

MITOCHONDRIAL NEWS

United Mitochondrial Disease Foundation

UMDF and the World of Mitochondrial Research

By Mark Fleming

UMDF Vice Chairman, Research Coordinator

Mitochondrial disease has existed for many centuries. Unfortunately, only recently has this complex group of diseases begun receiving the attention it deserves. The under-recognition of mitochondrial disease has led to the misdiagnosis of patients and under-funding of research. Fortunately, due to improved funding and better understanding of the science, things are beginning to change.

In 1989 the National Institutes of Health (NIH) funded only 39 grants related to the biology of mitochondrial disease. By 1999 the number had increased to 274, a 700 percent increase in just 10 years (see Figure 1: Extramural = outside NIH, Intramural = within NIH). Though not as dramatic as the increase seen in NIH grants, the number of publications related to mitochondrial medicine saw a 400 percent increase between 1965 and 1999 (R.K. Naviaux, MD, PhD).

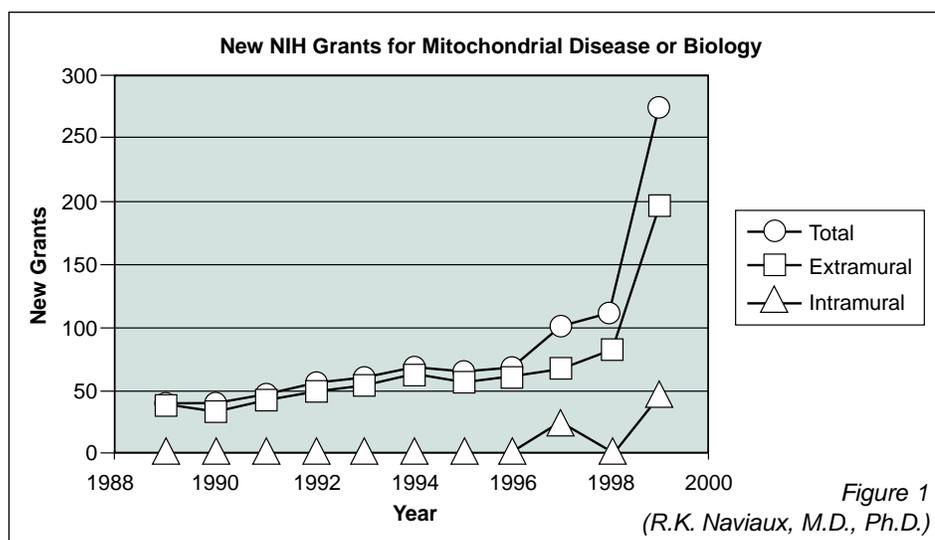
Yet, in spite of these increases in research toward mitochondrial disease, this malady received only 1% of

the NIH budget in 1999. These deficiencies in research did not go unnoticed by the UMDF.

The UMDF Responds

Early in 1997, the fledgling UMDF recognized the lack of a research focus into mitochondrial disease. We realized we were in a unique position to fund research directly into this vast field. After discussions with our Scientific Advisory Board (SAB), we initiated our peer-reviewed Research Grant Program. By the end of 1997 we funded our first grant for a total of \$30,000.

By 2002 our total grant award had increased to \$250,000. We were pleased to announce these awards during the 5th International Symposium on Mitochondrial Disease held in Dallas in June of 2002. This marked an important milestone in that our 6-year-old grant program had now funded nearly \$500,000 of peer-reviewed mitochondrial research (visit the UMDF website for a complete list of funded projects). In 2003 we will match that



Mark Your Calendars

UMDF International Conference on Mitochondrial Disease

Please mark your calendars and spread the word. The UMDF Symposium has been moved to 2004! During the Dallas 2002 conference, the UMDF Scientific Advisory Board suggested more relevant science will be available making 2004 more informative from a scientific standpoint.

Mark your calendars NOW for:
September 16-19, 2004
Westin Convention Center
Pittsburgh, PA

Based on historical experience, the Symposium Committee continues long range planning regarding future locations and the best times to host symposia. As for future topics and speakers, please visit the web site at www.umdf.org and click on Future Conference Questionnaire. Your input is invaluable and we want your feedback!

total with an additional \$500,000 of mitochondrial research grant funding (see Figure 2).

By increasing the amount of funding, the UMDF has experienced a jump in the number of applicants and the quality of projects. This supports one of our goals with the grant program: to draw new researchers into the field of mitochondrial medicine. It also will allow new researchers to generate enough data for a big-dollar NIH grant. Another way we are working to draw new researchers and physicians is with a Post-Doctoral Fellowship program. We have recently received a gift of \$150,000 to be used for a 3-year post-doctoral fellowship.

The UMDF has not limited its research activities to the grant pro-

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Chairman's Report

This final newsletter of 2002 brings exciting information on new happenings at UMDF. We have expanded the office, giving us additional space that will ultimately enhance and increase services to the membership. We have been awarded our first Fellowship Grant in the amount of \$150,000. This will fund a Fellow in Mitochondrial Research for the next three years. The Trustees have authorized and committed to award \$500,000 in research grants for 2003. The UMDF database is being updated which will help keep UMDF strategically positioned for future growth. And most importantly, the UMDF Trustees have hired a new Executive Director to orchestrate this expansion of space and services and the future of UMDF.



Chris Rice, UMDF Executive Director, hails from Indiana where he spent the last 18 years with Kiwanis International in the position of Manager of Program Development. Chris describes himself as a results-oriented leader who is looking forward to guiding UMDF to levels of success while maintaining a commitment and focus to the mission.

Chris sees UMDF Chapter development as a priority and is looking forward to meeting and working with all the chapter leaders. Chris's wife and his two children are looking forward to relocating to Pennsylvania where Chris's oldest son is a senior at the University of Pittsburgh.

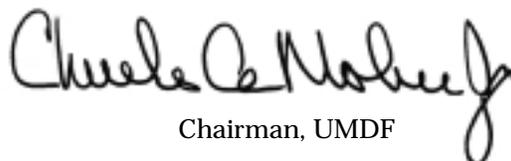
I want to thank the Search Committee and their chairman, Trustee Rand Wortman, for a job well done.

Another holiday season is upon us and once again I ask that we all remember to pause in sober contemplation of our UMDF families and the millions of people around the world who do not have happiness this holiday season, who have lost hope and are in need of support. We must be humbly grateful for the privilege of living in a country where spiritual values have not been completely subordinated to material things. Current world events have created sensitivities that help us realize that our freedoms still allow us to support initiatives that promote research, aid support, and help redefine hope.

When UMDF makes its "wish list" this holiday season, we will not ask for worldly possessions. Instead, we want only your good will ... to serve you so that you will continue to think well of us, as surely we do of you.

May your "wishes" come true this season, and if they do not, may you have the strength to continue to "wish" and work for them. May your sensitivities and good will continue so our mission of, *promoting research for cures and treatments of mitochondrial disorders and to provide support to affected individuals and families* also continues.

Yours toward a cure,



Chairman, UMDF

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UMDF and the World of Mitochondrial Research

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gram. In 2000 we created a task force to investigate the expansion of research and funding related to mitochondrial disease. The task force devised a plan now called the Research Expansion Project (REP), a 5-year project to take mitochondrial disease research to the next level.

The REP has as its three ultimate goals the establishment of: Mitochondrial Centers of Excellence, Multi-center Clinical Trials, and an Office of Mitochondrial Medicine at the NIH. Mitochondrial Centers of Excellence may include basic research, patient treatment, and clinical trials. These mitochondrial centers would form the basis for clinical trials throughout the world, conforming to agreed-upon protocols. The Office of Mitochondrial Medicine would help coordinate research within the government and encourage the creation of mitochondrial centers and clinical trials.

Of course, one does not achieve such lofty goals overnight. The REP includes many objectives to be achieved along the way, such as: defining the health-care burden through epidemiology, improving diagnostic techniques and standards, defining a clinical trials protocols template, expanded research funding, establishment of medical codes for mitochondrial disease, annual reports on the status of mitochondrial research, and congressional lobbying efforts. Many of these objectives are in process.

For example, in early 2002 we invited epidemiologists from several of the top Schools of Public Health in the United States to meet with the UMDF to provide input regarding our approach to determining the epidemiology of mitochondrial disease. Out of that meeting came the recommendation by the epidemiologists that, prior to initiating a full-fledged epidemiological study, the

UMDF should focus its efforts in three areas: improve diagnostic techniques, educate physicians regarding mitochondrial disease, and improve the gathering of patient data.

The UMDF is supporting several projects in direct response to these recommendations. This past June

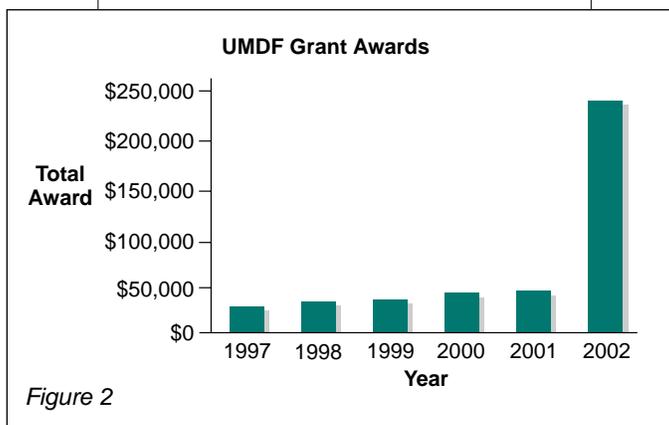


Figure 2

the UMDF sponsored the second meeting of the Mitochondrial Standards Workshop during which it was decided to establish a program to exchange tissue samples among labs in an effort to establish widely accepted standards of diagnosis. The Sample Exchange Program will begin operation early in 2003 in conjunction with the Mitochondrial Medicine Society.

