MAYO CLINIC SEEKS PARTICIPANTS FOR NEW BIOBANK

The Mayo Clinic in Rochester, MN has announced the creation of the first biobank in the United States developed specifically to study mitochondrial diseases. The Mitochondrial Disease Biobank began accepting samples in December 2009, and researchers believe that having this facility will make it easier to conduct research studies about mitochondrial diseases.

The Biobank is like a library for scientists. Researchers who study mitochondrial diseases often have to find participants to take part in their studies. Now they will have access to blood and tissue samples, along with patient data, from hundreds of people all in one place. Researchers may learn new information after examining the samples and information in the Biobank. When that happens, they will be able to share their findings with other scientists and doctors. As a result, medical care for patients with mitochondrial diseases may improve.

Affected individuals or those who are suspected of having a mitochondrial disease are eligible to participate. Family members may also be allowed to donate. If an affected individual wants to participate, they must learn about the project so they understand it before they enroll. Participants will be asked to fill out a short form describing their health and the health of other family members. Biobank staff members must be allowed to gather medical information from the patient’s medical records, and participants may be required to provide a blood sample. In addition, participants will be asked to allow the Biobank to have any clinical samples (such as skin or muscle biopsy, urine, etc.) that are no longer being used by a physician.

To address concerns about patient privacy, the Mitochondrial Disease Biobank will assign participant samples a one-of-a-kind code. Participant samples will not leave Mayo Clinic with a name, address, Mayo Clinic number, birth date, or social security number on them. No one besides Biobank staff will know which sample belongs to a specific participant just by looking at the label. Because the Mitochondrial Disease Biobank will be used for many years, there is no way to predict all of the ways that samples and medical information will be used. Genetic information, like a fingerprint, is unique to each participant. Mayo Clinic will take all reasonable measures to protect the privacy of the participants. However, since a lot of people at many places will have access to the Biobank, Mayo Clinic cannot guarantee that participant information will be kept private.

The Mitochondrial Disease Biobank will allow researchers access to the Biobank samples only after a strict application and review process. They will then provide them with anonymous tissue sample(s) and some medical information (clinical

(continued on page 2)
UMDF RECEIVES ACMS AWARD

The United Mitochondrial Disease Foundation (UMDF) has been honored with the 2010 “Benjamin Rush Community Organization Health Service Award” by the Allegheny County Medical Society (ACMS). The award was presented by the ACMS during its annual Gala and Award Ceremony at Heinz Field on January 30, 2010. The award is given by members of the ACMS in appreciation of outstanding contributions to public health rendered by a lay organization. The society chose the UMDF on behalf of the more than 3,000 physician members in appreciation of the outstanding contributions it has made to public health.

The UMDF was represented by CEO and Executive Director, Chuck Mohan, UMDF Board Members, Gerald Cook, John DiCecco, and Dr. Amy Goldstein. Along with UMDF staff members, Mark Campbell, Kara Strittmatter, Clifford Gorski, Marian Weil, Carol Milsovic and mitochondrial disease specialist Dr. Rajiv Varma.

Chuck accepted the ACMS award on behalf of all of those who are bravely battling mitochondrial disease and those who have lost their battle. “I am grateful to all of those who continue to spread our message and expand our mission. Despite struggles and adversity, they have chosen to become part of the cure and not a victim of the disease.”

Dr. Rajiv Varma, John DiCecco, Chuck Mohan and Jerry Cook
Living with mitochondrial disease presents many twists and turns and a maze of questions. UMDF is pleased to offer answers to some of those questions as taken from Ask the Mito Doc™ at UMDF.org. 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.

Responder for this issue: Russell Saneto, DO, PhD, of Children’s Hospital, Seattle, WA, Sumit Parikh, MD, of Cleveland Clinic, Cleveland, OH, Salvatore DiMauro, MD, of Columbia University, New York, NY, and Gerard Berry, MD, of Children’s Hospital Boston, MA.

THE QUESTION IS...
My daughter was diagnosed with complex one at a clinic six years ago by skin biopsy. We had recent blood work in a different hospital to check for other issues and the results came back negative for mito disease and for complex one. How can that happen and what would you suggest we do next?

RESPONSE FROM RUSSELL SANETO, DO, PhD:
I am sorry to hear about your daughter. I am sure this latest contradiction has you baffled as well as concerned for your daughter. One of the problems with diagnosing mitochondrial disease, is that there is no one single test that we do that says “yes, for sure you have mitochondrial disease.” So, we base our diagnosis on 1) clinical findings, 2) biochemical results, 3) muscle biopsy or in some cases skin biopsy, 4) Neuroimaging, and 5) genetic studies. When some or all of these align, then we say, you have “definite”, “probable”, “possible” or “unlikely” mitochondrial disease. I am not sure where your daughter would fall as I do not know the results of all these variables.

