic Vomiting *Continued from page 1*

been reported in individuals with the A3243G 'MELAS' mutation in the mitochondrial DNA (mtDNA). In addition, one child with CVS, developmental delay, seizures, growth delay and additional problems was reported to have a large mtDNA deletion and duplication. However, in my experience as a metabolic geneticist, CVS with or without additional problems is not rare in children with mitochondrial disorders, and among this group, 'routine' mtDNA analysis fails to identify previously known mtDNA mutations in most of them.

To date, I have personally evaluated about 15 children with CVS and suspected mitochondrial disease. These and an additional 50 cases collected worldwide with CVS and additional neuromuscular problems (a group at risk for possible mitochondrial disease) have been entered into an ongoing research study. Many of these children have a specific pattern of additional clinical and laboratory findings including GI dysmotility (reflux, delayed gastric emptying, constipation), dysautonomia (unexplained fevers, high heart rate, etc.), muscle weakness, chronic fatigue, seizures and pain (head, abdomen and/or extremities). The latter, referred to sometimes as "muscle cramps", is occasionally associated with swelling and skin discoloration in a manner suggestive of neuro-vascular dystrophy. No single child suffers from all of these problems, and when present in a given child the symptoms tend to be episodic and variable. In some of these children, cyclic vomiting itself is a minor part of the child's problems, and may disappear or never have been present. Intelligence ranges from gifted to severe mental retardation.

Laboratory analysis in children with CVS and mitochondrial disease demonstrates elevated lactic acid and abnormal urine organic acids (ketones, Krebs cycle intermediates, and/or ethylmalonate) early in vomiting episodes, but biochemical tests are rarely abnormal at other times. A few children have received muscle biopsies which revealed findings suggestive of mitochondrial dysfunction, including increased variation in fiber size, mitochondrial proliferation, and/or complex 1 deficiency. However, in my opinion, the most striking finding is maternal inheritance of the same kind of episodic problems seen in the affected children themselves, but usually to a lesser degree, including migraine, cyclic vomiting, GI dysmotility, dysautonomia, muscle weakness or pain, chronic fatigue, and/or seizures. At the time of this writing, at least 5 unrelated cases were found to have heteroplasmic (two different mtDNA sequences present in the same individual) nucleotide changes in the mtDNA control region. These molecular variants are maternally inherited (present in mother and siblings, even if they themselves are without symptoms) and were not found in over 100 children without mitochondrial disease. The same control region variants were found in children with mitochondrial disease but without CVS, and the significance of our recent findings are not yet

clear and are the subject of ongoing investigation. However, our data does demonstrate that mitochondrial disease with cyclic vomiting is often maternally inherited.

Unlike most published cases with mitochondrial disorders, disease progression appears to be rare in children with maternally-inherited cyclic vomiting. One exception to the general benign disease course is that a few families have had infants under age 2 years who died suddenly and were labeled as "SIDS". Most children, and especially their affected relatives, attend normal schools or have jobs/careers, and their lives are fairly normal between disease episodes. In many school-aged affected children, severe fatigue and muscle weakness has necessitated the occasional usage of wheelchairs and/or half day or home schooling. All too often, clinical care providers and/or school personnel have down-played the disease process, even to the extent of labeling the child/family as exaggerating symptoms, being psychologically disturbed, or having caused the illness (Münchhausen By Proxy).

The good news is that treatments are available for cyclic vomiting in individuals with mitochondrial disease. In mitochondrial disease, symptoms are believed to occur when energy supply cannot meet energy demand. Since often little can be done to increase energy supply, decreasing energy demand is a major part of therapy. In practical terms, this means the reduction of stress, including the avoidance of fasting, limiting exposure to environmental temperature extremes, and the prompt treatment of infections and dehydration. Cyclic vomiting and some other symptoms often improve with frequent feedings of complex carbohydrate, including between meals and at bedtime. Other children improve if awakened during sleep for a snack and/or placed on a low fat diet. In addition to physical stress, the reduction of psychological stress is important: not because this is the cause of the disease, but because stress increases energy demand and can trigger an episode. In cases in which the response to these simple measures is not adequate, anti-migraine medication including amitriptyline (Elavil), cyproheptadine (Periactin) or propranolol (Inderal) taken at bedtime or more often can reduce the number of vomiting episodes in most cases, sometimes dramatically. When they do occur, vomiting episodes are treated with IV fluids (10% Dextrose with standard electrolytes at a rate of 1.5 to 2 times maintenance) in a dark and quiet room in order to facilitate sleep. In some cases, ondansetron (Zofran) and/or medications to induce sleep (i.e. lorazepam/Ativan) are helpful.