Another UMDF-sponsored effort is the establishment of a World Registry of Mitochondrial Disease. The World Registry will be a place to log patients for the benefit of research, but will also allow doctors to track patient progress and responses to treatments. The information will be entered by medical professionals, thereby assuring its accuracy. Operation of the World Registry will also begin in 2003.

Other Research Expansion

Project-related activities include the establishment of multi-center clinical trials. Efforts are underway to begin the first such trial. It is important that these trials meet the same rigorous scientific standards

that are used in clinical trials for other diseases. This may require that the trials be placebo-controlled, meaning that the patient may get the experimental treatment, or may get the equivalent of a sugar pill. There may be the need for a cross-over design, meaning that at some point in the study, those getting the experimental drug will be switched to the placebo, and visa-versa. These

studies will also need to be double-blinded, meaning that neither the doctor nor the patient will know if the patient is receiving the experimental drug or the placebo. Such a study yields objective results because neither the patient nor doctor knows who is actually getting the experimental drug. The "end point" information we gathered at the San Diego conference in 2001 is being used to help define the goals

of clinical trials.

Another important activity is the effort to establish medical (ICD) codes for mitochondrial disease. Currently, only two vague codes are available. The situation means doctors are often forced to use less-than-adequate reimbursement codes when examining and treating patients. This could cause patients to be short-changed in their care.

Mitochondrial specialists inside and outside the UMDF are working with the World Health Organization to add sufficient ICD codes for mitochondrial disease. Gathering supporting information regarding the incidence of mitochondrial disease is an important part of this effort. Since we don't have firm epidemiological data, we must rely on extrapolations of available data. To support this effort the UMDF is researching death certificates (MICAR) to identify those who have died due to mitochondrial disease. However, this effort has met with limited success because the cause of death in mitochondrial patients, due to a deficiency of ICD codes, must

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often be attributed to something other than mitochondrial disease. Another way we are working to support the addition of new ICD codes is to define the burden of mitochondrial disease. The "soft" data we are gathering through the "Burdens Questionnaire" is only the beginning. (A copy of the Burdens Questionnaire is incorporated into this newsletter or you may complete it online at www.umdf.org). The World Registry will help us firm up these numbers.

In order to keep tabs on the status of research on mitochondrial disease the UMDF has decided to create an annual review of the status of both private and public research. This will help us to better gear our research efforts and will provide valuable information for other organizations funding mitochondrial disease.

Upcoming Activities

With our increased grant funding, we have the opportunity to support some large, cutting-edge projects. This year we funded some futuristic projects such as stem-cell research, gene therapy, gene shifting, and identification of a potentially new class of mitochondrial disease. The preliminary application process has already begun for 2003 and we are looking forward to, once again, pushing the envelope of research.

In early 2003 the UMDF will revisit the Research Expansion Project. It has been more than two years since the REP was initiated and it is important to keep the project up-to-date with any new developments. The results of such meetings as the epidemiology workshop and the Research Brainstorming meeting held in November 2002 will be incorporated into any revisions to the REP.

Another effort undertaken by the UMDF is to educate pediatricians and primary care physicians about mitochondrial disease. The need to "update" many physicians on mitochondrial disease was pointed out as

a key need by the epidemiologists at the recent workshop. Increased knowledge will lead to improved identification and care of mitochondrial patients. The Physician Education Project is managed by the UMDF's Education Committee.

The UMDF is also carrying the mitochondrial message to Washington, DC. We realize our goals for mitochondrial centers and significant increases in research funding may literally require an Act of Congress. We are developing several congressional contacts and are specifically looking for individuals willing to sponsor legislation to support our cause.

Our efforts in DC don't stop there. We are working within the National Institutes of Health to find senior people sympathetic to mitochondrial disease. The NIH does sponsor mitochondrial research; however, we hope to find those who will encourage more funding and also help coordinate mitochondrial research within the NIH. We have also made some key contacts at the NIH, which may help us acquire NIH funding for conferences.

Our Vision for the Future

While there are currently no proven therapies for mitochondrial disease, several hopeful therapies are being investigated. Therapies involving drugs take time to develop as they progress through the double-blind studies discussed earlier. Though such studies are lengthy and cumbersome, they are the only way to assure a safe and effective therapy. The UMDF will keep you informed as new clinical trials come to fruition. In the meantime, drugs to treat many mitochondrial disease symptoms can be quite effective as they improve and even extend the life of the patient.

Significant research continues on many fronts. The 2002 UMDF grant awards provide a striking example of cutting edge mitochondrial disease

research. In Dr. Schwartz's stem cell research project, neural stem cells will be harvested from healthy individuals and mitochondrial patients in an effort to understand the basic processes of these cells and how they respond to nutrients and drugs. Dr. Bai's gene therapy project is to find out if defective genes in the mitochondrial DNA can be "rescued" by genes in the nuclear DNA. Dr. Taivasallo's project is a clinical trial that attempts to reduce abnormal mitochondria by "shifting" (replacing them with) healthy mitochondria from precursor cells. Lastly, Dr. Hernandez-Yago's project will investigate the genetic cause of a potentially new class of mitochondrial disease related to protein transport.

Another interesting development is the expanding number of links to mitochondrial disease from other "more common" illnesses, such as diabetes, Alzheimer's, Parkinson's, Huntington's, and possibly even aging itself. The link between these diseases and mitochondrial disease will likely bring more funding which will help those with "traditional" mitochondrial disease. We hope to develop strategic partnerships with organizations representing these other illnesses. There may be a way for us to leverage our funds and lobbying efforts.

In Conclusion

No doubt, we all want that elusive cure. I recently heard a mitochondrial doctor say, "Mitochondrial disease is the most complex disease known to mankind." A complicated disease requires a complicated solution, or several solutions. There is no one cure for the myriad of mitochondrial diseases. Will we find the cures? Absolutely! We know it is just a matter of time and money, and persistence.

I would like to thank doctors Bruce Cohen and Robert Naviaux for their contributions to this article. More details on the ongoing activities of the Research Expansion Project can be found at the UMDF website (www.umdf.org) under "Research and Grants."

QUESTIONNAIRE REGARDING THE BURDEN OF MITOCHONDRIAL DISEASE

This questionnaire is designed to help quantify the burdens of mitochondrial disease on affected families.

This information may be used to help further epidemiology studies for mitochondrial disease.

Please circle the correct answer and fax or mail the completed form to the UMDF. This questionnaire is available, and has been since January 2002, on the UMDF Website (www.umdf.org) under "Patient Survey".

Please complete **ONE** questionnaire for each patient

1. To the best of your knowledge, how many physicians (specialists) did you/your family member see before you received a diagnosis of mitochondrial disease?
 - A. Less than 5
 - B. 5 to 10
 - C. 11-15
 - D. 16-20
 - E. More than 20
2. Approximately how much have you/your family member spent in healthcare costs pertaining to mitochondrial disease?
 - A. Less than \$5,000
 - B. \$5,000 - \$10,000
 - C. \$10,000 - \$30,000
 - D. \$30,000 - \$50,000
 - E. \$50,000 - \$75,000
 - F. \$75,000 - \$100,000
 - G. More than \$100,000.00
3. On average over the course of a 1-year period, how many hospitalizations have occurred with you/your family member diagnosed with mitochondrial disease?
 - A. None
 - B. 1 - 3
 - C. 4 - 6
 - D. 7 - 10
 - E. More than 10
4. Do you/your family member currently have medical insurance?
 - A. Yes
 - B. No
5. Has your/your family member's insurance company covered healthcare costs associated with mitochondrial disease?
 - A. No coverage
 - B. Partial coverage — less than 10%
 - C. Partial coverage — 10% - 30%
 - D. Partial coverage — 31% - 50%
 - E. Partial coverage — 51% - 79%
 - F. Partial coverage — 80% - 90%
 - G. Covers all costs
6. If you/your family member does not have medical insurance coverage, is it for any of the following reasons?
 - A. Cancelled after diagnosis of mitochondrial disease
 - B. Cancelled due to job loss or transfer
 - C. Other: _____
7. Have you/your family member suffered loss of gainful employment as a result of mitochondrial disease?
 - A. Yes
 - B. No
8. Do you/your family member consider this disease a cause of financial burden? If yes, to what degree?
 - A. Extreme
 - B. Significant
 - C. Not significant
 - D. None
9. Do you/your family member diagnosed with mitochondrial disease receive any financial assistance from outside sources?
 - A. Yes
 - B. No
10. Can you/your family member diagnosed with mitochondrial disease participate in extracurricular activities such as social and family gatherings?
 - A. Always
 - B. Almost always
 - C. Sometimes
 - D. Occasionally
 - E. Rarely
 - F. Never



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Chapter Activities

ARIZONA CHAPTER

Meet "Radiance" the UMDF Energy Bear

The Chapter continues to sell "Radiance" the UMDF Energy Bear, for \$10 each plus \$2.50 for shipping and handling (Please email the chapter at azchapter@umdf.org for shipping charges outside the US/Canada).



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

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

Trials and mishaps may come our way,

*For our cells lack energy everyday.
Through support we will endure,
As we work to find a cure.*

*Funding research is our plan,
To take us from where we began.*

"Radiance", the Energy Bear, will make a great gift for birthdays, celebrations, get-well gifts, teacher & therapist gifts, and for the holidays. Order your Energy Bear online! www.umdf.org. If you have questions or prefer to order by phone, contact the Arizona Chapter at 623-694-5151.

This past year, the Arizona Chapter made a few changes in their officers and UMDF would like to formally welcome them. Karen Lipps and Thom Montgomery are still serving as the President and Vice President. New additions, as of the Spring 2002, are Becky Lowe and Trudie Jones co-serving as Secretary and Linda Kolze as the chapter's Treasurer. Welcome aboard ladies and sorry for delay in announcing your new roles!

