

MITOCHONDRIAL NEWS

United Mitochondrial Disease Foundation

How Common Are Mitochondrial Disorders?

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Until recently it was generally accepted that disorders of the mitochondrial respiratory chain were very rare, and that the care of mitochondrial patients could be left to a few physicians with a special interest in these disorders. This view has changed following the publication of a number of recent studies which demonstrate that these disorders are far more common than was previously anticipated.

Mitochondria are small organelles that are found within every mammalian cell and perform a crucial role in energy production. This is achieved through the concerted action of a group of over 70 proteins situated on the inner mitochondrial membrane: the mitochondrial respiratory chain. The genetic code (DNA) for the vast majority of these proteins is found within the cell nucleus. Children presenting with mitochondrial disease are thought to have an underlying nuclear gene mutation responsible for their disease. Thirteen essential respiratory chain proteins are synthesized within the mitochondria from mitochondrial DNA genes (mtDNA). The majority of adults presenting with mitochondrial disease, and some children, have an underlying mtDNA mutation causing their disorder.

We recently determined the point prevalence of mtDNA defects in the North East of England (Table¹). The most prevalent mtDNA mutations cause Leber hereditary optic neuropathy (LHON). MtDNA deletions were the next most prevalent, typically causing chronic progressive external ophthalmoplegia (CPEO) or the Kearns Sayre syndrome (KSS). The second most common point

mutation was the A3243G leucine transfer RNA gene mutation that can cause mitochondrial encephalomyopathy with lactic acidosis and stroke-like episodes (MELAS), diabetes and deafness, or CPEO. Other mtDNA mutations, including the A8344G myoclonic epilepsy with ragged-red fiber mutation, and the T8993G/C mutation (which can cause Leigh syndrome or neurogenic weakness with ataxia and retinitis pigmentosa), were less common. Our study also included individuals with unique or family-specific point mutations. When we explored the family history in each of these individuals, we found that 12.48 / 100,000 of the population either had a disease due to a mtDNA defect, or were at risk of developing mtDNA disease. The prevalence of disease due to specific mtDNA mutations may vary throughout the world. For example, the T14484C LHON mutation is rare in Scandinavia, but common in Canada. In addition, a recent study suggests that up to 1 in 6000 individuals in Northern Finland harbor the A3243G mutation².

Two recently published studies of the prevalence of childhood respiratory chain disease produced strikingly similar results - despite the fact that they were carried out at opposite ends of the globe. Thorburn and colleagues documented the birth frequency of childhood respiratory chain disease from over 1 million births in Victoria, Australia³; and Darin and colleagues determined the point prevalence of childhood mitochondrial disease in Western Sweden⁴. In both populations, the

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LEGAL UPDATE



SSI AND SELF-SETTLED TRUST:
The Rules Are Finally Clear
by Ken Shulman, Esq.

The Foster Care Independence Act of 1999 made two important changes to the Supplemental Security Income Program (SSI). These changes have now been incorporated into the Social Security Administration's operational manual (the "POMS") and are of critical importance to parents of children currently or prospectively eligible for SSI.

SSI, of course, is a federal benefit program for disabled individuals who typically do not have enough earnings or credits to qualify for Social Security Disability Insurance benefits (SSDI).

The basic federal benefit level for the SSI program is \$530 per month (in 2001) and this amount is usually supplemented by an amount that varies from state to state. Importantly, eligibility for

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Chairman's Report

Many important topics have been written and discussed in previous Chairman Reports. I have bragged about the accomplishments of UMDF, the great distance we have traveled in the short time we have been in existence, the move from a small room to a large office manned with a professional staff. I have written and talked about the need for more volunteers, increased involvement and fundraising, the need to look beyond the inconveniences and labors of today towards the results they will produce tomorrow. The need to support and follow the mission: *To promote treatments and cures for mitochondrial disorders and to provide support to affected families.*

The accomplishments and achievements of UMDF have not, and will not, come without tremendous costs. While many continue with daily routines of getting up and going to work or school, cutting the grass, cleaning the garage and planning for the future, many lives continue moment to moment, consisting of abstract routines which, out of necessity, have been adopted as normal.

Life continues to show us the futility of "set plans?" John Lennon described life perfectly when he said, "Life is what happens when we are busy planning other things." We don't plan lives, we live them and deal with them the best way we can.

The strengths we develop, not the passing of time, will enable us to cope with our challenges and losses in the years to come. We will sense forever a commitment to affirm what is really important in our daily lives, which many never truly get to sense and feel.

I am reminded of the story about Donatello, an apprentice of the renowned sculptor, Michelangelo. Donatello, after spending many years under the guidance of the master sculptor, decided it was time for him to move on and open his own studio. He would put to use all the skills that he learned from his teacher, the world-respected sculptor, Michelangelo.

After setting up his studio, he ordered and received his first large slab of marble. This would be the slab that he would use to sculpt his first piece of art. Upon inspection of the slab he noticed a flaw that started at the top and ran all the way to the bottom of the marble. He was furious as he concentrated on the flaw shouting out loud, "how could I ever turn something like this into a piece of beauty?"

At this moment, Michelangelo visited Donatello to see how he was progressing at his new shop. Donatello, frustrated and near tears, pointed out the flaw in the piece of marble he had just received. Michelangelo looked at the marble and said to Donatello, "I will take this piece if you would rather look for another." Donatello agreed.

It was from this flawed piece of marble that Michelangelo sculpted his famous David. Michelangelo chose to concentrate on the good rather than the flawed; he saw beyond the imperfections to the potential the marble had to offer.

How many of us spend the majority of our time looking at the flawed side of our work, our friends, or our lives? When will we understand that we can dwell on our difficulties and flaws, or we can zero in on ways to overcome them. We can see only the flaws in our lives and choose to resign, or we can open our eyes to the potential abundance that lies just beyond.

Through God's maddening mystery of "flawed" lives, and premature death, our loved ones have given us a spirit and a strength, which no one can take away. We need to continue to focus this spirit and strength toward achieving the mission of the UMDF.

Yours towards a cure,

Charles A. Mohan, Jr.

Chairman, UMDF



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SSI AND SELF SETTLED TRUST *Continued from page 1*

SSI confers automatic eligibility for the beneficiary into the Medicaid program-crucial to disabled people in the community not only for basic medical care but also because it can pay for vocational, rehabilitative, social and residential services, etc.