Diagnostic work-up (testing) must be tailor-fit to each individual child. Of course, confirming the diagnosis of mitochondrial disease and ruling out other treatable metabolic disorders (urea cycle disorders, organic acidemias) should be pursued. I suggest that a minimum work-up should include serum electrolytes, routine urinalysis, plasma lactate, quantitative plasma amino acids and quantitative urine organic acids (including full quantitation of Krebs cycle intermediates and other potential 'mitochondrial markers'), with samples obtained early in a severe or typi-

cal vomiting episode. Mitochondrial DNA analysis should include at a minimum PCR for A3243G and Southern blotting. Unless the diagnosis of mitochondrial disease is firm and CVS symptoms respond to treatment, work-up for other potential causes of cyclic vomiting should be performed, possibly including but not necessarily limited to: upper GI series, abdominal ultrasound, brain CT scan, and testing for sinusitis, porphyria and pregnancy. Probably no single individual requires, or should receive, all of the studies listed, and it is important to discuss the work-up with your child's physician.

This is a very new and rapidly evolving field, and not nearly half of the answers are in yet. Much of our understanding of, and hopefully our ability to treat, this disorder will improve over the next several months to years. I am writing this article at this early stage in the hope that some children will be steered towards treatments now which may be somewhat helpful to them. For more information, the Cyclic Vomiting Syndrome Association USA/Canada, an organization much like the UMDF, may be helpful. I suggest browsing their web-site at:

<http://www.beaker.iupui.edu/cvsa>

In addition, information on any available studies in CVS (with or without mitochondrial disease) and their entrance criteria and procedures are listed there. Alternatively, you can reach the association by contacting:

Debra Waites  
CVSA Administrator  
3585 Cedar Hill Rd NW  
Canal Winchester, Ohio 43110  
614-837-2586

[cvsadwaites@msn.com](mailto:cvsadwaites@msn.com)

<http://www.beaker.iupui.edu/cvsa>

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## Ways to Get Involved with the UMDF Research Expansion Project

In this issue, UMDF Trustee Mark Fleming provides an overview of UMDF's Research Grant Program, the Research Expansion Project, the Epidemiology Study and the MICAR Query Project (see pages 6 and 7). He also notes that there are "many ways to get involved." Here's a quick checklist of how you can help:

- Completion of the UMDF Patient Registry Questionnaire - The questionnaire data will become extremely helpful as the Research Expansion project and Epidemiology Study progresses. If you do not want your name or a loved one's name released, just mark the appropriate boxes on the questionnaire and the contact information will be kept confidential. Please contact the national office at 412-793-8077 or [info@umdf.org](mailto:info@umdf.org) to check the status of your Patient Registry information. If you have never completed the questionnaire, ask for the form today and it will be mailed to you immediately.
- Fundraise, Fundraise, Fundraise - UMDF has approved additional research funding over the next 5 years that will exceed 5 million dollars. This means we need to keep on bringing in the big bucks. For fundraising ideas, call the national office or just take a look at some of our past fundraisers in this issue - lots of great ideas out there.
- Support the creation of new Mitochondrial Centers of Excellence - We hope to see new centers developing over the next few years across the United States. With the assistance of the UMDF national office, chapters and support groups can submit letters of support.
- Assist in the MICAR Query Project - see page 7 for details.