You should realize that testing has some important variables. First, the material that is tested is very important. Most feel that muscle biopsy yields the best results for electron transport chain enzymology. However, cultured skin fibroblasts are often used. Second, sometimes testing can vary, and vary between institutions doing the tests and with the timing of testing. I have seen the same piece of muscle get two different results from two different labs. This makes it very important to talk with your mitochondrial specialists to see what variables might have altered results or how testing might be different depending on what test was done and where it was sent. Test results also need to be viewed with all the factors involved in making a diagnosis.

Not knowing what all the testing that been done and the clinical symptoms your daughter has, it really is impossible for me to tell you what to do next. You need to sit down, look at all the data, talk with your physician, and see what would be the next steps. I truly am sorry that there is now this “uncertainty.”

THE QUESTION IS...
My family has NARP 8993 T-C mutation. In 1996 I was told the cut off point to have symptoms was 70% mitochondrial involvement. My eldest sister with 51% just had acute symptoms of ataxia, moderate asthenia and mental lapses, following a possible viral illness. Electromyography showed peripheral neuropathy and cranial MR mild abnormalities. The neurologist is relating this to the family disease. Question: can an adult with 51% mitochondrial abnormality have symptoms of the disease at 70 years of age?

RESPONSE FROM SUMIT PARIKH, MD:
Our understanding of mitochondrial DNA (mtDNA) and specific mutations has evolved (especially since 1996) and we now know that patients with the 8993 NARP mutation can have symptoms once their mutation approaches above 50% heteroplasmy. Thus this finding in your sister could explain her symptoms.

However, I would recommend that - despite her mtDNA mutation - other “common” and potentially treatable causes of ataxia - such as cancer and something called aparaneoplastic syndrome MUST be excluded prior to attributing her symptoms to her mtDNA problem.

THE QUESTION IS...
My 10 year old son has had muscle and skin biopsies. ETC testing showed Complex I defect. We do not yet have genetic results. I am curious as to whether there has been research of any type on a relationship between rh negativity and mitochondrial disease. I suppose more specifically-could the rhogam injection cause mitochondrial dysfunction in the unborn baby? My entire family (myself, my husband and our three children-two of which are twins) is RH negative. However, I did receive the rhogam shots as my husband’s blood type was unknown at the time. Myself and my son with mitochondrial dysfunction are B-, my husband A-., and our twins are AB- and A-. It’s probably a wild question but thought I would pose it anyway.

RESPONSE FROM SALVATORE DIMAURO, MD:
No, at least to my knowledge, there is no relationship between rh negativity (or the “rhogam shots”) and mitochondrial disease (in particular complex I deficiency). Nor can I conceive of a potential pathogenic relationship between the two conditions. It would be important, however, to establish the molecular basis of your son’s complex I deficiency.

THE QUESTION IS...
We have a 3 yr old daughter with Complex I & II, and 22q11.2 Deletion Syndrome. She continues to get re-occurring bladder (UTI) infections- which creates a vicious cycle of antibiotics (mostly Amoxicillin). I’ve read that repetitive antibiotics for Mito patients are not recommended. Any suggestions? Considering she has gut motility issues and is fed through a GJ Tube, it wouldn’t surprise me if she also had dysmotility or reflux issues involving the urinary tract. A VCUG (voiding cystourethrogram) has not been done. Are repetitive UTIs common with Mito children?

RESPONSE FROM JERRY VOCKLEY, MD, PHD:
While it is never a good idea to use antibiotics indiscriminately; untreated infections can be a severe metabolic stress to individuals with mitochondrial disease. So antibiotics should be used if clinically indicated. More importantly, the cause of the repetitive infections should be investigated (including a VCUG if necessary) and treated so that the risk for future infections can be reduced.

Submit your question to Ask the Mito Doc™ at UMDF.org. You can also contact the UMDF at info@umdf.org.
CHICAGO CHAPTER
- **January, 2010.** The Chicago Chapter raised $285 by selling coupon books for Carsons Community Day. Chapter members sold the coupon books in the month of January. Thank you to the Chicago Chapter for your dedication and continued fundraising efforts!

DELWARE VALLEY CHAPTER
- **March 1, 2010.** In conjunction with the Philadelphia 76ers, the Delaware Valley Chapter hosted a charity night at the Wachovia Center, in which a portion of the ticket sales were donated back to the UMDF. Thank you to the Philadelphia 76ers for your support of the Delaware Valley Chapter of the UMDF! Thank you to the members of the Chapter for coming out to the game to show your support of the UMDF and raise awareness of mitochondrial disease.