Eligibility for the SSI program requires that one be essentially impoverished. An individual can have only very limited amounts of "countable assets," e.g. cash, stocks, bonds (limited to \$2,000), life insurance (limited to a cash value of \$1,500), a car if necessary for a job or to access medical care (limited to \$4,500 in value), etc.

Curiously, from 1988 until the passage of the Foster Care Independence Act, if the beneficiary found himself suddenly over the asset limitation because he had received a gift or inheritance from an unsuspecting relative or had received a settlement from a personal injury claim, he could simply transfer the excess asset away in the month of receipt to a trust or a relative and resume eligibility in the following month. His SSI and Medicaid would be unaffected. No more.

With the passage of the new law, transfers by or on behalf of an SSI participant or applicant are subject to a transfer penalty. (For purposes of this discussion, a "transfer" is essentially a gift or a transaction in which the donor receives nothing of value.)

The penalty is the imposition of a period of ineligibility for the SSI program that is determined by dividing the value of the gift by the monthly federal benefit rate and state supplement. Regardless of the value of the gift, the maximum period of ineligibility is thirty-six (36) months. For example, if a SSI recipient receiving \$600 per month (\$530 from the federal government and a \$70 state supplement) receives an inheritance of \$12,000 and gives it away, he will be ineligible for SSI for 20 months ($\$12,000 \div \$600 = 20$). It is important to note that transfers are

subject to a 36-month look-back period meaning that the Social Security Administration can look back that period to see if there are any transfers that run afoul of the transfer rule.

There is an important exception to the transfer penalty that is similar to an exception contained in the Medicaid long-term care program. If the transfer by the SSI recipient is made to a so-called "Medicaid disability trust" or to a "Medicaid pooled trust," there will be no period of ineligibility. The rules for these trusts are strictly construed by the Social Security Administration and local Medicaid offices.

Among other items, the trusts must be for the sole benefit of the disabled beneficiary and must require that at the beneficiary's death, the state Medicaid agency be reimbursed for any expenses it paid out for the SSI recipient during his lifetime before there can be payment to third parties. The "Medicaid disability trust" may be created by only a parent, grandparent, guardian or court but not the SSI recipient.

In contrast, the disabled individual may establish the "pooled trust" which must be managed by a nonprofit association. For the purposes of investment management, the assets are pooled but a separate account is maintained for each beneficiary. Other subtle differences exist between the "Medicaid disability trust" and "pooled trust" and consultation with an expert is recommended.

It is important to understand that these new rules implicate only transfers by the SSI recipient himself and only self-settled trusts-that is, trusts established with the SSI recipient's own funds. There continues to be no limitation on the ability of parents or other third parties to establish and fund trusts for a disabled person's benefit. Basic estate planning techniques by parents and grandparents utilizing supplemental needs trusts are unaffected by these changes in the law. However, parents of younger

children need to be vigilant to make sure that their children have only limited funds in their names when they reach their eighteenth (18th) birthdays and apply for SSI. Whereas, one could simply transfer those excess funds in the past, the transfers will now be subject to the disqualification penalty.

Moreover, the Social Security Administration can now "look back" thirty-six (36) months prior to the application, so parents need to begin addressing the existence of UMTA accounts and other funds which may have been saved in their child's name before the child's fifteenth (15th) birthday and plan accordingly.

Please contact your estate planning and government benefits experts for more information. If you do not currently know or have access to these individuals, make it your business to find them.

This article is intended solely to provide the reader with a general understanding of the law relative to SSI and self-settled trusts.

The United Mitochondrial Disease Foundation would like to extend our heartfelt sympathies to the families who lost loved ones as a result of the unprecedented assault on American soil on September 11, 2001.



Just as our nation searches for answers to such a horrific attack on our freedoms, UMDF must continue to find answers to a disease that attacks loved ones from within.

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*The United Mitochondrial Disease Foundation wants to thank the many people who have made contributions that will support our initiatives.
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How Common Are Mitochondrial Disorders?

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THE MINIMUM PREVALENCE OF MITOCHONDRIAL RESPIRATORY CHAIN DISEASE

		Prevalence/ 100,000 (95% confidence limits)	Approximate disease frequency
Adults	MtDNA disease in the north east of England ¹ (study population = 2,122,290)	6.57 (5.30-7.83)	1 in 15,000
Children	Mitochondrial disease in Victoria, Australia ³ (study population = 1,710,000 births)	4.7 (3.2-5.0)	1 in 21,000
	Mitochondrial disease in western Sweden ⁴ (study population 385,616)	4.7 (2.8-7.6)	1 in 21,000
Total		~11	1 in 9000

prevalence of childhood mitochondrial disease was 4.7 / 100,000. The majority of these patients had established, or presumed nuclear genetic defects. Only a small minority was found to have the mtDNA mutations that are so prevalent in the adult population.

The data from these studies can be combined to give a crude estimate of the prevalence of mitochondrial respiratory chain disease in the community. Approximately 1 in 9,000 individuals will develop a mitochondrial disorder at some point in their life - which means that there must be at least 30,000 patients with mitochondrial disease in the US. It is important to recog-

nize that the studies performed so far are based upon our current understanding of mitochondrial disease, and as the spectrum of these disorders continues to widen, the recorded prevalence will also increase. Clearly these diseases are not a rarity. Mitochondrial disorders are often chronic and cause substantial morbidity and mortality, and the recent prevalence figures have significant implications for the distribution of health care resources. Most importantly, it is important that all physicians have a rudimentary grasp of mitochondrial medicine to facilitate rapid and accurate diagnosis, genetic counseling and supportive care.

References

1. Chinnery PF, Johnson MA, Wardell TM, Singh-Kler R, Hayes C, Brown DT, et al. Epidemiology of pathogenic mitochondrial DNA mutations. *Ann Neurol* 2000;48:188-193.
2. Majamaa K, Moilanen JS, Uimonen S, Remes AM, Salmela PI, Karppa M, et al. Epidemiology of A3243G, the mutation for mitochondrial encephalomyopathy, lactic acidosis, and strokelike episodes: prevalence of the mutation in an adult population. *Am J Hum Genet* 1998;63:447-454.
3. Skladal D, Bernier FP, Halliday JL, Thorburn DR. Birth prevalence of mitochondrial respiratory chain defects in children. *J Inher Metab Dis* 2000;23(Suppl 1):138.
4. Darin N, Oldfors A, Moslemi A-R, Holme E, Tulinius M. The incidence of mitochondrial encephalomyopathies in childhood: clinical features and morphological, biochemical and DNA abnormalities. *Ann Neurol* 2001;49:377-383.