### UMDF PATIENT REGISTRY

Yes, I want my (or my child's, spouse's, etc) information listed in the UMDF Patient Registry.

Please send me \_\_\_ copies of the Questionnaire form.

My (or my child's, spouse's, etc) information is already listed but I would like to provide an update. Please send me a photocopy of my Questionnaire and a blank form.

Send Information to:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Postal Code: \_\_\_\_\_

Country: \_\_\_\_\_ Phone: \_\_\_\_\_

Notes to the Office: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# FUNDRAISERS

## Friends of Matthew Strike Again

This past Fall, the "Friends of Matthew" Abato held a dinner and raised \$4,668 in Dutchess County, NY. Phyllis and Anthony Marinaccio decided to add to that number by selling hats and shirts to benefit UMDF. We thank Phyllis and Anthony for bringing in another \$468. We like your friends Matthew - they are awesome!



## Samantha's Invitation

Samantha Stahler invited her friends to celebrate her first double digit birthday and asked her friends to "take the money they would have spent on her birthday gift and send it to the United Mitochondrial Disease Foundation to help them find a cure for her cousin Bobby Arnold's illness."

Her friends are now cooking up more ideas this summer to raise money - holding lemonade stands, putting together an ice cream social and possibly a small carnival. Thank you girls and we wish you luck in all your fundraising efforts this summer - outstanding!

The Arnold family was also busy on a letter writing campaign this past Fall and raised \$1,345. Thank you Bobby for having such a caring and ambitious family.

## Special Holiday Cards from the DeArce Family

Beth and James DeArce design and produced their very own holiday cards this past winter and raised \$2,245 in honor of their children Erik and Juliana. If you add their project to the national office holiday card project, we are looking at over \$18,000 in holiday cheer!



Michelle Nelson and Meagan, her daughter, raised \$2,486.82 this past Fall at the Sandwich County Fair in Illinois. Fair attendees bought raffle tickets and all proceeds went to UMDF.

## 20 Below Zero Can't Stop the Mito-What? Ski Challenge

In Brighton, ME, the below freezing temperatures could not stop the Gaetjens and Vermette Families from hosting another successful Mito-What? Ski Challenge in honor of Michaela, daughter of Theresa and Ray Gaetjens. For a minimum of \$50 in pledges, skiers enjoyed the slopes, a homemade meal and participated in several raffles. The event raised \$7,291 and Victoria Vermette, Michaela's aunt, and Elaine Vermette, her grandmother, are already making plans for 2002.

"Our family benefited greatly from this effort. It brings our five children together in this endeavor driven by love we have for each other, especially Michaela. My husband & I have worked all our lives to foster this atmosphere for our family. In a situation like this when we all feel so helpless, this provides an avenue to feel like we are making a difference. My husband and I have been blessed with very supportive extended families that played a big part in our success." - from Elaine Vermette, Michaela's grandmother.



## Pennies from Heaven

How much good can a penny do? What about 191,600 pennies?

The National Junior Honor Society of Eastwood Middle School, Indianapolis, Indiana, recently made it their mission to raise money to fund the activities of the UMDF. Boy, did they ever succeed! In memory of her afflicted brother, Philip, Alexandra Neff convinced the Honor Society to organize a fundraiser for the UMDF. The Honor Society got the whole school involved in a contest; each class got a point for each penny contributed, but lost a point for money contributed that was not a penny. Classes fought pitched battles to bring in the maximum number of pennies, and brought in nickels, dimes and quarters to put in the buckets of other classes, in order to drive down their points.

Who won? The UMDF, and Eastwood, that's who! Eastwood raised \$1,916 to benefit the UMDF. The winning class got to duct-tape their principal, Mr. Smith, to a pillar. A plaque was awarded by Trustee Lee Neff to Eastwood, because this contest became the top youth fundraiser in UMDF history. Thanks Eastwood!