DELAWARE VALLEY CHAPTER

October Fundraisers ...
A Marathon Month

Freedom.con

Thanks to Mike Carr, and his new bride Shannon, for all their effort in putting together Freedom.con, an event for card game players of all ages to benefit DelValUMDF. This event was held in Lansdale, PA the first weekend of October. Mike did a terrific job of raising awareness of mitochondrial disease and the UMDF on the decktek website by allowing members visiting that site to make donations on line to UMDF and even gave away some prizes to those who visited the UMDF website and could answer some of his "clues" which had to do with mitochondrial disease. It was a busy

weekend for the DelVal UMDF volunteers who manned a table at the two day event — they were thrilled to raise over \$1,000 for UMDF. Thanks again Mike and Shannon!

Fashioning Hope for UMDF

"Fashioning Hope for UMDF" was held on October 19th at the Radnor Hotel in St. David's, PA. Thanks go out to Lisa Polsky for proposing this idea to the chapter members who were unanimous in deciding to adopt this fundraising event. The chapter is very grateful to Mary DiPietro, Lisa's Mom, who so graciously took on the job as chairperson and also became emcee extraordinaire at the luncheon! Over 100 ladies enjoyed an afternoon out for a delicious lunch and all were "ooohing & aahing" over the beautiful fashions courtesy of Chico's of Ardmore. We thank Chico's for allowing 10% of all sales at the luncheon and for a few days afterwards to go to UMDF. This first time fundraiser was a success and raised over \$4,000 for UMDF.

Other Chapter Activities . . .

Lorraine & Dawn Ciamaichela continue to show their support of DelValUMDF by handing out UMDF pamphlets, selling cookbooks and showing the UMDF video in their place of business, Harleysville's "Bagels & More". Our chapter is also

5th Annual You Go Girl Golf Outing Raises Over \$11,000 Without Golfing, HUH?

YES — on October 16, 2002, the annual You Go Girl Golf Outing was held in Flourtown, PA, but due to the "monsoons," the golf portion of the event was cancelled. Did that stop the Delaware Valley Chapter and Halligan's Pub from raising funds for research? NO — instead they held their luncheon at the pub and raffled off 100's of prizes reaching a total of \$11,777! *Incredible!*



Peggy Shelly, Bunny Doyle, Paula Berg, Donna Halligan and Janet Blosky were among many who made the event a success. Three VERY SPECIAL people not pictured are Happy Halligan, Joe Halligan and Kevin Lawn, owners of Halligan's Pub and key players in the continued success of this event.

Chapter Activities

grateful to Lorraine & Dawn for securing a spot for the chapter (free of charge) once again at Lansdale Bike Night on September 7th. The chapter sold raffle tickets, Energy Bears and Cookbooks and increased awareness of mitochondrial disease at this popular event.

The chapter held its 3rd Annual Family Picnic this past August. Over 50 people attended — this wonderful day gives adults and children alike the opportunity to enjoy each other's company in a relaxed enjoyable atmosphere!

As always, please keep in mind that "Hearts Full of Hope" Cookbooks make a great holiday gift for friends, neighbors, teachers, relatives, doctors, nurses, etc. and are in stock!!!

The Annual Holiday Party is set for December 15th at the Merion Tribute House. Regular DelValUMDF meetings will resume in January. All members on our mailing list will receive updates, times, locations through our DelValUMDF Newsletter. If you are in the PA, NJ or DE area and are not receiving our newsletter, please call or email our chapter or the UMDF office and add your name to our mailing list.

NEW ENGLAND CHAPTER

New England Chapter recently elected new officers — please join us in welcoming Justine Fargo as the new president and Bridget Willis as the chapter's new secretary. UMDF would like to thank Bill Shea, Deb Shea, and Eileen Mitchell for their outstanding work starting the New England Chapter, and we know they will continue to be an asset to the chapter for future events and activities!

Team Kayla Raises More Than \$9,300 for UMDF

By Kris Biagiotti of Franklin, MA

Well, we did it! Team Kayla successfully completed their first ever triathlon on July 27, 2002. Deb Henault, Rema Tomka, Aimee Fleurette, Kris Biagiotti, and Liza Pouliot (pictured from left to right) participated in the 2002 Danskin Women's Triathlon Series in honor of Kayla Biagiotti, my 7-year-old daughter.

We all did our personal best times and are looking forward to our next event.

I want to take this opportunity to thank our friends, family, and neighbors who have sent contributions, left notes of encouragement, and provided motivation while we were training. Without your help, we could not have been as successful as we were.

A special thanks to the women of Team Kayla. You are all special in Kayla's life and we thank you for all your hard work!



On Saturday, October 26, Cheryl Harrington and employees of the historic Hawthorne Inn in Salem, MA, ran a successful photo booth fundraiser at their annual Halloween Costume Ball and raised \$100.



Family Day at Davis Farmland

Pictured are some of the New England families that attended the 2nd Annual Family Day at Davis' Farmland, on September 21, 2002. Events included pony rides, a hay ride and water activities

First Annual Cooper Mitochondrial Open is a Success!

On October 10, 2002, Amy and Rob Caldicott organized the Cooper Open in honor of Rebecca and Julia Cooper. The event, held at the New England Country Club in Bellingham, MA, attracted 72 golfers and raised over \$10,000 for UMDF. Participants, family and friends enjoyed a barbecue after golf.



Chapter Activities

NEW YORK METRO CHAPTER

Vacation Towards a Cure Raffle - \$9,500+ Raised



The Vacation Towards a Cure Raffle came to a close on October 27th. This year, the grand prize was a five night Florida vacation. Air transportation, four round trip tickets were donated by American Airlines, condominium accommodations were donated by Peter and Mary O'Hara, (friends of the Rice's), and admission to the Walt Disney World theme parks was donated by Walt Disney World Co. Lisa Giordano of Locust Valley, New York was the winner; we would like to wish Lisa and her family a wonderful vacation.

This event was the first national raffle of the UMDF. We would like to thank all the chapters, and support groups who helped make this so successful. We are currently in the planning stages for next year's raffle. Remember that transportation will be arranged from any location in the continental U.S. If there is anyone who may be able to help us secure underwriters for this event, or can help in the selling of tickets, please contact Joe Rice of the New York Metro Chapter at NYMetrochapter@umdf.org or 631-862-8975.

Wine Tasting Dinner - \$4,500+ to Benefit UMDF

The New York Metro Chapter held its annual Wine-Tasting Dinner on October 27th at Café Testarossa in Syosset, New York. Billy Sassone (restaurant owner) once again offered his restaurant to host this event, prepared a delicious 4-course meal, and made the arrangements with Atlantic Wines and Spirits, who donated a fine selection of wines.

This year, we were very fortunate to have Johnny Bronet, (pictured above with Joe & Pat Rice) Danny Kaye's second cousin, graciously donate his time and talents to perform a selection of songs made popular by Frank Sinatra and Paul Anka. Johnny

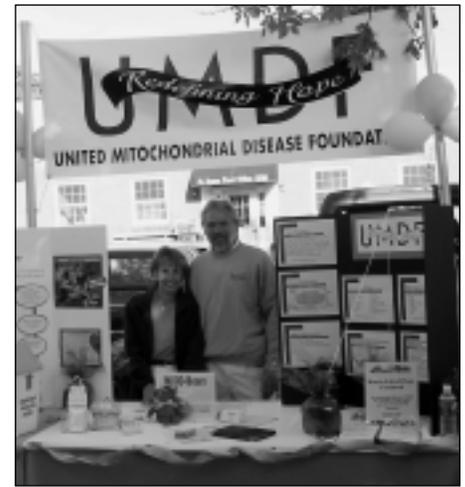


performs regularly at locations on Long Island, New York, and Florida. We also had a local New York artist, Nancy Ostrovsky, (sister of Sharon Shaw, president of the Southern California Chapter) display her artwork for our enjoyment and for purchase with a portion of sales going to benefit the UMDF.

Our annual wine tasting dinner was the forum for drawing the winning raffle ticket for the "Vacation Towards a Cure Raffle" (details noted above). In addition we had several consolation prizes.

Café Testarossa and Rossinis Restaurant located at 108 East 38th Street in New York City each donated dinners. The Remember When Dance Studio on Rt. 25 in St. James donated dance lessons for two couples, and Pat Rice, (known as the GOOD COOKie) donated two trays of her cookies.

Thanks to all of our family and friends who attended, for once again supporting the Chapter, our hopes, and dreams of some day finding cures for Mitochondrial Diseases.



St. James Day

On October 6, 2002 the town of St. James, NY closed Lake Avenue (the main street through the center of town) to vehicular traffic for its annual street fair. This event hosts local and distant merchants with displays of arts, crafts, food, and informational vendors. Joe and Pat Rice took the opportunity to create awareness by setting up a booth with informational displays as well as selling cookbooks, Mito bears, and raffle tickets for the "Vacation Towards a Cure raffle". They distributed more than 500 flyers with a brief explanation about Mitochondrial Disease mostly to young adults with small children. During this event they met some neighborhood nurses who never heard about "Mito" and armed them with information to take back to the doctors they work with.

SOUTHERN CALIFORNIA CHAPTER

This past July, the Chapter held its Annual "Family Garage Sale" in Lakewood. Chapter members, family, friends and neighbors all helped to raise over \$1000 for the UMDF! Thanks to all who participated this year!

The Albertson's Store Community Partners Card has been underway for several months. To date Albertson's has donated close to \$800 to the Southern California Chapter. Every time you shop at

Chapter Activities

Albertson's, a portion of the sales are donated back to the Chapter, up to \$1,800 a quarter! If you have an Albertson's in your city and would like to receive a Community Partner's Card, please contact the Chapter at 562-634-4588.