Publications to check out . . .



"Mitochondrial Cytopathy in adults: What we know so far"
by Bruce H. Cohen, M.D., Chief,
Section of Pediatric Neurology,
Departments of Neurology,
Neurosurgery, and the Taussig Cancer
Center, Cleveland Clinic and Deborah
R. Gold, M.D., Section of Pediatric
Neurology, Department of Neurology,
Cleveland Clinic.

The article is available in the
Cleveland Clinic Journal of Medicine,
Volume 68, Number 7, July 2001
or via the internet at
<http://www.ccmj.org/pdf/COHEN701.PDF>.

"Mitochondrial Abnormalities in
Alzheimer's Disease"

The Journal of Neuroscience
May 1, 2001, 21(9):3017-3023.

The United Mitochondrial Disease
Foundation through a grant awarded
to Dr. George Perry of Case Western
Reserve University, Cleveland, Ohio,
supported this work.

UMDF Symposia The More You Know

✓ Did you know? Registration fees for families, physicians and exhibitors are nearly \$100,000 less than the actual cost of the conference. UMDF must raise funds to cover close to half the cost of hosting a Symposium.

✓ Did you know? In order to reserve hotel meeting space, UMDF is under contract to guarantee a certain number of rooms to be booked for the conference. UMDF will be responsible for the cost of the rooms not booked. Help us keep costs to a minimum - register and reserve your rooms as early as possible.

✓ Did you know? It takes, on average, one full-time person to fundraise for, plan, and execute a Symposium? To date, all of the Mitochondrial and UMDF Symposia have been directed by volunteers with assistance from UMDF staff saving thousands of dollars.

Education and Your Child: Caveat Emptor

by Patrick Rodgers, Freelance Writer

When it comes to what parents of children afflicted with mitochondrial dysfunction can expect from the educational system, the news is potentially bleak. Knowing your way around the system can improve the odds of your child receiving a quality education that is not physically exhausting.

James Brozick, Ph.D., is a highly distinguished and experienced educator. An English instructor and department head at North Hills High School for 30 years, Brozick also supervised the student teaching program at the University of Pittsburgh.

He pulls no punches when describing the performance of teachers and the school system, especially regarding special needs students.

The average teacher, Brozick says, whether new or seasoned, is “ill-equipped” to teach students who require special attention. The demands placed on the public school system don’t help.

“We’re required by law to give all students the same education.

Everything depends on how you translate that, however. Oftentimes kids are ‘mainstreamed’ by being put into special ed programs that are little more than playtime. The work is easier, and the kids aren’t learning.”

“The public school system is set up to teach to the middle of the bell curve. Extremely bright students get by because they’re bright. But they’re never challenged.” What happens to mitochondrial kids who have a more difficult time keeping up with their education, let alone assessing it?

Because of their low tolerance for fatigue, kids with mito disorders are often mistakenly assessed as having lower IQs. In addition, a special ed teacher’s existence is justified by having enough challenged students to teach. This encourages them to expand their definition of a special needs student requiring special education. A bright mito child can easily find him or herself in classes that are simply wasting their time.

Brozick also noted that the typical

modus operandi of a public school is to have kids learn by rote, regurgitating facts rather than teaching them how to think critically. This presents a particular problem for mito kids. A child with mito is more likely to be able to think critically, a higher level skill, than to have the stamina to do the fifty arithmetic problems that are assigned to keep other students occupied. Reinforcement of skills by repetition may benefit some students, but it’s contraindicated in the education of a physically weak child.

So why does the system work the way it does?

According to syndicated columnist Walter Williams, education students are drawn from the bottom ranks of students entering college. Gone are the days when teaching was a calling and a distinguished profession. It’s more like a factory system now, and the results are discouraging.

“Most of them are just teaching for themselves,” Brozick commented.

Jim Brozick resigned his post at the University of Pittsburgh out of disgust at what he considered to be low standards being accepted as passing, and, in almost all cases, honors level work. According to him, feelings have become facts in student essays, and grade inflation runs rampant. Simply put, it seems to take more effort on a student’s part to fail out of an education program than it does to receive high grades.

It’s not just happening at Pitt. A La Roche College department chair who works with education students admitted to this writer on the record in 1999 that she inflates grades. No disciplinary action ever resulted.

Students take coursework in dealing with challenged students - one three-credit class is required. College students graduating in education with something between 120 and 130 credits are required to spend only 2½% of their academic careers studying the needs of the 30% of their students - those who require special attention for whatever reason.

Brozick says that there are bright

spots. Some teachers are dedicated and have a natural talent for reaching children no matter the circumstances. Unfortunately, he could remember them by name because they were the exception rather than the rule.

How about parochial and private schools?

From all accounts, they may be well worth your money.

Sue Tarquinio taught in the Catholic school system for several years before leaving to stay at home with her daughter, Meghan. Sue and her husband, Matt, are now expecting their second child.

Tarquinio said plainly that she was simply “willing to adapt to the needs of the kids.”

While she never worked with a mito child, Tarquinio’s experience teaching children with other learning challenges is telling.

She continued: “I had an easy time sympathizing with kids who had a hard time keeping up. Instead of giving them 15 spelling words, I gave them 10. In a set of math problems, I’d let them do the odd or even numbers instead of the entire exercise. The main thing is that you don’t want them to get frustrated, or they’ll quit.”

She also sent weekly notes home with special needs students, informing parents of what was transpiring in the classroom. Students having difficulties were not instantly earmarked for less challenging work.

Julie Turman, whose son Justin has a mito-related condition, transferred him to a small private school upon his entering seventh grade. Justin commented afterward that he wished he had gone there all along. A small campus that didn’t require him to walk long distances between classes was one improvement. Another was the teachers.

“Teachers that resented having to take extra time with a student when they felt they were already overburdened was the crucial thing. Often it is hard for the parent to get a handle on that until halfway through the year,” Julie Turman stated.

One preschool teacher Justin had in

the public school Early Education Learning Program (EELP) took an individual interest in her students and was described as a "top notch special educator" by Turman. However, Turman also noted that "ups and downs of Justin's education were different every year and depended a lot on the teachers awareness and ability to individualize."