## Tri-State Support Group Raises Money to Help Families Attend Conferences



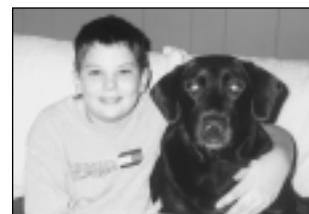
*Dr. Andrea Gropman and her husband, Barry, draw the winning ticket as Ricardo Jones looks on*

This past winter the support group (in the Washington, D.C. area) raised \$1,500 by holding a raffle. Per their request, the money was earmarked for scholarship funds to enable parents to attend national meetings. On behalf of our scholarship recipients, thank you!

## Upcoming Fundraising Events ....

*mark your calendars*

**Spring 2001:** Brad Burgener (pictured at right), of Hillsboro, NJ, is raising money this Spring by selling candy. Way to go Brad. Thanks for taking on a fundraiser to benefit UMDF.



**May 5:** Shelly's Heroes  
5K Run & 1 Mile Walk  
and Blosky Blast-off Tot Trots, Hatfield, PA

**May 6:** Megan E. Camaiani 5K Mito-What? Walk/Run, Coral Springs, FL

**May 12:** First Annual Matthew Dudgeon Memorial Walk/Dinner Dance, Chester, New York

**June 28:** Pittsburgh Golf Outing, Pittsburgh, PA

**June:** Sales begin on the Delaware Valley Chapter Cookbook

**June 29:** Wine Tasting and Barbecue, Ukiah, CA

**August 20:** Ohio Golf Outing, Cleveland, OH

**August 20:** Central Ohio Outing, Columbus, OH

**October 7:** Talbot Journey Begins - Starting in New York City  
Web Site <http://pws.ihpc.net/gbhpnet.mclella/mito>

For more information on these events or if you have a new event coming up, please contact the UMDF office at

## UMDF Chapters

*Chapters also serve as Support Groups for Members*

### Arizona Chapter

Contact: Karen Lipps, President  
Email: azchapter@earthlink.net  
Phoenix, AZ

### Delaware Valley Chapter

Contact: Maripat Shelly, President  
Email: delvalumdf@aol.com  
Philadelphia, PA

### New England Chapter

Contacts: Bill Shea, President or  
Eileen Mitchell, Treasurer  
Email: bshea@oceanspray.com  
Email: eimitch@nii.net  
Boston, MA

### New Mexico Chapter

Contact: Laura Owen, President  
Email: Abqowen@qwest.net  
Albuquerque, NM

### NY Metro Chapter

Contact: Joe Rice, President  
Email: umdfnymetro@aol.com  
Long Island, NY

### Ohio Chapter

Contact: Jennifer Lyman, President  
Email: ohiomitoinfo@yahoo.com  
Cuyahoga Falls, Ohio  
(Cleveland area)

### Southern California Chapter & Support Group

Contact: Sharon Shaw, President  
Email: shshaw@aol.com  
Orange, CA (Los Angeles area)

### Wisconsin Chapter

Contact: Anne Juhlmann, President  
Email: juhlmann@execpc.com  
Milwaukee, WI

## Support Groups

### Atlanta Area Support Group

Group is seeking a new leader or leaders. Please contact UMDF at 412-793-8077.  
Atlanta, GA

### Central Ohio Support Group

Contact: Shawna Steele  
Email: ssteele817@juno.com  
Columbus, OH

### Australia Support Group

Contact: Tara Collyer  
Email: tarac@powerup.com.au  
Kingston, Queensland, Australia