INDIANA CHAPTER
- **February 28, 2010.** In conjunction with Indiana Ice of the USHL, the Indiana Chapter participated in the annual Pack the House for Charity event at Conseco Field House, in which a portion of the ticket sales were donated back to the UMDF. A special thank you to the Indiana Ice for your continued support of the Indiana Chapter of the UMDF!

OTHER NOTABLE EVENTS (CON’T)

- **December, 2009.** Thanks to the Hokestra family the UMDF was the chosen beneficiary of the 2009 Festival of Trees Christmas event sponsored by the Rock Valley Chamber of Commerce. This three day event featured a Christmas decoration display and bake sale which raised over $3,000 for the UMDF in honor of Autumn Hokestra. This event helped raise awareness throughout the Rock Valley community and was a great success!

- **February, 2010.** The National Honor Society at Minnechaug Regional High School in Wilbraham, MA took part in their 5th Annual Themed Basket Raffle Fundraiser. Thank you to all of the students and staff for their continued support of the UMDF mission.

GIFTS FROM THE HEART

- Michael Moriarty, Winnetka, IL donated $60 of his baby-sitting money to the UMDF Chicago Walk in honor of Patrick Kelley.

- Ackerman, Link, & Sartory honored Michael & Christopher Link from Palm Beach, FL by raising $85 from their weekly Dress Down for Charity Day. Thank you Ackerman, Link, & Sartory!

- In their second annual Coins for a Cure fundraiser, Southwest Elementary School in Danville IL honored 11 year old Christopher Adkins by raising $476.06 to fund research for mitochondrial disease. The winning classroom won a pizza party. Although Christopher’s class didn’t win, they graciously invited him to their party. Thank you to Southwest Elementary School for your continued support in helping the UMDF.

- The Indiana Organ Procurement Organization (IOPO) raised $430 through a Jeans Day in order to honor Vinny Winegarden, the son of IOPO employees Eric and Kristi Winegarden. Thank you to the employees of IOPO and Philanthropic Committee.

- Merge Apparel Company donated a portion of its sales from its “ATP” t-shirt to the UMDF. Merge is run by a philanthropic young woman named Victoria Jones who was drawn to the UMDF and mitochondrial disease following a meeting with an affected adult in the New England Area. Thank you Victoria for helping raise awareness of mitochondrial disease.

- In lieu of Christmas gifts, Mrs. Burcham asked her students and staff to donate money to the UMDF to help find a cure for her grandson, Jackson Culley. As a result, $563.00 was raised in honor of Jackson. Thanks to all who helped raise awareness and funds for the UMDF.

- A motorcycle event called “Finding the Missing Link” was held in honor of Gavin Price. Thanks to generous donations over $2,000 was donated to the UMDF.

If you are having or have held a fundraising event, we want to hear about it! Email events@umdf.org or call 888-317-UMDF.
THE CHILDREN’S HOME OF PITTSBURGH

The UMDF Western PA Mito Group held a family meeting at The Children’s Home of Pittsburgh & Lemieux Family Center this past November. The speakers were Alicia Celotto, a Colleague of Dr. Palladino at the University of Pittsburgh and Dr. Amy Goldstein a pediatric neurologist at Children’s Hospital of Pittsburgh. The day began with a presentation on the UMDF & advocacy with UMDF CEO Chuck Mohan. He introduced Alicia Celotto who did an amazing presentation on the research that Dr. Palladino and colleagues are conducting at the University of Pittsburgh. They are using fruit flies with mutated mitochondria to measure the effectiveness of treatments for diseases that cause progressive deterioration of the nervous and muscular systems. Then, Dr. Amy Goldstein presented an equally amazing presentation on Mitochondrial Disease. Dr. Goldstein also allowed some time for question & answers. We were then treated to a brief description of The Children’s Home by a representative. After the meeting was over, we were able to tour the facilities. The Children’s Home has been an asset to the UMDF and we would like to thank them for their support!

The Children’s Home of Pittsburgh & Lemieux Family Center, established in 1893, is an independent, non-profit licensed organization whose purpose is to promote the health and well-being of infants and children through services which establish and strengthen the family. The Children’s Home offers specialized and personal care to medically fragile children, such as those with mitochondrial disease, and their families through Child’s Way® and the Pediatric Specialty Hospital.