What can you do to ensure that your child has the best learning environment possible?

- ✓ Inform your child's teacher in detail about the nature of mitochondrial disorders. (*see sample letter on Page 18 - this letter alone may not provide enough detail but is a good cover letter*)
- ✓ Know that you are holding the cards from a legal standpoint. No one can test your child for a special education program without your permission.
- ✓ Don't assume that a teacher is competent. It's an unfortunate but necessary precaution that

you may have already learned with your child's doctors. Just because someone graduated with a degree in education does not mean that they are qualified intellectually or emotionally to teach children. A teacher may be recommending a special ed program because they simply do not feel like expending any extra effort on your child's behalf. If you know that you're child's intelligence is in the normal range, be wary of this.

- ✓ Don't apologize for wanting the best for your child. You needn't feel guilty for inconveniencing a teacher. Doctors are awakened in the middle of the night by sick patients, and accountants are busy at tax time. Teachers simply have to work harder when assigned to instruct a child with special needs. They're not doing you a favor; they're doing their job.
- ✓ Stay proactive. A teacher who understands that you are staying

on top of the situation in your child's classroom is more likely to provide what's needed. Find out if your child's teacher has a prep period during the day so that you can visit and discuss any issues from time to time. Julie Turman worked at Justin's public school.

- ✓ Consider private, parochial, or home schooling if it seems necessary. Private schools seem to offer advantages to children with mito, but they are expensive. Look for financial aid. Many parents are home schooling children without special needs simply because of dissatisfaction with their local school. If you can handle the responsibility, it may be something to consider. You know more about your child's condition than his or her teacher. Nationally, home schooled children's standardized test scores have also typically been higher than those of public school students.

UMDF and Who Wants to be a Millionaire

THANK YOU JACK BLACK for Winning \$125,000 for Our Families!

On October 22nd, Jack Black (Actor/Musician/Comedian) generously made UMDF the recipient of his earnings on *Who Wants to be a Millionaire - the Comedy Edition*. Jack's sister was diagnosed with a Mitochondrial Cytopathy one year ago and since he lives in the Los Angeles area, he took the steps to contact Sharon Shaw of the Southern California Chapter to find out what he could do for UMDF.

Literally, after one conference call between Jack, his band agent, Sharon and his parents, Jack became involved immediately. Just as a starter, he offered to donate part of the proceeds of his Tenacious D show on November 27th at the House of Blues in Los Angeles. He has also committed a percentage of his Tenacious D band merchandise to the Southern California Chapter of

UMDF. This means so much to the UMDF to be able to have this kind of recognition at the national level. This is clearly an act of brotherly love...and spills into plain kindness and compassion. Thank you Jack!



Photo taken by Maria Melin/ABC

Chairman, Chuck Mohan and his wife Adrienne (far right) join Sharon Shaw and Linda Cooper (far left) of the Southern California Chapter to cheer on Jack Black (center) during the show's taping in September

Jack Black Actor, Musician, Comedian

In Jack's latest movie, he is co-starring with Gwyneth Paltrow, the film is called "Shallow Hal", release date is November 9th, 2001.

You might have seen Jack in "Hi-Fidelity" and "Saving Silverman" to name a few of his films over the past 10 years.

Jack is also in Tenacious D a rock, folk duo with Kyle Gass. They recently appeared on David Letterman and Conan O'Brien.

Jack and Kyle are currently on tour playing at many venues across the United States.

Heading to Texas in June 2002!

UMDF Symposium for Mitochondrial Specialists, General Practitioners, and Families

Symposium Program Directors: Kathryn Parsons and Jane McManus

Mark your calendars for June 6-9, 2002, in Dallas Texas for the best UMDF Symposium yet!

The Westin Galleria Hotel, a beautiful site only 15 minutes from the two major airports, will offer those extras many of our families have requested. Restaurants, ice-skating, shopping, and swimming are on location connected to the hotel by a short walkway to give you a respite before, after or between meetings. The family conference runs from Friday, June 7, through Sunday, June 9. UMDF has negotiated a special rate of \$140 per night, which is \$80 off the published rate.

MEETINGS ARE PLANNED FOR EVERYONE'S NEEDS

An exciting new addition this year - families will have the opportunity to attend the medical meeting for General Practitioner (GP) physicians and nurses including sessions with GI, Neuro, and Cardio specialists. Families who do not want detailed medical information will have the choice to attend meetings on other topics running simultaneously with the GP Medical Program. This new program, *Troubleshooting Difficult Cases for the GP*, is scheduled for Saturday, June 8. The 2002 conference will also offer a special session for affected adults led by Dr. Sandra Sirrs, an expert in metabolic diseases in adult patients. A special tract will be offered for newcomers to learn the basics of mitochondrial disease before the detailed medical sessions. Friday morning will be devoted to offering the attendees an opportunity to meet others facing similar *symptoms*. During the conference, additional time will be allocated to networking and R&R between meetings.

SPECIAL SERVICES FOR SPECIAL NEEDS FAMILIES

Some of the other topics that will be covered are issues that families with chronic illness need, but often

have difficulty finding the time or money to address. Sessions on insurance and legal issues, estate planning, and practical tools for couples and non-affected siblings will be led by experts in their fields. Dr. Lawrence Cohen, a nationally-recognized child psychology expert will be conducting a fun and informative session on "Making the Most of Incidental Moments" with your family.

MECHANISMS OF MITOCHONDRIAL FUNCTION AND DISEASE — SCIENTIFIC MEETINGS THURSDAY AND FRIDAY (JUNE 6 & 7)

Dr. Michael Bennett of The University of Texas Southwestern Medical School at Dallas, Dr. Fernando Scaglia of Baylor College of Medicine at Houston (Texas) and Dr. John Shoffner of Children's Healthcare of Atlanta (Georgia), are the Scientific Program Directors. They have worked diligently to offer an exciting program for mitochondrial specialists as well as the informative, practical program for GPs.

REGISTRATION WILL BEGIN IN FEBRUARY 2002

Complete details of this exciting 5th International Symposium will be mailed early next year, and the web



site will provide registration information as well. Be sure to register early as our conference will command the entire hotel and space is limited.

Family Registration will be processed through the National Office. For Registration questions, call 412-793-8077.

As our membership grows, we are able to improve and increase the programming as we always keep in the forefront our mission *to offer support to affected families*.