### Tri State Mitochondrial Support Group

Contact: Andrea Gropman, M.D.  
Email: agropman@nhgri.nih.gov  
Bethesda, MD

### New York, Western area

Contact: Angela Geising  
Email: angelageising@yahoo.com  
Buffalo, NY

### New York, Southern area

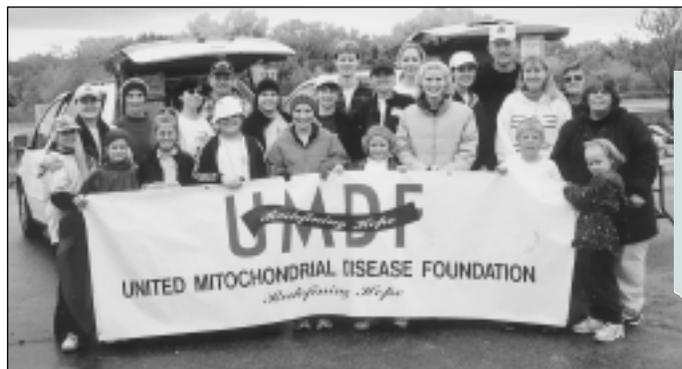
Contact: Beth and James DeArce  
Email: drc@infomine.net  
New Paltz, NY

### Desert Angels Support Group

In Process of Reorganizing-  
Anyone interested in attending meetings please contact UMDF at 412-793-8077.  
Phoenix, AZ

New Groups are trying to form in Illinois, Northern California, Michigan, Virginia, Northern Florida, and the Kansas City area.

Anyone interested in these areas or wish to start a group in another area, please call us at 412-793-8077.



### New Mexico Chapter

*New Mexico Chapter raises dollars during Fall 2000 "Trot for Tots" fundraiser.*

## Mark your Calendars!

The Ohio Chapter invites you to attend a special talk by Dr. Bruce Cohen on Sunday, June 10, 2001. Dr. Cohen will speak from 1:30pm to 3:00pm with a reception to follow. More information will be available on the web site under the Ohio Chapter (look under Support) - so keep checking in at [www.umdf.org](http://www.umdf.org) or call UMDF at 412-793-8077.

*As a special thanks . . .*

Dr. Cohen has dedicated many hours to the UMDF - writing newsletter articles, presenting at UMDF conferences and Ohio Chapter meetings, working with the Scientific Advisory Board, and his most recent contribution, answering questions on the new web site's Ask the Doc.

To thank Dr. Cohen for his generosity and ongoing support of UMDF and its families, please consider a donation to the June 10th meeting in the honor or memory of a loved one suffering from a mitochondrial disease. All donations to benefit UMDF and its 5-year total commitment of \$5,250,000.00 towards encouraging and funding research for treatments and ultimately a cure for mitochondrial disease. Can't imagine a better way to say thank you, can you?

## CHAPTER ACTIVITIES

### San Diego Symposium

All eight chapter had representatives at the San Diego Symposium and got down to the BUSINESS of finding a cure for mitochondrial disease during the annual chapter president's meeting.



Jim Heyer, Sharon Heyer and Eileen Mitchell attended the president's meeting in San Diego



Laura Owen and Thom Montgomery get down to business

### Delaware Valley Chapter

The Shelly's Heroes 5K & 1 mile run/walk and Bosky Blast off Tot Trot is scheduled for May 5 in Hatfield, PA. Registration begins at 8am. For more information, call 215-723-1957.

The Hearts Full of Hope-Recipes Gathered with Love cookbook will be published in June. The hard-cover laminated book contains over 500 recipes plus inspirational sayings, information on mitochondrial

### Southern California Chapter

*WHAT MORE CAN WE SAY BUT THANK YOU!*

Under the leadership of Sharon Shaw, chapter president, and the ambitious Cooper Family, the chapter raised over \$18,000 for the symposium. In order to keep registration fees down for our families, UMDF must offset the cost through fundraising and sponsorships. The chapter's assistance was crucial in raising the necessary funds for the San Diego meeting and the UMDF is fortunate to have such dedicated volunteers.

Future fundraising plans for Southern California:

June: Massive Garage Sale

September: Cut-a-thon

October: Arabian Nights Indian dinner and Silent Auction with an illusionist

The Chapter has also been chosen as a recipient of Johnny Rebs Southern Smoke House's "Shell Out for Charity" program.

A laminated card is placed on each one of their tables with a story of Chad Cooper, son of Bob and Linda Cooper.



Bob Cooper thanks Sharon Shaw for donating the \$500 cash prize back to UMDF during the 2001 Conference

disease and information about UMDF. All proceeds to benefit UMDF.