The Chapter is pleased to announce the appointment of Mr. Mark Clayton as the new Chapter Secretary. He brings his talent of organization and computer skills, along with his commitment of support to the UMDF and the Southern California Chapter. Welcome, Mark!

The Chapter continues with its "on-going" fundraisers — MRM Vitamins, North Bath and Body Shop, Albertson's Community Partners Cards, United Way and Hearts Full Of Hope Cookbook Sales.

OHIO CHAPTER

On-going Activities:

UMDF Cookbook sales, Radiance the UMDF Energy Bear sales, and preparing for the 2nd Annual Walk/Run set for May 31, 2003.

Check out the chapter's UMDF Apparel Form on page 11.

2nd Annual Adelstein Family and Friends Garage Sale to Benefit UMDF

For the second consecutive summer, Marilyn and Jerry Adelstein, grandparents of Cooper Adelstein (who suffers from Mitochondrial Disease), hosted a four-day garage sale and raised \$4,257.50 to benefit UMDF.

On July 25-28, the event drew hundreds of shoppers who were eager to sort through the household goods and clothing that were donated during the past 12 months by family, friends and Cleveland

Chapter members of UMDF. The sale was hosted at the Adelstein garage and driveway as well as next door neighbors, Dr. Fred and Linda Blank.

The successful event was covered by the Sun Newspapers and received a front page story the following week about the garage sale, lemonade stand (hosted by Cooper, his cousins and friends) and more importantly, about the history, severity and effects of Mitochondrial disorders.

Many thanks to the more than 30 adult and children volunteers who supported the cause all weekend by pushing merchandise and educating each customer about Mitochondrial disease.



Tomato Face Foods continues to raise dollars and awareness. Since its beginning in April of 2002, more than \$700 has been sent to UMDF from A & B Cuisine. To learn more about The Original Meatless "Meat Sauce" or Tomato Face Foods, visit them at their website: www.tomatofacefoods.com or email info@tomatofacefoods.com or write Tomato Face Foods, P.O. Box 22694, Cleveland, OH 44122.

Special Note of Thanks to Roofers Local 44, United Union of Roofers, Waterproofers and Allied Workers

Mike Vasey, grandfather of Mikayla Putrino, participated in the Ohio Chapter 5K Run/Walk this past June and at race time raised \$3,710 through a letter writing campaign to his business associates, family and friends. On August 12, 2002, he submitted another check raising his total to \$6,660!

Mikayla — you've got a very special grandpa!

New Clinical Trial

The UMDF is pleased to announce a new clinical trial that may be appropriate for some children and adults with lactic acidosis, pyruvate dehydrogenase deficiency and disorders of OXPHOS and electron transport chain function.

Dr. Peter W. Stacpoole, Ph.D. M.D. at The University of Florida in Gainesville is opening a new clinical trial. He and his group will be studying the effects of dichloroacetate (DCA) in patients aged 3 months to 60 years old with biochemical and/or molecular genetic proof of a defect in PDH, one or more respiratory chain complexes or a mitochondrial DNA mutation. Finally, patients must be able to maintain blood sugars of at least 60 mg/dl after short term fasting.

Dr. Stacpoole and his group believe the side effects of DCA may be due to the effects on tyrosine metabolism. This study will explore whether or not a low-tyrosine diet along with NTBC (a drug to help lower tyrosine levels) prevents those side effects, in addition to whether or not DCA is helpful in the disease itself. The study is funded and approved by the FDA.

The trial will be a double blind parallel model. This means that one-half the patients will be placed on DCA plus placebo for 12 months, while the other half will get DCA plus NTBC. Neither the doctors or the patients will know which treatment the patients are receiving.

Patients receiving NTBC will also receive a diet that is low in the amino acid tyrosine. Patients accepted into the study will first receive a month of dietary education and observation before drug administration. If everything is satisfactory, patients are randomized to 12 months of either DCA (25 mg/kg/d) + NTBC + low tyrosine diet OR DCA + placebo + tyrosine-supplemented diet.

A collaborator in this trial is Dr. Douglas Kerr at Case Western Reserve University, who will assist in conducting or confirming diagnostic studies of potential patients.

For more information please contact Dr. Stacpoole's study coordinator, Ms. Margaret Francis, at 352-392-6195.

SUPPORT GROUPS

Atlanta Area Support Group
Contact: Dan Dahl
Email: dahldenise@hotmail.com
Atlanta, GA

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

Central Ohio Support Group
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Email: drc@dept-one.net
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Virginia Support Group
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Email: whhawt@erols.com
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(Rays of Hope)
Contacts: Christine Golden
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Email: Goldenfamily5@aol.com
Melbourne, FL

Pacific Northwest Support Group
Contacts: Terri Mason
Cathy Akins
Emails: momalboe@hotmail.com
thomasakins@home.com
Portland, OR

Michigan Support Group
Contact: Ann Clark
Email: clarkak@tir.com
Detroit area, MI

Special Meeting Notice:

The Michigan Support group will be meeting on January 19, 2003 from 1:30pm to 4pm at the Canton, MI, Public Library located on Canton Center Road.

Melody Kondratek, who is a Physical Therapist, will be the guest speaker. She would like for us to survey the members for any questions they may have so she can be prepared and include in her presentation. Those questions can be emailed to Ann Clark at clarkak@tir.com. It would also be helpful if people could RSVP so we have a tentative number of people who will be attending.

If children are brought, perhaps another caregiver can come to allow the children to enjoy the library. Ann may be able to arrange with a local high school for some volunteers to help with the children if needed. If you need to bring your children and cannot arrange for someone to help you out, please email Ann at the above address as soon as possible.

Western PA Support Group
Contact: Karen Wilson
Email: info@umdf.org
Pittsburgh, PA

Wisconsin Support Group
Contacts: Anne Juhlmann
Pamela Dobke
Emails: juhmann@execpc.com
dbdobke@aol.com
Milwaukee, WI

New Groups are trying to form in Florida, Illinois, Texas and North Dakota. Anyone interested in these areas or wishing to start a group in another area, please call us at 412-793-8077 or email at info@umdf.org

CHAPTERS

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

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President: Maripat Shelly
Email: DelValChapter@umdf.org
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President: Joe Rice
Email: NYMetroChapter@umdf.org
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President: Jennifer Lyman
Email: OHChapter@umdf.org
Cuyahoga Falls, Ohio (Cleveland area)

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

UMDF Ohio Chapter Apparel Order Form

The UMDF Ohio Chapter is accepting orders for the following items:

All prices include shipping costs.

- **Adult Nylon Half Zip Hooded Pullover with Front Pocket**
Sizes: Small-3XL
Cost for small-XL: \$36.50
Cost for 2XL: \$38.50
Cost for 3XL: \$41.50
Colors: Navy Blue, Hunter Green & Black with tan embroidery
- **Youth Sweatshirt – Jerzees 50/50 8 oz. Pill-resistant fleece**
Sizes: 6-8, 10-12 and 14-16
Cost: \$20.00
Color: Lt. Gray w/Navy Blue Embroidery
- **Baseball Hats – 6-panel, low profile, unstructured, brushed twill**
Cost: \$20.00
Colors: Khaki w/black embroidery
Navy w/tan embroidery
Embroidery Imprint: UMDF logo on front and “One Step Closer To A Cure” on the back
- **Toddler Sweatshirt – Rabbit Skins 50/50 7.5 oz.**
Sizes: 2,3,4,5/6,7
Cost: \$18.00
Color: Lt. Gray w/Navy Blue Embroidery
- **Infant Sweatshirt – Rabbit Skins 50/50 7.5 oz.**
Sizes: 6, 12 and 18 month
Cost: \$17.00
Color: Lt. Gray w/Navy Blue Embroidery

General Information:

- Deadline to place orders: February 1, 2003
- Orders will be placed periodically up until February 1, 2003
- Please allow 3-4 weeks for delivery
- All Embroidery Imprints will read UMDF: “One Step Closer To A Cure”
- UMDF will not guarantee Christmas Delivery
- Make checks payable to: **UMDF Ohio Chapter**
- Send all order forms and checks to Lisa Arnold, Treasurer UMDF Ohio Chapter, 33375 Bainbridge Road, Solon, Ohio 44139. Questions? Please call Bill Hodges at (440) 235-2451.

Please fill in your information below (Print Clearly):

Name: _____

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Daytime Phone: _____

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The Jewish Community
Federation of Cleveland
The Pearl Rug Co.
The Rogoff Family
The Teri & Dan German
Family Foundation, Inc.
Timothy Zwick
Toby Siegel
Todd & Lisa Davis
Tracey & Rodney Simon
Troymill Manufacturing, Inc.
US Bank
Valerie Markowitz
Zircon Industries

EVENTS
\$40,000 - \$99,999
5th Annual Pittsburgh Golf Outing
AXA Foundation
Douglas Beckett
Garrow's Draft Service
GNC Live Well
Greg Adams Ins. Agency, Inc.

EVENTS
\$10,000 - \$39,999
Cooper Golf Open
Amy Caldicott
Sheds USA
Barbara Spinney

Hearts Full of Hope Cookbook
Debbie Schilling
Jennifer Lyman
Joe & Patricia Rice
Nancy & Ron Hansen
Randall & Sandra Anderson

*Percentage of Tenacious D
merchandise*
Kung Fu

*Mito What? 2002 Walk/Run
Tyler & Ingram Families*

A. W. Hastings & Co.
Bruce Tyler
By Design Landscape
Concepts, Inc.
Connect-Techs
Henry Owen Mulvey
Foundation for Children, Inc.
Jeffrey & Helen Vecchiarelli
Joseph D. Fitzgerald
Longmeadow Motor Cars, Inc.
Luanne Perham
Spartinou, Inc.
State Line Sevice, Inc.