Child’s Way, a day care and Head Start Supplemental Assistance Program, is designed to help children with special medical needs, such as mitochondrial disease, participate in a therapeutic and safe environment that includes activities of a typical day care. The staff of pediatric registered nurses and child care associates provides constant and consistent medical attention in order to assess the development of each child. Comprehensive services, treatments, and therapies are also available to the children. Dietary consultation, which is particularly valuable to children dealing with mitochondrial disease, is also provided in collaboration with Children’s Hospital of Pittsburgh of UPMC. The unique blend of medical care services, developmental care, and therapies in one location, makes Child’s Way an asset to parents of medically fragile children.

The 28-bed Pediatric Specialty Hospital serves as a home-like, family-friendly environment for children who are in-between the stages of hospital and home. The condition of children dealing with mitochondrial disease is easily worsened through physiologic stress. At the Pediatric Specialty Hospital, the nursing staff focuses on the specific needs of each individual child, while creating a calming environment for the child and their families in order to maximize healing and lessen stress. The care team, consisting of nurses, doctors, a respiratory therapist, social worker, and developmental specialist, is also readily available to answer a family’s questions and give recommendations on their child’s care. Families with children in the hospital have the opportunity to spend one or more nights in a private bedroom with their child, to practice providing care on their own, with the security of knowing that help from the nursing staff is just a second away.

Dealing with the conditions of a medically fragile child is challenging and often times very frustrating for families. The Children’s Home provides these services to take away stress and offer excellent care when children and families need it most.

The UMDF’s Western PA Mito Group will hold a second meeting at The Children’s Home on Saturday, April 10, 2010. Guest speakers will be Dr. Vockley from the Children’s Hospital of Pittsburgh & Helen Sims of Guyaux Mandler Mah Financial Group. Please contact Nicole Shanter at 888-317-8633 or email nicole@umdf.org for more information.

UMDF AMBASSADORS - LOCAL LIAISONS HELPING TO RAISE AWARENESS AND SUPPORT

What is a United Mitochondrial Disease Foundation Ambassador?

As an Ambassador for the UMDF, you are a local liaison in a community that does not have enough UMDF members for the formation of a Mito Group or Chapter.

What can I do as an Ambassador for the UMDF?

Each UMDF Ambassador agrees to provide support to callers in his or her region, participate on quarterly calls, submit quarterly reports and complete at least two of the following activities each year:

- Raise Awareness through an Awareness Activity
- Promote Physician Education/Awareness
- Host a fundraiser with 100% of the proceeds benefiting the UMDF
- Compile a Resource List
- Advocate

What is the United Mitochondrial Disease Foundation’s Role?

- Provide the written materials for education and awareness promotions
- Provide technical assistance for fundraising, awareness and physician education
- Provide the opportunity for quarterly telephone conference calls with other leaders

How do I become an Ambassador for the UMDF?

If you are interested in learning more about becoming an UMDF Ambassador, contact UMDF membership services at info@umdf.org or 888-317-UMDF, or view the Ambassador Guide and Agreement Form at www.umdf.org/ambassadorkit.

This is an exciting opportunity for families in areas where there is not currently a Mito Group or Chapter to help spread awareness! We look forward to working with all of you!
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MADDIE’S WISH
A Day in the Life of Madelyn Connaughton

The Make-A-Wish Foundation has been granting wishes to children with life-threatening medical conditions for thirty years. ABC’s Extreme Makeover: Home Edition is a reality TV show that has been providing home renovations to deserving families for the past seven years. The connection between the two is eleven year old Madelyn (Maddie) Connaughton.

Maddie has been watching Extreme Makeover: Home Edition for the past four years and has such empathy for every family on the show. “She will discuss the show with others,” says Terri, Maddie’s mom. “She would comment that she would like to help build a house, especially one for a little girl.” Maddie’s thought was that she would help with the little girl’s room and then become friends!

In 2008, Maddie’s Dad, Norman, submitted an application to the Make-A-Wish Foundation to see if Maddie would qualify for a wish. Maddie has a mitochondrial disease and was diagnosed with Complex III at four years of age. The Connaughton family received word that Maddie was approved and asked her what her wish would be. “Her first response was that she wanted to go to ‘Legoland’ in California,” said Terri, “because her brother, Nick, wanted to go there.” They explained to Maddie that her wish should be something that she wanted. She then said she wanted to meet Ty Pennington and help him build a house!