The cookbooks are \$15 each and can be ordered by sending a check or money order, payable to DelValUMDF, to DelValUMDF, 211 Alderfer Road, Harleysville, PA 19438-1901. If you would like a form or need more information, please call Maripat Shelly, Chapter President, at 215-256-0273 or email the chapter at [delvalumdf@aol.com](mailto:delvalumdf@aol.com).

# CHAPTER ACTIVITIES

## Ohio Chapter

Chapter president, Jennifer Lyman, submitted an article in her employer's newsletter about her daughter, Caroline, and the UMDF. The article was short and to the point with a brief description of mitochondrial disease and how to make a donation. Jennifer raised \$500 by simply asking for help through her employer's newsletter! Gotta love that!



Caroline with her favorite pom-pom!

The chapter is selling golf shirts to benefit UMDF. The shirts are navy blue, 100% cotton and have the UMDF logo embroidered in green on the front. Cost is \$25 per shirt plus \$5 in shipping and handling. To order, please contact Jennifer at 330-929-4430 or via email at [ohiomitoinfo@yahoo.com](mailto:ohiomitoinfo@yahoo.com).



Julie Grant, Jerry Grant, Ben Grant, Laura Owen and Josh Lange at the State Health Fair

## New York Metro Chapter

By Joseph Rice, President

On December 9, 2000, the first meeting to form the UMDF New York Metro Chapter was held. On January 25, 2001, we were honored to become an official chapter of UMDF. We would like to express our sincerest thanks to the board of directors for their vote of confidence.

The chapter will hold its meetings at The Manhattan Club located at 200 W. 56th Street, New York, NY. The Club's gracious donation of a meeting room has helped our creation and will continue to help our future.

Anyone interested in participating in the New York Metro Chapter should contact Joseph or Patricia Rice by phone at 631-862-8975 or email [UMDFNYMetro@aol.com](mailto:UMDFNYMetro@aol.com). Meetings are scheduled every other month and are held on Saturday mornings. Along with regular business, our meetings will often include guest speakers. Our goal is to be informative as well as supportive to our surrounding community.



## Arizona Chapter

The Chapter and the Desert Angels Support Group worked together to raise money once again through the Great Human Race. Final dollar amount raised will be announced in the next newsletter.

Barb Tucker and John Sheedy at the Great Human Race

## New Mexico Chapter

Mitochondrial Disease Awareness Campaign

On January 26 - 28th the New Mexico Chapter participated in the State Health Fair. Information on mitochondrial disease was given to University students, health professionals and families. The health fair had about 20,000 in attendance. The New Mexico Chapter has also placed materials in the Family Resource Center at the University of New Mexico Hospital and the Center for Disabilities and Development Library. The Albuquerque MDA now has materials to give out to all of their patients as well. We are spreading the word and consequently our chapter is growing very quickly.

## UMDF MEMBERSHIP AND DONATION FORM



- Enclosed are my \$35 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.
- Donors of \$40 or more wishing to receive a complimentary issue of Mitochondrial News.
- 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 can now accept MAC  
and VISA  
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  
P.O. Box 1151  
Monroeville, PA 15146-1151



UNITED MITOCHONDRIAL DISEASE FOUNDATION

## UMDF MEMBERSHIP RELEASE FORM

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_ FAX \_\_\_\_\_

Email Address \_\_\_\_\_

### 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 \_\_\_\_\_

Yes, I want to Network!

I will complete this form and  
send to UMDF.

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

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.



UNITED MITOCHONDRIAL DISEASE FOUNDATION

**P.O. Box 1151  
Monroeville, PA 15146-1151  
Phone 412-793-8077  
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email: [info@umdf.org](mailto:info@umdf.org)  
<http://www.umdf.org>**

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**ANNUAL MEMBERSHIP MEETING**  
June 14, 2001  
3:00 p.m. at the UMDf Offices  
8085 Saltsburg Road, Suite 201  
Pittsburgh, PA 15239

Any member is welcome to attend.  
Please call 412-793-8077  
for further information.