Danskin 2002 Triathlon/Team Kayla

Andrew Brand
Arthur Dalton
Bob & Patty Colford
Christine & Guy Lambert
Christine McGuire
Craig & Shawn Strok
David & Jean McElreath
Diane & Mike Jaros
Franklin Elks Lodge No. 2136
Gayle Gordon
Helen Lozoraitis
Henry Barnes
James Garrison
Jeanne & Peter McCluskie
Jeannine & Curtis Sawyer
John & Peg Griswold
John & Rhonda Doherty
John & Susan Norton
Karen Baldassari
Karl & Claire Hill
Lorna & Brian Klafit
Mark & Monica Woodward
Mark Korson
Martin & Christina Gill
Maurice & Jeannine Morin
Michael and Kerry Bartone
Michael Morin, MD
Mitchell Schechter
Peter & Linda Falat
Philip and Debbie Henault
Pierrette Kelly
Rene & Renee Fleuette

Richard Biagiotti
Robert Eremian
Shane & Lisa Carey
Sharon Hershon
Teresa & William Kilroy
Thomas & Paula Lovett
Westside Baseball

*UMDF Benefit Dinner/The Nunno
Family*

Aanensen's
All American Recycling Corp.
Augustitus Plumbing & Heating, Inc
Aw Van Winkle & Co.
Carol & Dennis Rorke
Circle Line Statue of Liberty
Ferry, Inc
David & Victoria Dziejawiec
Ed & Cathy Kubarewicz
Frank & Diane Pirella
Hourigan Elect. Contractors
Industrial Cooling Corporation
Inserra Supermarkets
Lewis & Dolores Rothenberg
Louise Palluzi
Montclair Cardiology Group, P.A.
Mr. & Mrs. P. Imbrenda
Norman Sheet Metal
Raymond & Pamela Nunno
Recycled Paper Board Inc. of Clifton
Reliance Contracting, Inc
Schoor Depalma
Seehaus & Walker Const. Co.
Vesey & Nunno Kidvertisers

EVENTS
\$5,000 - \$9,999

Vacation Toward a Cure

Anthony & Beatrice Nocerino
Antoinette Rampello
Caroline T. Pugliese
CCE Contractors, Consultants &
Electricians
Christine Pedalino
Clifford & Carol Berry
Clifford & Sherry Posner
Constance Marohn
Diane Lewis
Dorothy Nocerino
Drs. Caroline A. & Thomas Shubeck
Eleanor Mariani
Gerard Coraggio
Gordon & Danielle Mulvey, Jr.
James & Mary Waltz
Janice Geigle
Joe & Patricia Rice
John A. DiCecco
John L. Toomey, Jr.
Kara Strittmatter
Kathleen & Richard Berger
Kristine Biagiotti
Linda Graham
Linda Levick
Linda, Gary & Lauren Surprenant
Marc Acosta
Mary & Matthew Pisani
Michael Cammarota
Millicie International, Inc
Mr. & Mrs. Paul Scasino & Family
Mrs. Gladys Ricotta
Mrs. Hilma Dragan
Nicole & James Tobin
North Shore Kitchen, Inc.
Patricia Delaney
Patricia Obert-Thorn
Paul & Laura Nunno

Penn Plaza Brokerage LTD.
Robert M. Klos
Ruth Anna & Clifford Berry
Stephen Siciliano
Steven & Caryn Cohen
Strategic Aerospace Materials
Teresa Zillmann
Vincent & Karen Hunter

2002 Cruisin' Towards a Cure

Arc-Master Incorporated
Belmont Auto Sales, Inc.
Biondi Mitsubishi
Biondi Motor Company, Inc.
BJ Tree Service
Brinker Auto Sales
Cars & More Leasing
Charles & Victoria Sneddon
Classic Auto Refinishing
Cochran Automotive
Computer Fellows Inc
Day Ford
Derek Herforth, General Contracting
Donald and Janice Doerfler
Elite Custom Limousine, Inc.
Fedele Insurance Services, Inc.
Fisher Auto Sales, Inc.
G. K. Welding
G. Kidd, Inc.
Gasoline Alley Restaurant
George and Cindi Welsh
Greater Pittsburgh Mustang Club
Hamilton Buick, Pontiac, GMC
Imports by Day
Infiniti Real Estate Services, Inc.
Joe & Renee DiMatteo
Keiter Kars
Kruzin' Knights
Little Lou's Pizza
Luv-Us Flowers & Gifts
Mark Dale
Maxim General Contracting
Mohan's Restaurant
Monroeville Chrysler Plymouth, Inc.
Peterman's Car Care & Towing
Picasso's Autobody
Priceless Rent A Car
Raymond Hernandez
Rick Parr
Ron & Donna Miklos
Sam's Club
Sandy and Bryon Turi
Scott & Wendie Mack
Shining Arrow Assoc.
The Closing Specialists
Weimann's Innovative Interiors
Wieland Enterprises
Wm. H. Molyneaux Tile Contracting, Inc.
Abacus Nursery Fair
Christine Butterworth

Entertainment/Enjoy Books

Anthony and Roberta Proviano
Antoinette Renda Beasley
Arthur Holt
Bonnie & Albert Borgony
Bruce and Patricia Unks
Cary Hixson
Charles & Adrienne Mohan
Charles J Boone
Cheryl Kolb
Clarence & Patty Zahrobsky
Dale & Xina Marie Matuza
Daniel and Mary Lou Duerring
David and Sandra Moon
Donald Wei

Dorothy Alke
Francis and Frances Kramer
Gary and Jean Marshall
James & Cathy McBride
Janice and Edward Collins
Jean Mellor
Judy Pavlecic
Lawrence & Shirley Ratkus
Lee and Karen Hinkle
Marion Irons
Mary Jane and Rodney Lutz
MICON Development Inc.
Patrick Bonacci
Richard and Jean Seidel
Robert & Gail Miscovich
Robert & Mary Jean Cloherty
Ron & Donna Miklos
Thomas & Marilyn Dancisin
Thomas Mullen
Virginia Sauka
Wayne & Genevieve Graff

Wine Tasting 2002 in Memory of Heidi Marie Daniel

Betty & Ernest Austin
Bob & Patty Burke
Carol Peterson
Costless
Darlene Peck
Diana Cornell
Diane and Ronald Rucker
Evelyn Broaddus
Igor Zbitnoff
Jack & Kathy Starback
James & Carol Connerton
Jeff & Tami Mee
Jill & Greg Lononis
Jim & Cindy Thompson
Josephine M. Wold
Judy Johnstone
Kathleen Jones
Laura Bazzani-Cash
LaRee & Robert Rogers
Larry Nixon
Michael & Cindy Kelley
Michele & Patrick McBride
Mike & Kathie McBride
Nina Curtis
Norma Bartolomei
Norma Daniel Gibson
Patricia A. Caouette
Phyllis Davis
Richard & Bobbye La Malfa
Robert Johnstone
Robert Scaglione
Sandra Hendrickx
Sarah & David Downey
Shirley & Tom Schott
Susan & Daniel Pollesel
Tana K. Uriarte
Tim & Joanna Marsh
Ulysses & Jofrid Lononis
Zoeann Barbier

Wine Tasting/Raffle NY Metro

Antonette Benson
Brigitte Mazzaferro
Cathy & Brian Aubin
David Nunno
Debbie Colnick
Ella & Richard Bruns
Joe & Patricia Rice
Joseph Doyle
Linda & Richard Smith
Marie Franzoni
Mary O'Hara

Michael Cammarota
Mrs. Hilma Dragan
Nancy Conkling
Nicole A. Davis
North Shore Kitchen, Inc.
Peggy Miceli
Robert & Anne Hill
Robert & Joyce Damon
Robert Wolpert
Sandra & Richard Bruns
Stapleton Tree & Landscape Service
Teresa Zillmann
Thomas Minerva, Inc.
William Michaels

EVENTS

\$0 - \$4,999

Cut-A-Thon/In Honor of Macy Sullivan
Jill Desmarais & Daniel Frank

Radiance the Energy Bear

Joe & Patricia Rice
David & Angela Nunno

Charity Softball

Tournament/Physiotherapy Associates
James Vick

Dance Fundraiser, In Honor of Molly/Madison Cooper

Sycamore Twp. Firefighter Assoc.

Fourth of July Party/Chuck Mohan

Charles & Adrienne Mohan

Freedom Farmers 4-H Club/ In honor of Jordan Gresham

Belinda & Woodson Richardson
D. Scott Bowling
Kristi and Mike Gresham

Friends of Matthew Abato

CD Wang Enterprises, Inc
Orange & Rockland Building Corp.
Treasure House of NY, Inc.

Golf 2002/ Steele

Automotive Consultants Centerburg
Cindy Nye
Elford, Inc.
Gary Chandler
Hands of Faith Church
JAC Enterprises, Inc
Jess Howard Electric Company
Lisa Walt
Mark & Lisa Bayless
Marque Dental Associates, Inc
Phone Depot, Nippert
Communications
Shawna & Jason Steele
Timothy & Julie DuBoe

Hooters Golf Outing

Hooters of Monroeville

Mohan Car Cruise

Ron & Donna Miklos

Multi-Family Garage Sale/ Cooper Adelstein

Betty & Synita Brazil
Daryn, Kevin, and Cooper
Adelstein
Devona Miyoshi
Dr. & Mrs. Gerald Adelstein
Ella Mae King

Fred and Lynda Blank
Martin & Susan Cahen
Melvin & Diane Ginsberg
Michael & Denise Clayton
Rochelle & Robert Cygan
Timothy & Robyn Aiken

Plum Faculty Bowl-a-thon/UMDF
Dr. D. P. Nebel

Shop for a Cause/Monroeville Mall

Strittmatter Pig Roast
Kara & Joe Strittmatter

Sweet Tomatoes Restaurant/In Memory of Megan Camaiani, Carly Carieri, & Michelle Vanderveer

Angela Schmalz-Ginsberg
Beatrice Lipsitz
Beverly & Mark Banta
Bob & Lori Camaiani
Carl & Rosemarie Carieri
Colette Vanderveer
DBA Souplantation & Sweet Tomatoes
Eileen Levine
Martin Fealk
Mr. & Mrs. David Bloom
Nina Nachman
Pacific Healthcare Group, Inc
Patrick and Joan Clare
Premiere Investigation Serv.
R.P.T. Management, Inc.
Susan Kaplan
Therapy, Inc
Vanderveer Motors, Inc
Walter & Jennifer Little

Tomato Face Foods
A & B Cuisine, LLC

Tour de Kids Fundraiser
Ann Arbor Velo Club

Mark Your Calendars NOW!