UMDF Grant Check Presented at Cincinnati Children's

On behalf of UMDF, Jennifer Cooper, mother of Molly and Madison, and her fiancé presented a \$33,000 UMDF grant check to Cincinnati Children's researcher Dr. Min-Xin Guan (far left) to study the mitochondrial basis of certain types of deafness.



How You Can Help

A major initiative is underway to educate general practitioners about the complexities of mito diagnosis and treatment. As most families have witnessed first-hand, many family doctors, pediatricians, pediatric specialists, internists, neurologists, GI specialists and nurses from all fields do not know that mitochondrial diseases can affect ANY INDIVIDUAL, AT ANY AGE, in ANY ORGAN.

For every doctor or nurse who becomes better informed about mitochondrial disease, hundreds of patients can be helped more effectively. Since a large majority of information about mito disease has been discovered in the last ten years, it is difficult for physicians who have already completed medical school to be properly informed. It is vital we get as many General Practitioners to the meeting as possible. The GP Medical Meeting Saturday, June 8, at the UMDF Dallas Symposium will cover all the basics medical professionals need to know to appropriately refer and treat mitochondrial patients.

But, how can we get them to attend? As we all know, many physicians are over-worked and bombarded with more information than they can process; it is possible that the Registration Brochures can be innocently discarded. However, if a doctor's or nurse's patient personally delivers a Brochure, he or she might take notice of the conference. Deliver with some cookies or flowers...even better!

Karen Lipps, president of the Arizona Chapter, and the national office will be coordinating a grass roots effort to bring attention to the GP Program. Please contact the national office at 412-793-8077 (ask for Toni or Kara) or Karen at AZChapter@umdf.org to sign up to deliver Registration Brochures to your physicians. Karen will also be personally contacting UMDF members in the South and Southwest (Texas, Louisiana, New Mexico, Arizona, Oklahoma, Arkansas, Mississippi, Alabama, and Tennessee) to enlist support.

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 or Eileen Mitchell
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
Email: SCalChapter@umdf.org
Orange, CA (Los Angeles area)

Wisconsin Chapter
President: Jim Heyer
Email: WIChapter@umdf.org
Milwaukee, WI

SUPPORT GROUPS

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Email: dahldenise@hotmail.com
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 (newly forming)
(subsidiary of S. California Chapter)
Contact: Jen DeMeo
Email: jendemeo@aol.com

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

Michigan Support Group (newly forming)
Contact: UMDF Office
Email: info@umdf.org
Detroit area, MI

Western PA Support Group (newly forming)
Contact: Tracy Lengyel
Email: Info@umdf.org
Pittsburgh, PA

New Groups are trying to form in Illinois, Northern California, Southern Ohio, and South Carolina. Anyone interested in these areas or wish to start a group in another area, please call us at 412-793-8077.

Fundraisers

Cruisin' Toward a Cure in Southwestern Pennsylvania

The First Annual Car Cruise and Family Day on October 6, 2001, from noon to 5 p.m., at the Community College of Allegheny County's Boyce Campus in Monroeville was a grand success. Over \$5,000 was raised at the event and over 142 classic car enthusiasts attended to support the UMDF and the crew of the 1936 Talbot.

A vintage 1936 Talbot race car was shipped to the United States from England by the parents of Angus Scrivener, Julia and Danny Scrivener on October 5th. In 1999, Angus died of a mitochondrial disorder at the age of three. Angus' family made Monroeville their first stop before they continued their journey across America, from New Jersey to California, to raise money for mitochondrial disease research and to raise awareness of this devastating disease. Danny Scrivener and Andrew McLellan (Julia's brother) were the drivers of the Talbot with John and Marjorie McLellan (Angus' grandparents) driving a backup car. The Scrivener and McLellans were such a joy to talk to and were very excited about the long journey ahead of them. In order to get the car to the United States by October 5th, the family had to ship the car soon after the World Trade Center incident, but the terrorists did not win; the family still kept their mission in mind - to raise awareness and funds to stop a disease that took their little Angus. This is a brave and compassionate family.

T-shirts were provided to the first 100 cars and to all the volunteers with a picture of Angus and the Talbot on the front. When Danny Scrivener saw the shirts, overcome with emotion, he said "That's my Angus."



Pictured from left to right - Danny Scrivener, Marjorie and John McLellan and Andrew McLellan. For the Journey, the Talbot crew accepted donations to sign the car and they raised \$1,300 as of mid October.



Event Coordinators, Ron and Donna Miklos (wearing the cruise t-shirts) and Chuck Mohan (far right) accept a check from Linda Matthews of the Kruzin' Knights

UMDF Cooking up Dollars

Hearts Full of Hope-Recipes Gathered with Love Cookbook has been available for over two months and has already brought in over \$2,400 at the national office alone. The Chapters are also hitting record sales and with the sale of each cookbook, the words Mitochondrial Disease will reach more homes and touch more lives.

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.

To order your cookbook(s), please contact the chapter nearest you or the national office at 412-793-8077. The cost is \$15.00 (plus \$2 shipping and handling). Order forms are available via the UMDF web site or the national office.

Mito-What? Margaritaville Cruise, hosted by the Kozuch Memorial Foundation, raised \$3,500 for UMDF in honor of Morgan Kozuch.

Kara & Joe Strittmatter decided to raise money for UMDF at their annual pig roast. Family and friends gathered as usual but this time dipped in their pockets for UMDF and raised over \$600.

Good food, good friends and a great cause. The Strittmatters designated the funds in memory of Heidi Marie Daniel.

Brad Burgener and Hillsborough Middle School raised over \$900 with a Bowling for Bucks fundraiser and of course, Brad's candy sales alone have brought in \$211 for UMDF. Keep up the great work Brad!

Fundraisers

Students of Osbornville Elementary, of Brick, New Jersey, raise \$280 during a used clothing drive in memory of Anthony Stella



Jordan Birdsong and Alyssa Hill show off their sign

2001 Wine Tasting for Heidi raises \$5,904

On June 29, Norma and Morgan Gibson hosted their 3rd annual wine tasting for Heidi Marie. According to Norma, the sunset offered a breathtaking view for the evening festivities. Heidi was very pleased.

Heidi Marie Daniel lost her battle with MELAS on September 9, 2001. It is with great sadness that UMDF says goodbye to Heidi but we will never let go of her memory. Heidi represents the best parts of UMDF. She had strength, compassion and perseverance -- nothing stopped Heidi from raising funds and awareness to support the UMDF mission. The office staff will most definitely miss her phone calls.