In December 29, 2009, Maddie received a phone call from Erin & Jen, the Make-A-Wish wish granters, to let her know her wish was granted! The whole family found themselves on a plane to Myrtle Beach, SC to the site of a house scheduled to be built from January 11th to the 14th. Once on site, the Connaughton Family was introduced to the home builder, Harry Dill. Harry was instrumental in putting together Maddie’s wish as he is on the board of the South Carolina Chapter of Make-A-Wish. Harry had a surprise for Maddie; he was going to take her to meet Ty Pennington! “Maddie was speechless when she first saw him,” said Terri. “She had tears in her eyes and started to slowly back away from him.” Ty was extremely kind to Maddie and she mustered enough courage to answer his questions. Maddie had her photo taken with Ty and he gave her a stuffed elephant.

After meeting Ty, Maddie was then introduced to two of the shows designers, Johnny Littlefield and Ed Sanders. Maddie had no problem opening up to the two. She told them all about her dog, Emma, and talked about the show and what she liked about it. The family went on a tour of the property, the equipment and production trailers and were able to watch the designers remove things from the home. Unfortunately, because of the cold weather and the time, Maddie was not able to stay and watch the house get demolished.

The next day, Maddie met the third designer, Paige and spent some time with her in the VIP tent. While in the tent, Maddie was presented with a hard hat that had been signed by Ty. Maddie had her photo taken with Ty and he gave her a stuffed elephant.

To read more about Maddie’s Wish, go to www.umdf.org/nengchapter and click on the 2010 Spring Newsletter. To learn more about the Extreme Makeover: Home Edition family, go to www.extremehorry.com. This episode will air on April 11, 2010.
FROM THE CHAIRMAN

In our last newsletter, we discussed the exciting development of the North American Mitochondrial Disease Consortium (NAMDC). Work is continuing to develop the software needed for the NAMDC. The UMDF’s role in this consortium is to serve as a resource connecting patients and their families to the scientific and medical community as they attempt to recruit patients for appropriate clinical trials. The UMDF has been investigating the technology required to provide the secure infrastructure needed to make this process seamless for patients and families. We hope to have some exciting developments to report to you in the coming months.

The Mayo Clinic in Rochester, M.N., is also part of the NAMDC consortium, along with several other medical facilities across the nation. We were very excited to learn about the new Mitochondrial Disease Biobank that is now up and running at the Mayo Clinic. For the first time in the United States, mitochondrial disease patients, or those who are suspected of having mitochondrial disease, are able to “bank” skin or muscle biopsy tissues or other samples at the Mayo Clinic Mitochondrial Disease Biobank. Why is this important? The samples allow researchers the ability to study and learn more about mitochondrial disease and the opportunity to share that research with other scientists. This can be critical in developing new treatments and cures. I invite you to read more about the Biobank and how you may participate in this newsletter. We also have a link to the Biobank information on our website www.umdf.org.

Speaking of the website, in January, we launched the new UMDF website. While it will always be a work in progress, we hope you find it easier to locate the information that you need. The new design also allows us to have the website translated into a number of languages for mitochondrial disease patients around the world. We have also made it easier to find chapters, groups and events.

With spring just around the corner, the UMDF National Office swings into high gear with the planning of a number of projects and events. For example, the UMDF’s Grant Review Committee will be gathering in Pittsburgh on April 22-23. Initially, the UMDF received 178 ‘Letters of Inquiry’ from scientists requesting that their projects receive research funding. The UMDF only funds research projects that demonstrate the ability to bring us one step closer to an easier diagnosis, effective treatments or potential cures. With that in mind, the Grant Review Committee has invited 38 researchers to send full proposals for their review in April. In our next newsletter, we will be able to tell you which of those projects will be funded and at what level.

Our Special Events Department is also gearing up for the Spring Walk Season. In January, chapter representatives from around the country gathered again in Pittsburgh for the second part of our new pledge based fundraising training provided by Biondolillo and Associates. During the two day training, important issues like volunteer recruitment, sponsor development and the creation of walk-related advertising materials was discussed. Most of our events plan to transition to the new walk model later in 2010.

Work on our advocacy effort to support H.R.3502 and S.2858 continues. In mid-February, we asked all members, their families, friends and colleagues to participate in a “call to action.” Our “call to action” invited you to plan a visit, write a letter, or make a call to your member in the House of Representatives and U.S. Senate asking elected officials to co-sponsor each important piece of legislation. We will report on the results of that effort online and in an upcoming newsletter. Additional cosponsorship is needed on both bills in order to secure a hearing that will move us closer to the passage of the bills. We still have a long way to go, so I hope you participated. If not, it is still not too late, visit www.umdf.org/advocate today.

