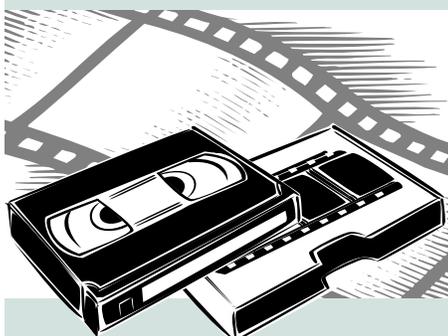


MITOCHONDRIAL NEWS

United Mitochondrial Disease Foundation

FISA Foundation Grant Helps UMDF Spread the Word Through Video

During the Mitochondrial Medicine 2001 Conference in San Diego, UMDF unveiled its very first promotional video. From raising awareness to raising funds, the video has already come in handy for several events across the United States. The video was made possible through funding provided by FISA (Federation of Independent School Alumnae) and through the generous in-kind support from Gregg Rempel of New Perspectives.



Established in 1996, the FISA Foundation's 20-member, all-women board provides support to many organizations in southwestern Pennsylvania. According to Mary (Dee) Delaney, in a relatively short time since becoming a charitable foundation, FISA has awarded nearly \$4.5 million to non-profit organizations that are successfully addressing the health and human service needs of women and girls and quality of life issues for people with disabilities.

Gregg Rempel of New

Continued on page 7

Pseudo-obstruction in Mitochondrial Disease

By Amy C. Goldstein, M.D., Division of Child Neurology, Children's Hospital of Pittsburgh

Patients with mitochondrial disorders may experience gastrointestinal symptoms, such as vomiting or chronic constipation. In fact, GI symptoms can be one of the very first symptoms of mitochondrial disease, presenting at birth or within the first few months of life, only later to develop other organ system involvement, such as myopathy or seizures. Some of these patients may also have dysmotility of their GI tract, which may be due to a clinical condition called pseudo-obstruction. Pseudo-obstruction is a disorder of gastrointestinal motility characterized by a failure of the gastrointestinal tract to propel its contents through an unobstructed lumen. It is a clinical diagnosis, because although the signs and symptoms indicate bowel obstruction, there is no physical or mechanical obstruction or gross inflammatory disease found on radiographic studies or surgically. It may occur as an acute process, a chronic process or an intermittent (episodic) process and is not limited to any one part of the GI tract, but may affect any organ containing smooth muscle and regulated by the autonomic nervous system.

When pseudo-obstruction was first described in 1958, it was not until the 1970's and the use of intravenous nutrition that allowed survival of these patients. It became more frequently diagnosed and noticed to occasionally run in families. With its 'popularity', overuse of the diagnosis became problematic for clinicians, and the medical community needed strict criteria for its proper use. A consensus working group was formed and published the following definition of pseudo-

obstruction in 1997: "a rare, severe disabling disorder characterized by repetitive episodes or continuous symptoms and signs of bowel obstruction, including radiographic documentation of dilated bowel with air-fluid levels in the absence of a fixed, lumen-occluding lesion". This definition is sometimes too strict, because it will exclude children who have intermittent dilatation or a venting ostomy preventing the formation of air-fluid levels.

The symptoms of pseudo-obstruction in children include nausea and vomiting, abdominal distension and abdominal pain, constipation, failure to thrive/poor feeding, and occasionally, autonomic nervous system involvement including difficulty in urination, sweating abnormalities, and fluctuations in heart rate and blood pressure. Adults may have dyspepsia and diarrhea in addition to the above symptoms.

Pseudo-obstruction can be very difficult to diagnose delaying identification and treatment. The symptoms may overlap other GI disorders such as Hirschsprung's disease, cyclic vomiting syndrome, or irritable bowel syndrome or lead to psy-

Continued on page 3

**Turn to the center
of this issue for
the United
Mitochondrial
Disease
Foundation
3rd Annual Report**

Announcing the Official Journal of the Mitochondria Research Society

The Mitochondria Research Society (MRS) is a non-profit international organization of scientists and physicians.

The purpose of MRS is to find a cure for mitochondrial diseases by promoting research on basic science of mitochondria, mitochondria pathogenesis, prevention, diagnosis and treatment throughout the world.