Norma said that she will continue supporting the UMDF with the wine tasting and that she knows that Heidi will be looking over her shoulder counting every penny that comes in.



Dear UMDF,

On August 4th 2001 we had a sale to collect money for UMDF and JDF. We sold bracelets, rings, necklaces, popcicles, lemonade, koolade, and cookies. We decited to give the money to a charity to help others. We are giving the money to two gropes - UMDF and JDF (Juvenile Diabetes Foundation). We pick UMDF becuse our friend/cousin has a mitachondrial disease. His name is Cooper Henry Adelstein. It made us feel good inside because we were doing something for someone else instead of our self.

Hope this helps with research,

Sincerely,

Jordan Birdsong (8 yrs old)
 Alyssa Hill (8 yrs old)
 Ashlyn Hill (5 yrs old)
 Chase Birdsong (6 yrs old)
 Robert (6), Richard (9)
 and Michael (9) Holland



The Tritsch family sponsored a booth at the Festival of the Horse On September 28-29th and raised \$6461 in honor of their son, Cameron.

Melissa Tritsch (pictured far right), Cameron's mother, and her band of volunteers helped spread the word about UMDF and Mitochondrial Disease during the festival — A big THANKS to you all!

UMDF Holiday Cards were mailed out this month.
NOTE: Membership dues notices were included in this mailing.
Please consider joining or renewing with UMDF today.

Fundraisers

Friends of Dr. & Mrs. Martin Markowitz sent in \$990 in Honor of the Markowitz' 40th Wedding Anniversary.

In Honor of Riki Kusuhara's 3rd Birthday this past May, the family asked for donations to UMDF in lieu of gifts and over \$250 was donated.

Dudgeon Family & Friends
Raise Over \$50,000

In the Spring of 2001, over \$50,000.00 was raised at the 1st Annual Matthew Dudgeon Memorial Walk/Dinner Dance. On September 22, 2001, the Dudgeon's hosted a dinner for their event committee volunteers and made a formal check presentation to UMDF. According to Gina's original letter to UMDF regarding the event, "It is our hope that the proceeds from these events will help to "Redefine Hope" and to keep the memory of our sweet son alive in the hearts of many." A huge THANK YOU to the Dudgeon's and to their dedicated volunteers in making their first annual event such a success.

1st Annual Golf Outing in Columbus, Ohio raised over \$5,000. Event coordinators, Jason and Shawna Steele, were excited about the outcome and hope to make it even bigger next year. The Steeles, along with UMDF members Richard and Donna Noble, have already started planning for next year.

Sysco Food Service of Pittsburgh Annual Golf Outing chose UMDF as its charity this year and raised \$23,179.16 for the foundation. Chuck Mohan met with the Sysco President, Len Pentroska, earlier this summer and had no problem convincing him that the UMDF mission was a worthy cause.

2nd Annual Ohio Golf Outing Raises \$99,559.90

Making their rounds during the golf outing, Stan and Carole Davis



Stan & Carole Davis and their golf committee, which includes a very determined fundraiser Norma Markowitz, almost doubled their proceeds from the year before and plan to exceed that amount in 2002. The committee already has plans for some exciting new additions for the event.

During the evening dinner, the First Lawrence Koreness Humanitarian Award was presented to UMDF Chairman, Chuck Mohan. The family of Lawrence Koreness support the UMDF on behalf of their close friends, Stan & Carole Davis and Martin & Norma Markowitz. Mr. Koreness lost his life in an automobile accident this past summer and to honor his memory, family and friends donated over \$5,000 to UMDF.

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!
- ✓ January 2002
Pennies Challenge Western Pennsylvania, St. Bernadette Catholic School.
- ✓ February 2, 2002
The Mito Mystery Party Benefit, Dallas, Texas. Funds will help offset cost of the 2002 UMDF Symposium in Dallas. For more information, contact Jane McManus at mcmansj@worldnet.att.net.
- ✓ March 16, 2002
3rd Annual Mito What? Ski Challenge for Michaela Rae Gaetjens to benefit UMDF, Bridgton, Maine. For more information, contact Victoria Vermette at victoria@bellevuesearch.com.

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.

UMDF
Redefining Hope

UNITED MITOCHONDRIAL DISEASE FOUNDATION

Dear fellow UMDF members,

It is with great pride and excitement that I introduce UMDF's first Director of Development and Programs, Dr. Georgette Demes. Georgette brings to UMDF 16 years of experience in development for national research centers with particular expertise in raising funds for technical research from the National Science Foundation, industry, and state government.

She served for 10 years as the executive director and chief external liaison of The Engineering Design Research Center, a national center funded by the National Science Foundation at a level of \$2-3 million per year at Carnegie Mellon University. The mission of the NSF research centers program was to promote basic research in new high-impact interdisciplinary fields and to involve the research's industrial beneficiaries as partners in strategic planning. When federal core support for the center lapsed in 1996, she spearheaded the formation of a partnership with a sister center at Lehigh University in Bethlehem, PA which resulted in an unprecedented university-state-industry partnership focused on accelerating economic growth and reducing brain drain in Pennsylvania. The resulting grant program, known as



The Pennsylvania Infrastructure Technology Alliance, resulted in both centers' successful transition to state core funding and leveraged support from partnering companies. It also enabled Carnegie Mellon to launch the Institute for Complex Engineered Systems, the successor to the former national center.

Georgette intends to keep our membership informed through the newsletter regarding the progress and activities in Development and Programs.

"Major breakthroughs in a new field like mitochondrial medicine will require growing a significant funding base for basic research by building local, state, national, and international recognition of mitochondrial disease. I am looking forward to working with UMDF, bringing my development experience and familiarity with the research enterprise to a most worthy mission."

Again, we welcome Georgette into the UMDF family and look forward to exciting developments in 2002!

Sincerely,
Yours Toward A Cure,

Charles A. Mohan, Jr.
Chairman, UMDF

On Being a Champion

From the book *Journey Through Heartsongs*, by Mattie J.T. Stepanek. 11-year-old Mattie and his mother, Jeni, have dysautonomic mitochondrial myopathy. Jeni & Mattie were kind enough to share one of Mattie's poems - according to mom, one of his favorites.