MitoSpan Meeting
Saturday, April 5, 2003
10:00 AM to 5:00 PM
Children's Hospital in
Los Angeles (CHLA)

This unique meeting will provide presentations in Spanish on the basics of mitochondrial disease for Spanish speaking families and medical professionals. The meeting will also provide an opportunity for the families to network and gather information. Literature will be provided in both English and Spanish.

For more information, please contact Ariela or Stacey at the CHLA Genetics Department at 323-669-2178.

Assembling the Puzzle of Getting Your Healthcare Bills Paid

By Michael S. Friedberg, CHE

Corporate Director, Liberty Healthcare System, New Jersey
(father of Zachary Friedberg pictured below)

One of the challenges that we are all presented with in having a chronically ill family member is making sure that our bills are paid by our insurance company. This article will give you an overview of the different types of bills you may receive, the different types of insurance plans and some helpful hints on what to do to get your bills paid.

Based on the complexities of the system and the variability of laws from state to state this article is not intended to give specific advice but will hopefully act as a general guide so that when you make an inquiry, you will better understand some of the language of the industry.

I am the proud father of a four-year-old boy who suffers from Pyruvate Dehydrogenase Deficiency and a six and a half year old boy who is not affected by mitochondrial disease. During the day I am a corporate director for a three-hospital health system in New Jersey with responsibility for the admission and registration, financial counseling and a portion of the outpatient billing for the system.

Here are a few helpful hints before we discuss how things are paid by insurance companies.

- 1) **BE ORGANIZED!** We all have notebooks filled with test results, physician reports, etc. You should also have a "billing" notebook in which you keep all correspondence with your insurance company as well as all of the EOB (explanation of benefits) which is the form that comes in the mail to explain what was paid (or sometimes not paid).
- 2) Read and know your policy. Look at the special sub limits and restrictions. Know how many PT (Physical Therapy) visits you are allowed and check to make sure that you are given what you are entitled to.
- 3) Try to call and make a friend of a claims supervisor at your insurance company. Your human resources department can arrange this if you work for a larger company or you can try on your own. This way when you have a problem you have someone who already knows the situation and you don't have to explain yourself over and over again.
- 4) It never hurts to ask for special treatment. Call the provider (physician or hospital) that is billing you and ask to speak to a supervisor or manager. Tell them you can't afford the co-pay or balance bill since you have a chronically ill child. You would be surprised at how many of these bills I have gotten them to reduce or forgive. If they say no, try to go to the next level. This doesn't work all the time but if it works sometimes, you may save some out of pocket money.



- 5) Save a copy of every receipt for co-payments, vitamins, and any other out of pocket expenses.

- 6) Know what your appeal rights are. If your insurance company denies a treatment, you can appeal the decision and they have to consult an expert. If they deny the first appeal there are second level appeals -- insist that they find an expert in mitochondrial disease. You can even suggest an expert. You must demonstrate medical necessity.

A short aside — my son was put on a ketogenic diet. My insurance company at first would not cover the RCF formula and microlipids he needed. We appealed and they again denied us stating that, if he was tube fed they would cover it, but since he was drinking the formula, it would not be covered. We went to a second level appeal and provided a paper from a journal explaining the use of RCF in Zachary's disease. It took six months but we eventually won the appeal and had all of our back bills paid.

You should talk to your accountant on the federal tax side. Un-reimbursed medical bills are deductible above 7.5% of your adjusted gross income. For example if you make \$50,000 a year as a family, any money you pay out of pocket above \$ 3,750 would be deductible. This includes co-payments, vitamins, durable medical equipment (wheelchairs, etc.). In addition this may also be a state deduction, but you must speak with a tax professional in your state to get the specific rules.

All medical bills can be divided initially into two categories 1) technical bills and 2) professional bills.

Technical bills - This is the bill you will receive from the hospital or other health care facility for a visit. This is how the hospital is compensated for the nursing staff, the electricity, the food, and so forth. If there is operating room or recovery room time, this is all billed under the "technical bill."

Professional bills - This is the bill you will receive from the professional who provides you care (this is generally a physician, but can be a physician's assistant, nurse practitioner, therapist or others). This does not include nurses as they are part of the Technical bill.

In the physician's office, they will bill a global fee, which includes both the technical and professional components.

As you all know, there are many different types of health insurance. I have broken them into the following categories:

Indemnity - This is traditional health insurance where your bills are paid based on the charges submitted by the

provider and after you satisfy your deductible, the bills are paid with a co-payment (a percentage of these charges, usually 80%) up to a certain amount and then the bills are paid at 100%. All of these bills are subject to an insurance company's "usual and customary limit" — this means that they have a top price that they will pay for any procedure and that is the maximum they will allow. Most providers will accept this payment as payment in full but sometimes you have to ask. However, you are responsible for any amount not paid for by the insurance.

PPO Plans - Preferred Provider Organizations. These plans (usually offered by larger employers) have a network where they have negotiated discounts from the providers. These plans usually have co-payments for office visits and other visits and procedures. They do not generally require referral forms, but many procedures and especially hospitalizations will require authorization (this should be obtained by the provider, but it is your responsibility to check). It is hard to generalize, but in most instances if you are in network you will not be responsible for the difference between a provider's charge and the amount this insurance pays.

HMO Plans - These are the most restrictive plans, as they require you to stay within their network and they will not pay for care outside of their network. These plans require you to go through a primary care provider and get referrals to see specialists. You must obtain authorization for everything in these plans and it is important that you know your responsibilities. In most instances a provider agrees to accept the rate paid by the HMO and you cannot be balanced-billed for the difference between the charges and the insurance payment.

POS Plans - Point of service plans. These are a mix between HMO/PPO and indemnity. These are the plans that have an out-of-network option. So, if you stay in network, you only pay the co-pay; but if you go out of network, you are responsible for a deductible and a percentage of the charges.

Medicare - This is the federal plan for those over 65, the permanently disabled (there is a very strict definition to be met here) and those on renal dialysis. The decision to apply for Medicare is difficult, and you should consult a health care attorney before you take this step. Medicare pays based on a fee schedule and there is a deductible for each hospitalization and a deductible and co-payments for physician visits similar to indemnity insurance. The advantage of Medicare is that most providers if they participate agree to the fees in advance. You can only be billed the co-payment, not the excess above payment to get to charges.

Medicaid - This is the federal program administered by the states for the poor, and disabled. In my opinion, unless you are unemployed and do not have other options, this should be a last resort. Many physicians do not participate in Medicaid and so your choices are very limited (mostly to hospital clinics). However, many states now have programs called CHIP programs for children,

and they put you in a managed care plan and generally have richer benefits. You can call your local hospital and ask to speak to a financial counselor. They will have information as these programs vary from state to state.

Those of you who work for large employers have an advantage and should use your human resources departments as a resource. In my opinion, even though the cost is higher, you should always pick a plan with an out-of-network option. You don't know who will come up with a treatment, and if you want to get a procedure or see a doctor in another city, you can at least get part of the bill paid.

Those of you that work for smaller employers or are self-employed have it much tougher and the best scenario is to form a relationship with someone in the insurance company so that they understand your history and can serve as an advocate for you.

In conclusion, this basic overview is meant to be a generalization and you should check with your human resources department or others that I have suggested throughout this article to get advice related to your specific situation.

It is hard enough to deal with physicians and understanding the disease, it is sometimes just as hard to make sure your bills are all paid properly. Stay organized and stay calm. Good Luck!

**Editors Note: In the next issue of Mitochondrial News, look for an article based on the transcription from Mike Dodge's talk on "Billing and Getting Paid", UMDF Symposium, June 2002, Dallas, TX.*

NFL Community Quarterback Awards

Chuck Mohan nominated several UMDF members who exemplify leadership, dedication and a commitment to the UMDF mission. To date, here are two of the success stories:

New York Jets

Nominee Joe Rice, President NY Metro Chapter, was named a top ten finalist and awarded \$1,000 to benefit UMDF. All your hardwork does pay off!!!

Dallas Cowboys

Nominee Jane Clarke McManus, UMDF Trustee, was given a Certificate of Achievement.

Emergency Preparedness for your Child

The American Academy of Pediatrics and the American College of Emergency Physicians developed a two page Emergency Information Form in 1999 for Children with Special Needs. For more information (copy of the form is on the web site), visit the AAP web site at: <http://www.aap.org/advocacy/emergprep.htm>

Ask the Mito Docs and They Will Respond

In the Spring of 2001, UMDF introduced a new look for its web site and added a feature called Ask the Mito Doc. Members ask questions regarding mitochondrial diseases and they are forwarded to a mitochondrial specialist to respond. The questions and answers have been very informative and UMDF felt compelled to share some responses with all its members (especially for those who do not have internet access). Please note that information contained in "Ask the Mito Doc" is for informational and educational purposes only. Such information is not intended to replace, and should not be interpreted or relied upon, as professional advice, whether medical or otherwise.

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

THE QUESTION IS:

When a patient with mitochondrial disease sleeps excessively, where do you draw the line between allowing them to sleep/rest or pushing to maintain some level of activity. What about trying caffeine?