The Society fosters public education, training and provides a platform for communication and dissemination of knowledge among scientists, physicians and others interested in mitochondria. MRS conducts regular national and international scientific meetings on mitochondria and publishes a professional journal named "Mitochondrion" and a newsletter "MitoMatters."

The Mitochondrion is a definitive, high profile, peer-reviewed international research journal. The scope of Mitochondrion is broad, reporting on basic science of mitochondria from all organisms and from basic research to pathology and clinical aspects of mitochondrial diseases. The journal welcomes original contributions from investigators working in diverse sub-disciplines such as evolution, biophysics, biochemistry, molecular and cell biology, genetics, pharmacology, toxicology, forensic science, programmed cell death, aging cancer and clinical features of mitochondrial diseases.



Mitochondrion will include:

The Mito Mew: Editorial and news of general interest.

Review Articles: Reviews of major importance in mitochondrial biology.

These articles will be peer-reviewed. Articles may be of any length; however, unusually long articles should be discussed with the editor before submission.

Fast Track Articles: Peer-reviewed, short studies that are refereed rapidly and published generally within 10 weeks. These papers should be a concise complete piece of work of special significance and timeliness and should not exceed 4 printed pages (i.e., 10 pages of double-spaced typescript, including tables and figures up to a total number of 4).

Original Articles: Peer-reviewed, high-quality, concise research investigations that represent new and significant contributions to science.

Letters to the Editor: Comments on papers published in the Journal and on other matters of interest to mitochondria researcher.

Book Reviews: solicited by the editorial office.

Announcements and Calendar: Providing notices of forthcoming meetings, courses, and other events relevant to mitochondria researchers.

For more information, please contact:

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www.mitoresearch.org

United Way and You

The following was received from one UMDF member and it sheds some light on how United Way can help raise funds for the UMDF mission.

"My company has over 3,000 employees and get a United Way pledge from over 80% of its employees. The amazing thing is many of these people do not have personal circumstances similar to a mito parent, yet they're willing to contribute. I give \$50/month, my company gives \$50/month. That's \$100/month or \$1,200/year. If I get 9 people to do the same: That's \$1,000/month or \$12,000/year."

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 as follows:

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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.



Pseudo-obstruction in Mitochondrial Disease

Continued from page 1

chiatric diagnoses such as functional abdominal pain, school phobia, malingering or somatization disorder. Sometimes a multi-disciplinary team is required to make the proper diagnosis, and may include a pediatric gastroenterologist, pediatric pain management specialist and a child psychiatrist (to evaluate the child and family's behavior in response to pain). Mitochondrial disorders should be considered in patients with unexplained GI symptoms, especially with a suggestive family history when taken by a clinician that is familiar with mitochondrial disorders.

Testing for pseudo-obstruction varies from center to center, and may include an upper GI with small bowel follow-through (oral barium contrast is given and x-rays taken to follow the transit of contrast over time through the proximal small intestine), gastric emptying scan (a radioactive substance is followed through its transit over time), electrogastrography (evaluates electric activity of the stomach), full-thickness biopsy anywhere along the GI tract, and motility studies (antroduodenal and colonic manometry). Motility studies are done with pressure monitors called manometers, which can be inserted along the GI tract and measure the pressure waves of peristalsis in the stomach and proximal small intestine or in the large intestine. Manometry can determine if the transit problem is of a nerve or muscle origin, which has implications for long-term prognosis and therapeutic options. When the nerves are involved, the contractions have their normal strength but are not properly coordinated to propel the contents forward. Various medications may help the nerves coordinate their actions. When the muscle is affected, the contractions may be coordinated but are very weak, leading to dysmotility, and this problem is not helped by the current medications available.

Chronic pseudo-obstruction continues to be a life-threatening disease, with a 30% mortality rate for infants in the first year of life. Dietary treatments include frequent, small meals low in fat and fiber. Patients may require feeding tubes or intravenous nutrition with total parenteral nutrition (TPN) to supplement or replace enteral feedings. The medications currently available are prokinetic agents that enhance motility, but these drugs, such as erythromycin and octreotide, are only occasionally effective. Other treatment options currently available are surgical, including intestinal transplantation. Future developments include drugs that will target specific neurotransmitters in the gut.