On Friday, October 19th, Oprah Winfrey interviewed this extremely talented young man on her show. Mattie has written hundreds of insightful, touching, upbeat, philosophical and occasionally humorous poems. His poems were published this past year, with a Foreword by Jimmy Carter, and he shared his message of peace on Oprah. This young man has a mitochondrial disease but has not let it shake his philosophy -- "I want people to know my life philosophy, to remember to play after every storm."



To play after every storm. Any family battling mitochondrial disease can relate to the storms.... just don't forget to PLAY too!

*A champion is a winner,
A hero...
Someone who never gives up
Even when the going gets rough.
A champion is a member of
A winning team...
Someone who overcomes challenges
Even when it requires creative solutions
A champion is an optimist,
A hopeful spirit...
Someone who plays the game,
Even when the game is called life...
Especially when the game is called life.
There can be a champion in each of us,
If we live as a winner,
If we live as a member of the team,
If we live with a hopeful spirit,
For life*

UMDF Chapter Activities

DELAWARE VALLEY CHAPTER

The You Go Girls! Golf Outing was another fine success on October 10. More details to come in the next newsletter.

The chapter is planning a "Hearts Full of Hope" Affair near Valentine's Day to be held at the Merion Tribute House, Merion, PA. The event will include an inspirational speaker, appetizers & desserts from recipes in the UMDF Cookbook, donated wine from local wineries, etc. The chapter is also busy with their member directory, the Kevin Blosky Memorial Library and they have a new program - an Equipment & Medical Supply Exchange.

Tentative date for the next Shelly's Heroes 5k run is April, 6, 2002. Check the UMDF web site for any changes in the Spring.

NEW ENGLAND CHAPTER

Correction: In the last issue, the newsletter had a picture of Kacey Gaffey but the woman pictured with her wasn't her mother.

Please accept our apologies Jackie and this time, there is no mistaking this lovely mother/daughter combination!

As Kacey's daddy, Michael, put it - "Two angels that God has put in my Life"



Eileen Mitchell, of the New England Chapter, helped organize a UMDF Dice and Dine Cruise on October 12, 2001. Totals are not available yet but the event raised over \$9,500 as of September 13th.

ARIZONA CHAPTER

The chapter continues to work on their Mitochondrial Awareness Map (for physician education) and they have wonderful fundraising plans for 2002. In March, they will again participate in the Great Human Race. If you live in and around Phoenix, please join the chapter by gathering pledges for the Race.

The chapter is also investigating the possibility of selling Charity Bears, which are something like a Ty Beanie Bear. This special bear will be designed to raise funds and awareness for UMDF and mitochondrial disease. For more general information about Charity Bears, please visit www.charitybear.com or contact the chapter at AZChapter@umdf.org.

OHIO CHAPTER

Ohio Chapter members participated in the Cleveland Golf Outing in August and have been busy with planning and implementing fundraising activities such as sweatshirt sales, cookbook sales, and a 5K Walk/Run to be held June 1, 2002.



Ohio families enjoyed a chapter picnic on September 15th - Smiles all around!

BACK BY POPULAR DEMAND . . .

UMDF GOLF SHIRTS & SWEATSHIRTS

Fundraising Effort Coordinated by the Ohio Chapter of UMDF

UMDF GOLF SHIRTS are still available (100% Cotton, waffle weave fabric. Navy with Kelly Green UMDF Logo).
COST: \$25.00 +\$5.00 shipping/handling.

UMDF SWEATSHIRTS

Please allow 3-4 weeks for delivery.

PRICING: Adult shirt: (M-XL) \$32.00/each
(2XL) \$34.00/each

Youth shirt: (2T, 3T, 4T) \$12.00/each
(6-8, 10-12, 14-16) \$15.00/each

STYLES: Adult - Lee 9.5 oz. 50/50 Quarter Zip Sweatshirt,

COLOR: Heather Gray. Youth shirts will be a basic crewneck 50/50 sweatshirt in light gray or neutral. LOGO COLORS: Hunter Green and Navy Blue.

For order forms, contact the national office at 412-793-8077 or the Ohio Chapter at 440-235-2451 or via the Chapter's web site page at www.umdf.org

Make Checks Payable to UMDF Ohio Chapter and send to:
Lisa Arnold, Treasurer
Ohio Chapter
33375 Bainbridge Rd.
Solon, OH 44139

SOUTHERN CALIFORNIA CHAPTER

The Shell Out for Charity at Johnny Reb's Restaurant raises over \$5,000 for the chapter in the month of September.



Vitamin Fundraiser Continues to benefit the Southern California Chapter of UMDF. MRM Vitamin Company (Metabolic Response Modifiers) is offering discount prices for UMDF members. For more information, contact Sharon Shaw at ScaChapter@umdf.org. Visit MRM's web site at www.metabolicresponse.com or call them at 800-948-6296 and request a catalog.

**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/manufacturer who can offer similar discounts, call the UMDF office at 412-793-8077.

The Talbot Car completed its Journey in Los Angeles and the Southern California Chapter gave the crew a warm welcome.

Donation money banks are being designed by the chapter to be placed in various business locations to raise funds and awareness. Once the design is complete, the chapter will make them available to anyone interested.

NEW MEXICO CHAPTER

The chapter welcomed the Talbot crew into the fine city of Albuquerque on October 13, 2001.

On November 3, 2001, the chapter participated in the 2nd Annual StORm & TiGeR's TrOt for Tots event to benefit UMDF and the Tyler for Life Foundation. More details to come.

WISCONSIN CHAPTER

Wisconsin chapter participated in a Brew Fest which was held at the Milwaukee War Memorial On The Lake on November 2, 2001 from 7:00 p.m. until 11:00 p.m. The Brew Fest featured regional micro brews. The Kiwanis Club of Metropolitan Milwaukee Nights hosted the event with a portion of the proceeds from the \$20.00 tickets going to help "Redefine Hope." According to Jim Heyer, the event was a success and the preliminary attendance count was about 600. Well done!

The chapter is investigating fundraising opportunities through local college sororities and continues to educate families and physicians in the Milwaukee area.

UMDF Chapter Activities

NEW YORK METRO CHAPTER

On November 11th, the chapter hosted a wine tasting dinner and announced the winner for their raffle -- a Las Vegas Trip for two. Thanks to the New York Metro Chapter, the national office has added to its database over 20 physicians who manage mitochondrial patients in the New York Metro area. The chapter sent out 800 informational letters physicians to publicize UMDF and the chapter in the medical community and to seek physicians who manage mito patients.