On a related note, we have received a response to the letter sent to President Obama from more than 70 distinguished physicians and scientists emphasizing the need for additional research into mitochondrial medicine. Kathleen Sebelius, Secretary of Health and Human Services responded by saying that mitochondrial research will continue to be among the areas considered for research support and as new initiatives are developed across the National Institutes of Health. “Please be assured that my Department and this Administration are committed to supporting research initiatives that advance science and medicine,” wrote Secretary Sebelius.

Finally, I invite you to attend “Mitochondrial Medicine: 2010.” Our annual, international symposium will be held at the Camelback Resort Scottsdale, AZ. Scientific meetings begin June 16, 2010. Family meetings start on June 18, 2010. During the symposium, patients and families meet others who, like themselves, are seeking knowledge. They may be parents or an individual with similar experiences or someone that lives close to them. Patient and family attendees are given many opportunities to meet some of the top mitochondrial specialists from around the world. The symposium encourages the exchange of information and cultivates networking among physicians, researchers, patients and families. I hope to see you there!

Energy to all,

W. Dan Wright, UMDF Chairman

The Grant Review Process - Formal Proposal Phase

The Grant Review Process is in the Formal Proposal Phase. The proposals will be scored based on the following criteria:

1. Significance/Impact: The extent to which the project, if successfully carried out, will make an original and important contribution to the detection, diagnosis, treatment, management, and family care of mitochondrial disease patients.

2. Approach: The extent to which the conceptual framework, methods, and analyses are properly developed, well integrated, and appropriate to the aims of the project. The effective use of grant funds.

3. Feasibility: The likelihood that the investigators can accomplish the proposed work. Consideration will be given to the investigator’s documented experience and expertise, past progress, preliminary data, requested and available resources, institutional commitment, and (if appropriate) documented access to special reagents or technologies and adequacy of plans for the recruitment and retention of subjects.
Seventeen year old Kristen Charleston’s family will be hosting their final Kites for Kristen Fundraiser on May 21st. Kristen has MELAS.

UMDF DEVELOPMENT EXPANDS ITS FOCUS

The Development Office of the United Mitochondrial Disease Foundation (UMDF) has taken steps to expand its fundraising focus. The recent addition of Marian Weil to the staff as full-time Director of Development brings the Development Office a seasoned professional to lead all efforts devoted to winning gifts and grants for the UMDF. She will be responsible for enhancing the UMDF’s success in individual giving, corporate and foundation gifts, and planned giving initiatives.

Marian has a strong and successful background in development and the non-profit world. For over 20 years she was president of First Side Partners, a consulting group based in Pittsburgh and Ohio, that offered fundraising and marketing services to the not-for-profit sector with a particular focus on capital campaigns. She has been active on several local Boards of Directors. Marian moved to Pittsburgh from New England and was educated at Boston University.

“I'm delighted to join the UMDF team. I hope to add my experience and knowledge to enhance UMDF's ability to attract more grants and gifts from across the nation. My first priority is to get to know our many generous donors. I want them to know how much we appreciate their generosity and commitment to UMDF.”

Marian’s arrival signals a new era in UMDF Development. The Department will be focusing on broadening the UMDF fundraising portfolio by strengthening our stewardship efforts, individual giving, corporate and foundation philanthropy, and planned giving initiatives.

As part of her duties, Marian will be concentrating initially on introducing herself to UMDF donors in order to thank them for their generous giving and brief them on the latest developments at the UMDF. Visits to various parts of the country in conjunction with UMDF activities will allow her to meet with key donors and friends of the UMDF.

The development office will be working to encourage individual support of local and national activities, research funds and projects of special interest. The corporate and foundation programs will focus on establishing strong partnerships with organizations that will work with UMDF to support local and national projects and enrich the research program.

As we enhance the corporate and foundation program, we will be looking to our chapter leaders to identify funding sources in their own communities that UMDF can approach. Companies wishing to be good corporate citizens will support organizations in communities in which their employees live and work and UMDF’s many nationwide chapters provide a strong base from which we can ask for support. The Development Office will work with chapters to develop proposals that may be invited from this interaction.

Planned giving is another important part of UMDF’s development program. Individuals are encouraged to evaluate their financial situation with the help of a financial planner. UMDF offers the services of a veteran financial specialist, Nick Nicholson, who will be pleased to talk with individuals and families about providing for their future with strong financial planning. Even if you are currently working with a financial planner, Nick is available to provide a free evaluation of your financial plan to confirm that your assets are protected and that your financial wishes are fulfilled.

The Development staff is available to answer any of your questions. Marian can be reached at marian.weil@umdf.org. Grant writer, Don Gielas, is available at don@umdf.org.