Mitochondrial disorders are just one of the causes of pseudo-obstruction. Other causes which need to be excluded include infection with certain viruses, prenatal alcohol exposure, and in adults can be secondary to many diseases such as diabetes, thyroid conditions, certain prescription drugs, and connective tissue disorders (like lupus or scleroderma). There is much research in the area of gastrointestinal symptoms and mitochondrial disorders and new point mutations, complex deficiencies, and clinical syndromes have been described over the past several years.

At Children's Hospital of Pittsburgh, the departments of Gastroenterology, Genetics and Child Neurology have been investigating a group of children with documented pseudo-obstruction to look for mitochondrial disorders such as point mutation 3243 (MELAS) and MNGIE. Mitochondrial Neurogastrointestinal Encephalomyopathy (MNGIE) syndrome is a rare mitochondrial disorder, clinically described since 1983, with symptoms that include gastrointestinal dysmotility/pseudo-obstruction, ptosis, progressive external ophthalmoplegia, leukoen-

cephalopathy, thin body habitus, peripheral neuropathy and myopathy. Some of our study patients had muscle and/or skin biopsy prior to referral to our center, and in two of these patients, a complex deficiency in the electron transport chain (ETC) was detected. Both of these children had a family history suggestive of possible mitochondrial disorder. We hope to learn much more about pseudo-obstruction and the incidence of mitochondrial disorders within this population of children.

For more information on pseudo-obstruction, contact:
American Pseudo-obstruction and Hirschsprung's Disease Society, Inc.
158 Pleasant Street
North Andover, MA 01845-2797
Phone: (978) 685-4477
Fax: (978) 685-4488
Web site: www.tiac.net/users/aphs
e-mail: aphs@tiac.net

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The DCA/MELAS Clinical Trial at Columbia University

by Petra Kaufmann, MD1, Salvatore DiMauro, MD1 and Darryl C. De Vivo, MD1,2

Departments of Neurology1 and Pediatrics2, Columbia University College of Physicians & Surgeons, New York, NY

We are conducting a three-year, randomized clinical trial to evaluate the effectiveness and the safety of dichloroacetate (DCA) in MELAS (mitochondrial encephalopathy, lactic acidosis and stroke-like episodes).

MELAS is probably the most common mitochondrial encephalopathy and is most often associated with the A3243G mutation in the tRNA^{Leu}(UUR) gene of mtDNA. Onset is usually in childhood or young adulthood. MELAS is a multi-system disorder that can have a large range of symptoms. As in other mitochondrial encephalomyopathies, organs that are highly dependent on oxidative metabolism, such as the brain, are particularly affected. The impaired energy metabolism leads to the abnormal buildup of a substance called lactic acid. The resulting acidosis can be life-threatening and interferes with functioning of the brain and other organs. In addition to the stroke-like episodes, patients may have seizures, migraine headaches, diabetes and gastrointestinal symptoms. Some patients with MELAS experience difficulties with concentration, thinking, and behavior, and may be depressed.

In our ongoing cohort study investigating the natural history of mitochondrial syndromes we have been following 25 families with MELAS for several years. Although this study is still underway and we continue to enroll new participants, our preliminary analyses have yielded important findings. MELAS is more severe than other syndromes associated with mitochondrial DNA point mutations. For example, when compared to patients with MERRF (myoclonus epilepsy with ragged-red fibers), another relatively common mitochondrial encephalomyopathy, MELAS patients have more cognitive difficulties, more psychiatric problems, and are more

dependent on help in their activities of daily living. The most striking finding in our study was the severity of cerebral lactic acidosis. We assessed lactic acidosis in the brain by MRSI, a special type of magnetic resonance imaging. The severity of brain lactic acidosis in MELAS patients goes along with the severity of their symptoms and the degree of their impairment on neurological examination and neuropsychological testing.

One plausible explanation for this observation is that excessive lactic acid in the brain may contribute to nerve cell dysfunction in MELAS patients. This hypothesis is supported by laboratory experiments showing that lactic acid is, in fact, harmful to nerve cells. Indirect evidence for a deleterious effect of lactic acid on the brain also comes from anecdotal reports of clinical improvement in adults and children with various types of lactic acidosis treated with dichloroacetate (DCA), a lactate lowering agent.