RESPONSE FROM: RICHARD BOLES, MD

This is a very difficult question for which there is no correct answer. Perhaps here, culture and belief are more relevant than medicine and science. The determination to "be as normal as possible" and to exceed one's previous limits is a powerful force that I have seen people with mitochondrial disease use to overcome many obstacles. The price is a lot of will power, discomfort, and the many "mito-bumps" on the road to this goal. However, such determination is difficult to continually impose on another person (like a child), and the best that one can do is to live those same values and hope that your child adopts them.

Having said this, in mitochondrial disease there are some medical issues here. Some form of exercise, or at least an active life, is important

in maintaining the current level of strength and stamina, as well as possibly to improve them. As everyone knows, obesity and inactivity will reduce anyone's "energy level". In mito patients, they are double-hit with the disease. Exercise should be fairly frequent (such as at least twice a week), and to push the individual to the point of fatigue. Excessive exercise, especially in the presence of cramps or in hot weather, can precipitate a dangerous metabolic decompensation and should be avoided. The problem lies in determining "the point of fatigue." Distinguishing true metabolic fatigue from simple laziness is not always easy.

Another possibility that should be given serious consideration is that of a "chemical" depression. In my experience, depression is very common in mitochondrial disease and can look a lot like fatigue and laziness. I have found that depression in mitochondrial disease responds to the same antidepressant medications as those that are generally prescribed. Some signs of depression are a lack of pleasure in activities previously enjoyed and/or a change in sleeping or eating habits. If you think that you or your child may possibly be depressed, please discuss this with your physician.

Depression can be very serious, often is progressive, and is treatable. Regarding caffeine, I frequently suggest this treatment for dysautonomic symptoms such as migraine, cyclic vomiting and arm/leg pain. Caffeine appears to be safe in patients with mitochondrial disease. It does not "cure" the underlying cause. If you think that it helps, I see no problem with using it. The fatigue likely will come back when the caffeine wears off. However, caffeine is not an appropriate substitute for exercise or antidepressants.

THE QUESTION IS:

Which anticonvulsant has had the best dual affect i.e., seizure control and movement disorder control?

I have a child who is on Tetrabenazine (it has been a miracle

drug for her dystonia with no side effects), Artane, Klonopin and Baclofen for her dystonia and spasticity with good success. She takes Neurotin for seizures, which also helps her complex movement disorder. Since last year we have had to more than triple her Neurotin to manage her seizures and we are at the maximum now. There has been no significant weight gain that would require the increased dose so we are investigating why she is needing more. We are considering adding an additional medication with the thoughts of changing medications altogether rather than dealing with two meds. My daughter has a diagnosis of Leigh's Syndrome with no identified mutation.

RESPONSE FROM: BRUCE COHEN, MD

There is no one best answer to your question. The movement disorders as a group are difficult to treat and some patients do not respond to any medication. You may wish to share this information with your doctor regarding my personal experience with my patients. As far as I know, no one has written a paper comparing any of the medications I have mentioned.

My first choice is generally Lamictal. It is difficult to use because it takes "forever" to get enough of this medication in the system to do any good. Going slow with the dose increases is the key to preventing a terrible skin rash. It could take 2-3 months to taper up the dose to see a therapeutic benefit. If you get impatient and try to increase the dose too quickly, a life-threatening rash could occur. Lamictal is neuroprotective, an excellent antiseizure medication and helpful with many myoclonic movements (myoclonus is a sudden jerk) that so many of my patients have.

I have found Gabitril to be very helpful with pain and cramping, and sometimes relaxes the dystonic (dystonia is a slow twisting movement) component of some movements. It is a good anticonvulsant but not really used first-line as a single agent

anticonvulsant. I have had a number of patients that have had great success as an add-on anticonvulsant. If dystonia and seizures are the two target symptoms in your child this may be the best choice. I tend to start with a night time dose of 2 mg in the young child and work up if tolerated.

Keppra is an excellent anticonvulsant for partial seizures and is also helpful for some types of dystonia and chorea (chorea are rapid movements involving different muscle groups each going in random directions). In about 10% of my patients, Keppra causes irritability and meanness (90% have no problem).

The old time drugs Mysoline and Dilantin have been used to treat movement disorders for years, but I do not use them because of sedation (Mysoline) and drug-drug interactions (both). Both are excellent anticonvulsants.

I do not have any practice using Topamax for movements, but it is an excellent anticonvulsant as well. I have not found Tegretol/Carbatrol/Trileptal helpful for movements. Depakote can cause a tremor, and I would also avoid this medication in any person with a mitochondrial disorder (although I have had many patients do well with this medication and do not stop it if they have tolerated it.)

It is trial and error, sometimes called the "art of medicine" and not the "science of medicine."

THE QUESTION IS:

If a child has a diagnosed oxphos disorder, what specialty type physician would be the best to oversee this child's case? We are having trouble as the neurologists who see him do not have the knowledge or time, and the geneticists just want to argue the diagnosis.

RESPONSE FROM:

K. Michael Gibson, PhD, FACMG

To my thinking, management of the care of a patient with an oxphos disorder has to be multi-faceted, and can not be a solo opportunity. The PCP must be actively involved, as should be the attending neurologist and the metabolic specialist (who will have a close liaison with the biochemical genetics laboratory). The latter individuals provide the key biochemical interpretations that benefit both PCP and the neurologist involved.

Mito Adults Corner

Dreams and Genes

*By Tara Collyer of Queensland, Australia
UMDF Member and Support Group Leader*

First there were dreams...career, marriage, family, holidays, living the good life. A plan. All within my grasp.

Then there were genes. A mutation that would change my life as I knew it, and touch the lives of so many around me.

So many years of poor health. Each year, each birthday brings a new symptom. So many doctors, so many different diagnoses. Just one of those unlucky people with so many different health problems. That's the way the cookie crumbles...

Then I got married — an understanding man and a nurse — the perfect combination. Then I fell pregnant. It should have been the happiest time in our lives. But this was the straw

that broke the back of my fragile DNA. Not long after the birth of my son came the new diagnosis, "You have mitochondrial disease." Relief, finally an answer after so many years. But then, the prognosis, "There is nothing we can do for you. Go home, put your affairs in order, make the most of what time you have left."

No more dreams. The focus becomes defective genes. Our lives revolve around doctors, tests, hospitals, medication, research. Then our son becomes sick. Could it be Mito? Have I condemned him?

Depression. Pessimism.

Then a friend tells me I have a choice. What choice could I possibly have? What will I allow to control of my life — a disease or me?

A choice. I choose life. My life. I learn all I can about my disease for knowledge is power. I take control of my treatment by finding a team of doctors and therapists, who will work with me, not just tell me what they can't do. I change my lifestyle — less hours at work, more rest. I acknowledge those things I can no longer do. I use aids to help me to conserve my precious store of energy — hearing aids, sit instead of stand at work, use a cane or a wheelchair when moving for longer distances. More time with my family and less time with the dust bunnies under the furniture. It does not matter to me now if my house is untidy. I join support groups (on-line, as I find it hard to go out at a set time). People who understand what my life is like. Friends. Five years pass.

Now I have new dreams. A plan. Life.

I dream of watching my son grow up to be a healthy young man.

I dream of growing old. 30 is too young to die.

I dream of more good days.

I dream of many years of love with my husband.

I dream of greater awareness for mitochondrial disease.

I dream of a viable treatment for Mito.

I dream of a cure.



Fundraisers

Holiday Card 2002

The national office launched the Holiday Card Program this Fall and as of November 18, 2002, \$11,220 has been received in honor of and/or in memory of loved ones affected with mitochondrial disease. Special thank you goes to Chris O'Brien, of Iowa Falls, IA, for once again creating a beautiful watercolor for the card. Fifteen UMDF members requested additional cards to send to family and friends-over 300 additional cards were sent. More information on the program will appear in the Spring newsletter.

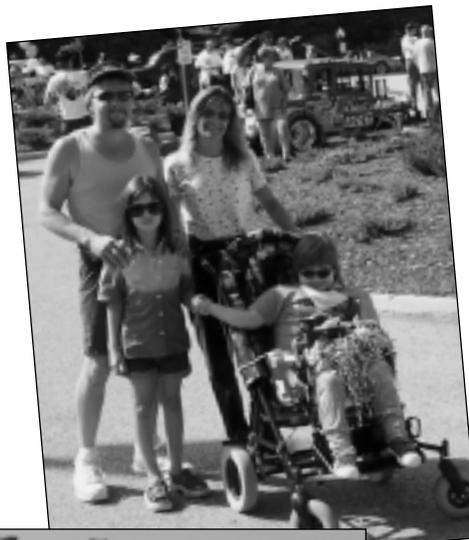


Third Annual Ohio Golf Outing raises over \$100,000

This year Stan Davis, UMDF Trustee and Event Chairperson, and his committee added a special event for Ladies Only which included golf, a luncheon with Bridge - PLUS the evening dinner for all the participants. You are the best Stan! Special Thanks to Fifth Third Bank for their generous annual sponsorship of this event and to Nancy Kelchert, Amy Rogoff, Carole Davis and Jill Platt for their dedication to the event's success.

2nd Annual Cruisin Toward a Cure

The Second Annual "Cruisin' Towards a Cure" was a huge success raising some \$8,900. Over 325 cruisers were in attendance, and the UMDF families who attended this year's event were in awe over the support of the cruiser community. Special Thanks to Donna and Ron Miklos for their endless hours in preparing for this event and for introducing UMDF to such a fantastic group of people - Cruisers have big hearts!



Wedding Bells Ring in Honor of Brian Thomas MacDougall

Erin Habitz and John Niezgoski of Brownstown Township, MI, are sharing their special day on December 14th with their godson by donating \$625 to UMDF. In Honor of Brian Thomas MacDougall, son of Erin's cousins Jamie and Jason MacDougall, the couple made this donation in place of wedding favors at their wedding. Thanks Erin and John - and Best Wishes for a bright and HOPEful future for your entire family!