Ways You Can Help

• If your company has a matching gift program, make sure you use it to double the value of your donation to UMDF

• Talk to your company’s community relations representative about support for your UMDF chapter

• Ask your friends to inquire about support for UMDF at the companies in which they work

• Find connections to people who know the funders in the community, help open the doors for UMDF to meet with funders in your area

• Plan for the financial future of your family and loved ones and work with UMDF’s planned giving representative to ensure that your wishes are upheld.
WHY I CHOSE TO BE A MEMBER OF THE UMDF - BY: SUSANNE LEACH, MD

My husband and I received the diagnosis of mitochondrial disease for our son four years ago. Our first thought was to start our own foundation to raise money for research. We also did a lot of our own research regarding existing foundations that focus on mitochondrial disease and dysfunction. Along with the information we received from our doctor regarding the diagnosis was material on the United Mitochondrial Disease Foundation (UMDF).

We vigorously read all the material, searched the internet and discovered many other mitochondrial groups and made numerous phone calls. I have to say, I probably inundated the UMDF’s phone lines at the beginning of my pursuit, yet no one ever seemed bothered. Rather, everyone always took the time to listen and be compassionate. I found that even staff who are not affected personally by this disease, work with the same sense of urgency as do us parents and patients themselves.

It quickly became apparent that we should join the UMDF and that this foundation should be the foundation for everyone affected by mitochondrial disease. While there are many wonderful organizations out there, none is all-inclusive as is the UMDF. Their mission is the most broad-based, from raising awareness to helping/educating members and increasing research.

There are many reasons why we chose to support the UMDF. We believe that research offers the best hope for our son and the thousands of others afflicted by this disease. UMDF has a scientific advisory panel comprised of the leading scientists and physicians in this field. They have a rigorous grant review process, similar to that of the National Institutes of Health (NIH). They are also the biggest private funder for research into mitochondrial disease. I absolutely love that the majority of money raised for UMDF goes towards research. There is absolutely no comparison with what they can achieve and have achieved as compared with a foundation we would have started ourselves.

Families have the option of setting up a research fund in a loved one's honor/memory. We have chosen to do this and every year, we do a letter-writing campaign. For us, money is the answer to help the research agenda. UMDF gave us the avenue by which I can pursue my agenda. As a parent, I need to know that I am doing everything possible to help save my son’s life and further the medical knowledge in this field. In addition, UMDF has vital resources to help its members in their various fund-raising quests. One need not feel that they are going at this alone!

The UMDF Annual Symposium is second to none. Every year, the UMDF organizes a conference bringing together the top researchers and clinicians from around the world in mitochondrial disease and includes a conference platform for family members as well. Lucky for us, we received the diagnosis right before one of the conferences and we were able to attend. Since then, I look forward to these conferences every year. All the family topics are always extraordinarily useful. The two conferences run virtually simultaneously, allowing for the ability to meet the doctors on a causal basis; further more, the “UMDF Doctor Is In” session is amazing. Families bring their records and questions and speak personally to a variety of leading doctors. We have gotten more information during these sessions than in our years of searching around the country for answers to our son’s many problems. All the doctors and scientists participating in “The Doctor Is In” session exhibit the highest level of expertise, knowledge and care. Many of them have spent decades working in this field; they are clearly driven to better understanding of the basic physiology of the mitochondria and to find better non-invasive diagnostic testing and treatments for mitochondrial diseases. They obviously care about each person they meet and their empathy is palpable. All the clinicians feel the pressure to improve the lives of those who suffer. For UMDF to have such a close knit relationship with these amazing medical personnel is a testament to the heart of the foundation.

The quarterly newsletter is wonderful. The UMDF presents relevant topics and latest research. They thank everyone who has raised money and truly believe every dollar helps. It is moving to see when a child in kindergarten leads her or his class in a UMDF Coins for a Cure collection and such donations are mentioned. Their “Ask the Mito Doc” section is extremely valuable. It is also another example of the connection UMDF has among its members with the leading doctors.

Lastly, it is like one big family across this county and around the world. Our Leach family is now part of an extended family consisting of over 65 UMDF Chapters and groups across the USA. Even my parents are taken into this big, loving family. Everyone is welcomed and given ample opportunity to participate.

I believe probably every mitochondrial organization offers something positive and often something different. Some stress member support for example while another stresses funding a clinical fellow in mitochondrial disease. I am sure there is a role for most of these organizations, but I believe that all the groups should work together. We can all support each other’s endeavors and be inclusive.

As mentioned, I believe the UMDF is the single organization that involves everyone’s interests; and being connected to the world’s leading experts, it truly is the National (or International) Mitochondrial Disease Foundation, and the foundation for everyone.