DCA stimulates the activity of an enzyme called pyruvate dehydrogenase (PDH). This enzyme, which is present in mitochondria, controls the rate at which cells metabolize sugar (glucose) and its major breakdown product, lactic acid, to eventually produce carbon dioxide, water and energy (ATP). Thus, DCA lowers the lactic acid level in blood, spinal fluid and tissues by stimulating PDH and favoring the oxidation of lactic acid to harmless byproducts, while at the same time increasing the efficiency of mitochondria in generating ATP for normal cellular work. DCA is the most powerful stimulator of PDH ever administered to humans, and exerts its effects in virtually all tissues, including brain, heart, muscle, and liver. DCA crosses the blood brain barrier and effectively lowers brain lactate, thus favorably improving cerebral pH. DCA may therefore help patients

with MELAS and chronic brain lactic acidosis due to cerebral energy failure. To the extent that chronic acidosis contributes to the pathophysiology of the neurological impairment, we hope that DCA will decrease the brain injury associated with mitochondrial dysfunction. DCA can be given by mouth or intravenously and has generally been well tolerated. However, it has been reported to cause neuropathy in some cases. The neuropathy is thought to be reversible.

When DCA was given to MELAS patients in the past, it seemed helpful in several cases. However, we cannot be sure that DCA is safe and effective for MELAS patients from such anecdotal reports. DCA is currently not approved in the United States unless under investigational protocols. We are therefore conducting a double-blinded clinical trial of DCA in MELAS patients. The term "double-blinded" refers to a design where the safety and effectiveness of DCA is compared to a placebo. A placebo is a pill without any active ingredient. All patients enrolled in the DCA/MELAS trial will receive DCA or placebo at different times during a three-year period. Neither the patients nor the research team will know which type of pill, DCA or placebo, participants are taking at any given time. A medical monitor will review study results to ensure the participants' safety. Patients of at least 6 years of age who are fully symptomatic and who have been diagnosed with the A3243G mutation may be eligible. Regardless of which pill participants take, they will be given a special vitamin combination at no cost throughout their participation in this study. The study is funded by the National Institutes of Health (NIH)/National Institute for Child Health and Development (NICHD). Participants will receive periodic evaluations by our MELAS research team at Columbia

Presbyterian Medical Center. They will be admitted to the research unit and undergo a comprehensive evaluation including neurological exam, laboratory tests and, in some admissions, Magnetic Resonance Imaging and Spectroscopy Studies (MRI/MRS) and nerve conduction studies. All evaluations are provided at no cost to the patients. Travel assistance is available.

One question that patients frequently ask is why study participants will receive a placebo during some periods of the trial. They are wondering whether it would not be better for them to be sure to receive the active DCA pill. We feel that it is our responsibility as physicians and researchers to subject new treatments to controlled clinical trials for several reasons.

As with every serious disease for which there is no cure, physicians and patients alike strive for effective treatment and are understandably ready to embrace any new hope. This aspect of human nature is well captured in the expression "grasping at straws" and makes it difficult to establish whether a new therapy is helpful or harmful. Everyone wants to take the new treatment and everyone involved wants to believe that it works. The history of medicine has many examples of treatments that were associated with considerable discomfort, cost, or even danger, and that were used on many patients until finally they were proven ineffective or even harmful in controlled clinical trials.

Controlled clinical trials are now widely accepted standards in medical research. Most patient advocacy groups, including networks of cancer and HIV patients, support controlled clinical trials. The FDA requires proof of safety and effectiveness in controlled trials before approving any new medication. The National Institutes of Health guidelines for funding of clinical research encourage medical researchers to design rational, controlled trials.