The Expansion of Research into Mitochondrial Disease

In early 2001 the UMDF laid out a plan to expand research into Mitochondrial disease with the following goals: establish Mitochondrial disease research centers; establish multi-center clinical trials; and establish an Office on Mitochondrial Medicine at the NIH. These goals are in conjunction with the UMDF's plan to fund \$5 Million of research into Mitochondrial disease over the next five years. Such an ambitious plan obviously requires the support of UMDF members and contributors, but also the support of congress and decision makers at NIH.

In light of this the UMDF has created a Position Paper detailing the goals and reasons for the expansion of research. UMDF member, Michael Friedberg, has approached his United State Senator's office with this information and has received a favorable response. If you would like to contact your congressional representatives regarding this initiative contact the UMDF at 412-793-8077 or at info@umdf.org. We will be happy to send you a cover letter and a copy of the Position Paper, which includes the following goals:

Short-term goals:

- Initiate and fund a full-scale, multi-year epidemiology study.
- Increase NIH funding for mitochondrial disease research.

Long-term goals:

- Establish an Office of Mitochondrial Medicine at the NIH to: collaborate upon relevant research efforts (at the NIH), coordinate various mitochondrial projects, and develop long-term objectives in the field of mitochondrial medicine.

These are exciting times for the UMDF and the Mitochondrial community. We look forward to your continued involvement as we work to find a cure.

Mark Fleming

Vice Chairman, Board of Trustees
UMDF Grant Research Coordinator

Sample Letter to Educators: Mitochondrial Disorder and its Implications for Teachers of Mainstreamed Students

by Jeany Maccione, Teacher of Exceptional Education.
Ms. Maccione was kind enough to share a letter that she has used in her schools.

Mitochondrial disorder, simply put, is the lack of energy in a cell. The mitochondria are like tiny "power plants" within a cell's cytoplasm. Their job is to supply each cell with energy. In a healthy person, they produce oxygen to convert fatty acids, carbohydrates and proteins into energy. In someone with this disease, this process is lacking and instead of getting energy, they will be fatigued in 3 main areas of the body - the heart, the brain, and the skeletal muscles. Damage to the mitochondria results in chronic fatigue. Having lack of oxygen in these 3 major areas can impair a child's ability when in the mainstream classroom.

As we know, students do enter the regular education classroom with IQ scores anywhere from 70 - 80 to 100. These students do not qualify for exceptional education programs and are considered to be in what we call the "gray area" of learning. Students with mitochondrial disorder may have these similar IQ scores, although these scores may not be a true indication of IQ. If their brain is fatigued they may not be able to think or react quickly in testing situations. These children tire more easily and may not always be able to physically keep up with their workload. We need to first learn about their condition and make common sense adjustments in the classroom. (This rule of thumb should apply to any handicapping condition).

As teachers and professionals we need to keep "the main thing, the main thing." When we are executing a lesson on adding double-digit numbers, what is our goal? Our goal is for each student to master learning how to add double-digit numbers. When we are confident that mastery has taken place and the practice worksheet is passed out to

the class, the student with mitochondrial disorder may do much better answering the first 10 problems, or 10 of your choice rather than all 50 like the rest of the class. He will finish at the same amount of time as the others because of the fatigue factor, but will leave the lesson with a sense of accomplishment and the mastery, which was your goal in the first place.

By no means should these students or any student be "let off the hook" from learning what is required in each subject area. Their individual learning styles need to be taken into consideration when assessing mastery of a skill. These students tend to be auditory learners. When taking a spelling test, they may do better orally. They should be required to know all the spelling words but it may be difficult for them to pass if they have to write them all out on a timed test.

The teacher could set up what is called an "adjusted day" during which the student works in each subject area, in combination with their learning style, to show the educator that they know the material. The oral spelling test is an example of this. Using markers, for say, math, because of the easy flow, is much more helpful than using a pen or pencil. Some do well using a hand held tape recorder to speak reports into. When walking to another classroom or activity, it may be necessary to have a "buddy" to carry books. Often these students will be slower in line and having a friend there will be helpful to the disabled student as well as encouraging compassion in the non-disabled student. These special situations may not be necessary for each subject because time of day may be a factor, but it may be necessary with some and should be considered when educating these students.

Some educators may feel that these students should be in the low reading or math group since they are slower, but their slowness is often due to fatigue only and not a reflection of their cognitive abilities as stated above. By being in the middle or higher group, they would learn and retain more since many students, as previously mentioned, are such auditory learners. They will pick up more just by listening to others. We as educators just have to get creative and again use common sense to educate any special needs student without going to the extremes of pity or excusing them from work. They have the right, like anyone else, to reach their fullest potential.

Having a special needs student in your classroom is a wonderful learning opportunity. It will enhance your classroom in ways you never have imagined. You and your other students will be better for it. You just have to be willing to grow and learn. Enjoy!

Newsletter Deadlines



We want to hear from you.

If you are holding a fundraiser or have ideas for future articles, please contact us!

Please note the following deadlines:

Spring 2002 Issue:

February 1, 2001

Summer 2002 Issue:

June 1, 2002

Fall/Winter 2002 Issue:

September 1, 2002

All items will be considered and printed upon approval.

UMDF MEMBERSHIP AND DONATION FORM



- Enclosed are my \$40 Annual Membership Dues (Outside U. S. \$50 in U. S. Currency)
- Enclosed is my gift of \$ _____ to UMDF to help sustain research and family support.
- Donors of \$40 or more wishing to receive a complimentary issue of Mitochondrial News.
- Change of address

MEMBER / DONOR

Name _____

Address _____

City _____ State _____ Zip _____

Phone: Home _____ Work _____ FAX _____

Email Address _____

PLEASE CHECK

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

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

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

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

UMDF can now accept
MAC, 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



UNITED MITOCHONDRIAL DISEASE FOUNDATION

UMDF MEMBERSHIP RELEASE FORM

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____ FAX _____

Email Address _____

GENERAL RELEASE

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

DO DO NOT include my phone number.

DO DO NOT include my email address.

Signature _____ Date _____

Yes, I want to Network!

I will complete this form and
send to UMDF.

Please give me the appropriate
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 anytime, you may
revoke your approval by delivering a written
request to UMDF. Confidentiality is of utmost
importance to UMDF and is essential to
encourage networking among members.



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