Great Human Race in Durham Raises \$1,586.32

In March, 2002, several UMDF families in North Carolina gathered to raise funds at the Great Human Race in Durham. Although it was a chilly morning, they raised almost \$1,600 on behalf of the UMDF. UMDF families who participated in the walk/run were Karen and Steve Haneline and their kids Madeline and Matthew, Crystal and Ashley Bledsoe and their sons Michael and Christopher, and Valerie Eatmon.

In early Spring, Val had UMDF send a letter to UMDF families in her area to ask for help in obtaining pledges or volunteering their time for a booth. The above families



Event Coordinators, Ron & Donna Miklos, graciously accept a check for \$200 from UMDF supporters, the Kruzin' Knights of Butler, PA.

Fundraisers

responded to the letter and the end product was a success story. The money and awareness raised is extremely important to the UMDF mission, but the support found through working together toward a common goal (to find a cure!) is always priceless. Thank you to all of those who participated in this event and we look forward to your continued support in 2003.

3rd Annual 5k Mito-What?
Walk/Run Brings in over \$11,500
to Benefit UMDF



Emily Tyler and Dominique Ingram are the driving force behind this big event and quite the little helpers!

The Tyler and Ingram families strike again in Longmeadow, MA, with another successful Walk/Run. Regardless of the rain and cold, participants from miles around joined the festivities on October 13th at Bay Path College on Route 5. Thanks Jackie, John, Dan and Beverly - and we look forward to your continued support in 2003!

The Matthew Dudgeon Memorial Walk and Dinner Dance Raised \$25,000 this past spring to benefit UMDF. Special thanks to Gina Dudgeon and her committee for another grand success. Mark your calendars for next year's event - May 10, 2003. For more information, visit <http://themattyfund.org>.

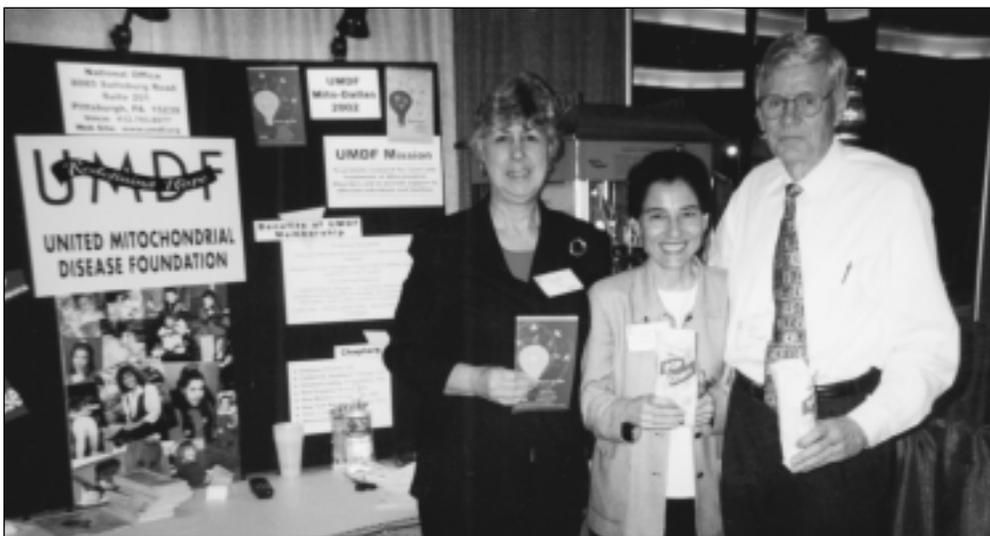


The ATO Fraternity at Duquesne University of Pittsburgh, PA, presented a check to Chuck Mohan as a result of their ATO Twenty Gallon Challenge which raised \$2,110. Chuck Mohan (son of Mohan) is a member of the fraternity, and he initiated the event in Memory of Gina Marie Mohan.

More and More Fundraisers Special Thanks to . . .

- Jason and Shawna Steele, of Columbus, OH, organized the Olivia Steele Memorial Golf Outing, raising \$1,322.60.
- Hooters of Monroeville, PA, raised \$500.
- Sycamore Township Firefighter Association, IAFF #3907, of Cincinnati, OH, raised \$1,700 in Honor of Molly and Madison Cooper.
- In Memory of Angus Scrivener, of Gloucestershire, UK, \$293 was raised during the Abacus Nursery Fair.
- Entertainment/Enjoy Book Sales - Ron Miklos raised thousands to benefit UMDF. Thanks Ron!
- Strittmatter Pig Roast - Kara & Joe Strittmatter invited friends and family to join them once again to honor the UMDF Families and raised \$742.
- Tomato Face Foods continues to raise dollars and awareness. Since its beginning in April of 2002, over \$700 has been sent to UMDF from A & B Cuisine. You can find this no-fat spaghetti sauce at all 14 Greater Cleveland Heinen's Supermarkets, the West Point Market in Akron, Internationally acclaimed Jungle Jim's, located just out side of Cincinnati, Ohio. Thanks to some our UMDF families in Wisconsin, the sauce is now available at Woodman's Food Markets, a nine store chain in Wisconsin! The Original Meatless "Meat" Sauce may also be purchased through Stello Foods by calling 1-800-849-4599 or by Fax 814-938-8769. Ten percent of the proceeds go to the United Mitochondrial Disease Foundation to support research. To learn more about The Original Meatless "Meat Sauce" or Tomato Face Foods, visit them at their website: www.tomatofacefoods.com or email info@tomatofacefoods.com or write Tomato Face Foods, P.O. Box 22694, Cleveland, OH 44122.





UMDF and Physician Awareness

UMDF continues to raise awareness in the medical community throughout the year. Jane Clarke McManus, Georgette Demes, and Jerry McManus spread the word about mito at the Texas Medical Association Meeting this past summer.

Development News

By Dr. Georgette Demes, UMDF Director of Development

I had the pleasure of presenting the UMDF booth at the American Society of Human Genetics Meeting in Baltimore on October 15-18, 2002. The term "American" is a misnomer because the meeting was international in scope. Meeting attendance was approximately 5,000, composed of scientists, clinicians, genetics counselors and students from around the world, as far as Bahrain, Israel, South Africa, and Australia. I came away with strong indications that mitochondrial disease is prevalent worldwide and one day needs to be addressed as a global concern.

Special thanks to UMDF members Elizabeth

Hefferon, Lynda McGrath, and also Christine Curtis, assistant to Dr. Andrea Gropman, for assisting at the booth. Thanks also to Dr. Gropman for helping with volunteer recruitment.

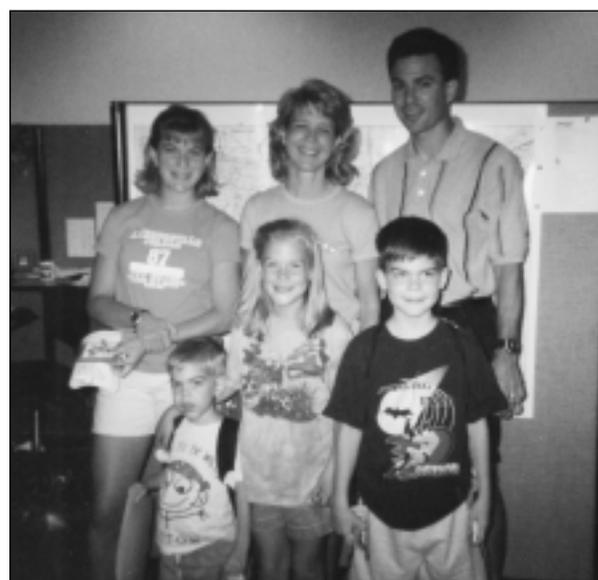
By participating as exhibitors at various medical conferences, UMDF strengthens its connection with the medical community worldwide and increases awareness of mitochondrial disease. Attendees visiting the UMDF booth took great interest in all of the UMDF literature on display and hundreds signed up to receive more information.

In the future, UMDF chapters and support groups will take part in representing UMDF at various medical conferences across the United States. Together — we will make a difference.

Visits to UMDF National Office



Rafael Villarroel, of Chile, came to Pittsburgh during his summer hospital stay in Cleveland. Rafael's son, Joaquin, is a patient of Dr. Bruce Cohen.



The Juhlmann Family, of Waukesha, WI, made a stop into the national office this past summer on their way east for vacation.

UMDF MEMBERSHIP AND DONATION FORM



- Enclosed are my \$40 Annual Membership Dues (Outside U.S./Canada \$50 in U.S. Currency)
- Enclosed is my gift of \$ _____ to UMDF to help sustain research and family support.
- My gift is \$40 or more, please send me a complimentary issue of the Mitochondrial News (Dues paying members automatically receive the Mitochondrial News three times a year).
- Change of address

MEMBER / DONOR

Name _____

Address _____

City _____ State _____ Zip _____

Phone: Home _____ Work _____ FAX _____

Email Address _____

PLEASE CHECK

- Patient Spouse
- Parent Relative
- Friend / Teacher / Other
- Medical Professional
Specialty _____
- Professional Organization
Name _____

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

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

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

UMDF accepts MAC, VISA or Mastercard credit card charges for donations and dues. Fax or mail the following information to UMDF: credit card number, expiration date, names as listed on the card and signature.

Mail membership, donations and address changes to:
UMDF
8085 Saltsburg Road, Suite 201
Pittsburgh, PA 15239



UMDF MEMBERSHIP RELEASE FORM

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 form 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 any time, you may revoke your approval by delivering a written request to UMDF. Confidentiality is of utmost importance to UMDF and is essential to encourage networking among members.



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UMDF MISSION
To promote research for cures and treatments of mitochondrial disorders and to provide support to affected individuals and families.

Deadline for next issue is 2/1/03