If we were certain that DCA helps

patients with MELAS, we would not have to do a clinical trial. If at any point during the trial it became clear that patients taking DCA do significantly better or worse than those without DCA, the trial would be stopped and we would be able to give the appropriate recommendations to MELAS patients. Until and unless we have these results, the only way that individual patients with MELAS, their family members, and the community of mitochondrial patients can obtain crucial information on the efficacy of DCA is through a double-blinded trial. We strongly believe that participation in controlled clinical trials is in the best interest of patients with mitochondrial diseases and their families. Especially when dealing with relatively rare diseases, it is of crucial importance that potential therapies are investigated at designated research centers and in controlled trials. In doing so, patients and researchers will have the greatest chance to reach their common goal, that is, to improve the situation of patients with mitochondrial disorders. These studies greatly reduce the inconvenience, risk, and expense that many patients and family members encounter when they feel obliged to take suggested treatments without knowing whether the treatment will actually help or when they should stop taking it. Clinical trials allow us to rationally test treatments, eliminate ineffective treatments rapidly, and, hopefully, find an effective and safe treatment soon.

For further information on the DCA/MELAS clinical trial please contact:

Ms. Kristin Engelstad, Research Coordinator, at the the Neurological Institute of Columbia University (9th Floor), 710 West 168th Street New York, NY 10032
Tel: (212) 305 8025
Fax: (212) 305 0431
Email: melas@columbia.edu.

Spread the Word Through Video

Continued from page 1

Perspectives developed the video by using footage from the national office archives, the UMDF Chapters and from various home videos provided by UMDF members. Pat Meehan, who has a niece affected by the disease, volunteered his time and talents to videotape Ohio Chapter members. With the help of Scott Palmer, newscaster for the local ABC affiliate in the Philadelphia area, and Marilyn Woblick, of the Lafayette Hills Studio, Delaware Valley Chapter provided excellent footage for the video. Although Rempel could not use the footage provided by Arizona and Southern California Chapters, there will be more videos in the future and all of the UMDF Chapters will be called upon to participate.

On behalf of the UMDF Board, the Chapters, and all those affected by mitochondrial disease, THANK YOU to FISA, Rempel and all those who gave their time and talents to this very important effort.



UMDF Symposium 2002

Don't forget to mark your calendars for the next UMDF Symposium
June 6-9, 2002
Westin Galleria, Dallas, Texas

2001 The Curtain Rises Again World Congress & Exposition on Disabilities (WCD)

September 28-30, 2001

Georgia International Convention Center, Atlanta

An education event with over 65 conference sessions, CME and CEU accredited, produced, promoted and endorsed by the EP Foundation for Education, Inc.

For Information: 877-923-3976 x847, 201-226-1446 or www.wcdexpo.com

UMDF Chapter Activities

Delaware Valley Chapter

The Shelly's Heroes 5K & 1 mile run/walk and Blosky Blast Off Tot Trot was another success this year raising approximately \$17,000. The day's festivities included the 5K run, the 1 mile run/walk, the Blosky Tot Trot, Chinese auction, face painting, bake sale, children's games and crafts, and more. The Delaware Valley Chapter members rallied together to volunteer their time and talents. Well done!

The Chapter will be busy this Fall with the upcoming "You Go Girl" golf outing on Wednesday, October 10th and they have committed to selling at least 1000 cookbooks!



Brendan Shelly enjoys Shelly's Heroes while his godson sleeps on his lap.



Janet Blosky, organizer for Blosky's Blast Off Tot Trot during Shelly's Heroes Run, instructs the Tots on how to Trot.



The true Shelly's Heroes — the volunteers who organize the event! Special thanks to Sherrie (2nd row, 2nd in from the left) for taking such an outstanding leading role!

Southern California Chapter

Vitamin Fundraiser

Now you can buy your Co-Q10, Carnitor, and all your Essential Vitamins and Supplements and give back to our cause.

The Southern California Chapter of the UMDF has created a way, with the generous contribution of MRM Vitamin Company (Metabolic Response Modifiers) to allow UMDF members to purchase our "vitamin cocktails" at WHOLESALE PRICES.

Here is how it works:

Call the MRM Company at 800-948-6296 give the "password" UMDF and place your order. Pricing is at wholesale prices plus shipping and handling. MRM Company will donate back to the UMDF a portion of all proceeds that come from your orders. For more information on MRM product call their 800 number listed above, or visit their web site at www.metabolicresponse.com Feel free to call MRM Company and request a catalog. If placing your order via mail, simply write the password "UMDF" to receive the discount.

Internet access will be available soon, we will keep you posted.

**This offer does not constitute the endorsement by UMDF of MRM or any other vitamin company. Your purchase of any vitamin product is at your discretion. If you know of a vitamin distributor/manufacture who can offer similar discounts, call the UMDF office at 412-793-8077.*

Shell Out for Charity

Johnny Reb's Restaurant has chosen the California chapter as the next recipient of their Shell Out for Charity Program. Several locations will keep a large donation jar with a picture and story of six year old Chad Cooper, son of Bob and Linda Cooper. The story of Chad will be on each table from July 16th through September 16th. So, go to Johnny Rebs Southern Roadhouse for great food and free peanuts! For more information, contact the chapter!

Chapter garage sale raised over \$1,600 and they have plans for a carnival this upcoming fall.

New England Chapter

Eileen Mitchell, chapter officer, is working on a charity boat cruise which is set for September 11, 2001 with Horizon's Edge in Lynn, Massachusetts.

Kacey Gaffey and Friends Run 2000

Kacey Gaffey shows off her Friends of Kacey Gaffey t-shirt as her mother Jackie looks on



Ohio Chapter

During Dr. Cohen's June 10th presentation of "Mitochondrial Cytopathies: Past, Present, and Future", the chapter raised over \$1,700 through donations and the sale of UMDF apparel. Food and refreshments were provided by chapter members ... a big thanks to those who helped coordinate a successful event. However, our biggest thanks goes out to Dr. Cohen for his continued dedication to UMDF and our families.

Ohio chapter is participating in the national cookbook fundraiser and has made a commitment to sell 500! Golf shirts are also still available for \$25. Information is posted on the website or call Jennifer Lyman at 330-929-4430.

In conjunction with UMDF Trustee Stan Davis' Ohio Golf Outing, the chapter will be selling \$5.00 raffle tickets for prizes during the outing on August 20th.

Wisconsin Chapter



Wisconsin Chapter 2001 4th of July Parade Float.

The Wisconsin Chapter represented UMDF and all those affected by Mitochondrial Disease during the Mequon-Thiensville, Wisconsin, Fourth of July Parade!

Chapter members, Dave Dobke and Jim Heyer, organized teams of volunteers to staff Milwaukee's Cajun Festival this past Spring. In return for their efforts, money will be donated to UMDF.

UMDF Chapter Activities

New York Metro Chapter

The chapter is working on a Las Vegas Raffle and has been busy with a letter writing campaign geared toward Long Island's most successful companies.

In September, plans are underway for manning a booth at a local street fair.

Arizona Chapter

Great Human Race raised over \$3,500 this past spring for the Arizona Chapter.

The Chapter is preparing a MAP (Mitochondrial Awareness Program) which will serve as an educational tool for new members and for the medical community.

Upcoming Fundraising Events mark your calendars . . .

SUMMER/FALL 2001

Brad Burgener, of Hillsboro, NJ, is still raising money by selling candy. Keep up the good work Brad!

AUGUST 20

Columbus, Ohio, Golf Outing

AUGUST 20

2nd Annual UMDF Ohio Golf Outing, Cleveland, OH

SEPTEMBER 11

Horizon's Edge Charity Boat Cruise, Lynn, MA

OCTOBER 10

You Go Girl Golf Outing, Flourtown, PA

OCTOBER 5

Talbot Journey Begins - Starting in Baltimore, Maryland, with a kick-off Car Cruise and Family Day on Saturday, October 6, 2001 in Monroeville, PA. For more information about the kick-off or the Journey, please contact the national office.

OCTOBER 13

Benefit Dinner in Rutherford, NJ for Nicholas & Brendan Nunno

OCTOBER 21

Mito-What? 5K Run, Longmeadow, MA
(for info call Jackie at 413-567-5435)

NOVEMBER 2001

Entertainment Book Sales Begin for Western PA

For more information on these events or if you have a new event coming up, please contact the UMDF office at 412-793-8077 or via email at info@umdf.org.

CHAPTERS

Arizona Chapter
President: Karen Lipps
Email: AZChapter@umdf.org
Phoenix, AZ

Delaware Valley Chapter
President: Maripat Shelly
Email: DelValChapter@umdf.org
Philadelphia, PA

New England Chapter
President: Bill Shea
Email: NEngChapter@umdf.org
Boston, MA

New Mexico Chapter
President: Laura Owen
Email: NMChapter@umdf.org
Albuquerque, NM

New York Metro Chapter
President: Joe Rice
Email: NYMetroChapter@umdf.org
Long Island, NY

Ohio Chapter
President: Jennifer Lyman
Email: OHChapter@umdf.org
Cuyahoga Falls, Ohio (Cleveland area)

Southern California Chapter
President: Sharon Shaw
Emails: SCalChapter@umdf.org
Orange, CA (Los Angeles area)

Wisconsin Chapter
President: Anne Juhlmann
Email: WIChapter@umdf.org
Milwaukee, WI

SUPPORT GROUPS

Atlanta Area Support Group
In process of reorganizing -
anyone interested in helping out with
the group should contact UMDF at
412-793-8077.
Atlanta, GA

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

Central Ohio Support Group
Contact: Shawna Steele
Email: ssteele817@juno.com
Columbus, OH

Kansas City Area Support Group
Contacts: Pam Johnson, M.D. or
Heidi Harmon
Emails: pammiejmd@aol.com
bzyHeidi1@aol.com
Kansas City, MO

Canada - Ontario Support Group
Contact: Valerie McGarry
Email: vmcgarry@attcanada.ca
Toronto, Ontario, Canada

Tri-State Mitochondrial Support Group
Contact: Andrea Gropman, M.D.
Email: agropman@nhgri.nih.gov
Bethesda, MD

New York, Western
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

Virginia Support Group
Contact: Shelby Hawthorne
Email: whhawt@erols.com
Williamsburg, VA

San Diego Support Group
(subsidiary of S. California Chapter)
Contact: Jen DeMeo
Email: jendemeo@aol.com

New Groups are trying to form in
Illinois, Northern California,
Southern Ohio, South Carolina
and Michigan.

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



UNITED MITOCHONDRIAL DISEASE FOUNDATION

Fundraisers



Julie Hughes, UMDF staff, looks on as Steve Rossi (UMDF accountant) digs for his ball in a gopher hole. Is this Caddy Shack revisited?

Fourth Annual UMDF Pittsburgh Golf Outing Raises over \$42,000

This year the outing took on two corporate sponsors, S & T Bank and PromiStar Bank, and added more opportunities for participants to support the UMDF. A Chinese auction was part of the day's festivities as well as a putting contest. S & T Bank's program book ad stated "We look at it as 18 means to one end. A cure." Golfing with the UMDF is most definitely one more way to bring us closer to that one end.



Paula Quinn with Steve Rossi closer to the real hole

Kites for Kristen, Jump-a-thon, Basketball-a-thon More Incredible Youth Fundraisers

Pat Charleston, of Chicago, Illinois, raised over \$5,000 and told a local paper that she felt it was her mission to raise funds for research and educate the public on the disease. "After the diagnosis, instead of sitting around crying, I wanted to do something positive," Charleston said.

And, wow, did she do something. More than \$5,000 was collected at the "Kites for Kristen" fundraiser held at her brother David's school, St. Daniel the Prophet. The Charleston's asked students to donate to decorate a kite and then held a drawing for prizes. A Grand Prize was awarded to the class who donated the most money.

The Charleston's didn't stop there. At Kristin's school, Byrne Elementary, more than 500 students participated in a combination jump-a-thon, basketball-a-thon and dress down day.



Pat, Kristen and David Charleston

One student said that "he was shooting baskets because he wanted her to live the same life that we have." They took pledges and also donated \$1 for the opportunity to dress down - "Out of Uniform Day". Over \$1,200 more was added to the Charleston's fundraising efforts. Outstanding!!

Charleston was touched by the compassion of the people at both schools. She was quoted in her local paper saying, "Sometimes a disease makes you feel very isolated, but I realize I'm not alone."



David Charleston and his friends decorated the lunchroom walls with kites

Fundraisers

New National Fundraiser

The Hearts Full of Hope- Recipes Gathered with Love Cookbook

The Delaware Valley Chapter created and designed this special cookbook which has 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.

The chapter graciously decided to make this a national fundraiser in dedication to all the chapters and families of UMDF. The cost is \$15.00 (plus \$2 shipping and handling). To order your cookbook(s), please contact the chapter nearest you or the national office at 412-793-8077. Order forms will also be made available via the UMDF web site.

For those of you who have already placed orders, thank you and please be patient with delivery. The books have been printed and will be shipped out in August. There was a slight delay in printing-please accept our apologies, but remember, all proceeds benefit UMDF! So, start "cooking" up some ideas on where to sell them, or give as gifts, and order your cookbooks now.

Fifth Annual Megan E. Camaiani 5K Mito-What? Run Raises Over \$8,000.00

Each year Lori and Bob Camaiani, along with a committee of wonderful volunteers, organize the run and each year it just gets better and better. Once again, American Recruiters was a major sponsor for the event.

Pictured here are: the Camaiani family, Clare family, Carieri-Mollnhauer family, Golden-Foss family, Josie and Carl Elrod, Nina Nachman and Cindy Teeto.



Fundraisers

Take the Pennies Challenge

In the last issue of Mitochondrial News, the National Junior Honor Society of Eastwood Middle School, Indianapolis, Indiana, raised \$1,916 to benefit 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.



St. Ignatius 6th Graders with Piggy

Guess what? Another youth pennies fundraiser surpassed this amount by \$11. Each year St. Ignatius has a penny saving project during Lent and this year UMDF was the recipient of the money raised. Sister Clara Mohan, an IREP teacher for St. Ignatius, lost her grandniece, Gina Marie Mohan, to mito in 1995. The project raised \$1,927.

Just think if every member of UMDF joined the "Pennies Challenge" and started similar projects at their schools. 30 schools at \$1,927 equals \$57,810!!! And think of the awareness - these kids will remember the word mitochondrial for years to come.

Multi-Family Garage Sale Nets \$4,215.90 for UMDF Research

On June 22nd, 23rd and 24th, 2001, Friends and Family of Cooper Adelstein executed the 1st Annual Multi-Family Garage Sale for UMDF research in Cleveland, OH.

Coordinated by Daryn Adelstein and Cooper's paternal grandparents, Dr. Jerry and Marilyn Adelstein, the event drew everything and anything imaginable from the homes of more than 25 families throughout Cleveland's East Side and as far as Cooper's Aunt and Uncles homes in Dallas, TX and Chicago, IL.

The large circle of friends and family that donated their time and merchandise, ensured that the quality of goods present the first day remained throughout the entire weekend in

order to draw returning customers and continuous foot traffic. In addition to the selling of the endless articles of clothing, electronics, kitchen appliances, furniture, toys, sporting goods - just to name a few - money was also raised by Cooper's Cleveland Cousins - Melanie, Jake, Sydney, Jeremy and Avery Adelstein, who wanted to



Cooper and his cousins help the garage sale proceeds by selling lemonade

help the cause through a lemonade stand with all proceeds benefiting UMDF.

While weekend volunteer Goldie Ermine managed the clothing sales at next door neighbor Dr. Fred and Linda Blank's home, Danny Ermine managed the funds ensuring that every customer received a UMDF brochure and explanation of Mitochondrial disease and how it affects Cooper and so many others.

Thanks to the dedication and commitment of so many Friends and Family of Cooper Adelstein, the Multi-Family Garage Sale resulted in a \$4,215.90 donation to UMDF research. The Adelsteins are also active members of the Ohio Chapter.

For information on how to successfully coordinate this type of event in your market, please feel free to contact Daryn Adelstein @ 440-684-9776.

Mitochondrial Disease Strolls Through Frontier Days in Milford, Ohio

Jennifer Cooper, mother of Madison and Molly, 4-year-old identical twins, manned a fundraising booth at the Frontier Days in Milford, Ohio, and raised over \$8,500 to benefit UMDF. The event was much more than a mere fundraiser because the local media took a strong interest in Madison and Molly's story.

Local events such as this provide a great opportunity to get the word out about Mitochondrial Disease in your communities. If anyone is interested in setting up a booth at a local event, please call the UMDF office for materials to distribute or display.



Jennifer Cooper with her 4-year-old twins, Madison and Molly