The UMDF, for instance, is currently pursuing a legislative endeavor to urge the government to start ramping up research dollars – an effort I am positive is in everyone’s best interest. Under their leadership, there are now bills in the House and Senate that would establish an Office of Mitochondrial Medicine within the National Institutes of Health. There would be the most wonderful snowball effect with creation of such an office; it would lead to more scientific meetings, escalating the exposure of the field to residents and medical students, resulting in growing numbers of young doctors and researchers choosing to go into this field, increasing the amount of research being performed in mitochondrial disease and increasing the number of research grants being approved.

Perhaps most touching is that the UMDF was started by someone who lost a child. He is racing the clock to help our son and thousands of other children and adults with this awful disease. He does not have to do this work, but he is driven to help save others. He is tireless in his pursuit to find a treatment for mitochondrial disease. His actions and sincerity to help every single patient and family member today are a testament to this organization’s highest level of professionalism and inclusivity to all.
ATLANTA CHAPTER
• April 24, 2010. The third annual All Aboard for a Cure Walk and Family Fun Day will be held at Thrasher Park in Historic Norcross, Georgia. For more information, please visit www.allboardforacure.com.

CHICAGO CHAPTER
• May 21, 2010. The 10th final Kites for Kristen event will be hosted by the Charleston family at the European Chalet in Chicago, IL. The event, which benefits the Kristen Charleston Research Fund with the UMDF is held in honor of Kristen Charleston and will feature dinner, music, raffles, a silent auction, and more! For more information, please visit www.umdf.org/KitesForKristen.

MIDDLE TENNESSEE CHAPTER
• March 27, 2010. The first annual Jackson Culley Mito-What? 5K will be held in Millington, Tennessee at USA Stadium. For more information please contact Angie Hayes at angie.hayes07@gmail.com or visit www.mitowhat5k.blogspot.com.

NEW ENGLAND CHAPTER
• May 23, 2010. The first annual Energy for Life Walk-A-Thon will be held at MIT’s campus. For more information please contact Stefan Bush at UMDFMom@aol.com or Lindsay Hocz Knops at lindsayknops@hotmail.com. Go to www.energyforlifewalk.org/newengland and register today!

OHIO CHAPTER
• May 8, 2010. The Wild for a Cure Walk will be held at the Cleveland Metroparks Zoo. The event will include a 1 and 3 mile walk through the Zoo so you can enjoy the wildlife! For more information or to register, please visit www.wildforacure.org.

ST. LOUIS MITO GROUP
• April 3, 2010. The seventh annual Mito What? Family Fun Day will be held at the Shrine of Our Lady of the Snows in Belleville, IL. For more information, visit www.umdf.org/stlouisrace or contact Marsha Hohe at 618-233-6919 or Joni Schnitzler at 618-624-0216.

WESTERN PA MITO GROUP
• May 8, 2010. In conjunction with the Pittsburgh Pirates, the UMDF will be hosting an awareness night at PNC Park when the Pirates take on the St. Louis Cardinals. This opportunity will allow the UMDF to raise money and awareness in the Pittsburgh area. For more information or to purchase your tickets, go to www.umdf.org/pirates.

AROUND THE COUNTRY
• March 20-21, 2010. Preston’s March for Energy will be held in Virginia Beach, Virginia. The event will be held in conjunction with the Shamrock Sportsfest. In 2009, more than $40,000 was raised by the Shamrock Sportsfest Community. The proceeds from this year’s event will be donated to the UMDF in honor of Preston Buenaga. For more information, go to www.shamrockmarathon.com and click on ‘Charities’.
• April 23-24, 2010. The fifth annual Caroline’s on My Mind Walk/Run offers all participants a fun-filled experience with friends, refreshments, mitochondrial disease resources, and much, much more! The weekend will also include the annual barbecue and golf outing in honor of Caroline Pulliam which will benefit the Caroline Pulliam Research Fund with the UMDF. For more information, visit www.umdf.org/carolinesonmymind.
• June 3, 2010. The second annual Landon’s Hope 5K and Family Fun Day, in memory of Landon Weatherby and Marie Schlachter will be held at Eastman Park in Windsor, CO. For more information, please visit www.umdf.org/Landon’sHope.

FEATURED FUNDRAISER
• Tea for Mito. Mother’s Day is just around the corner! It’s the perfect time to hold a tea party to raise money for mitochondrial disease research. Simply register online at www.teaformito.com and tell us how many invites you would like. The UMDF will then send you the Tea for Mito hostess kit that includes your invitation cards, response cards, envelopes and tea bags. Then “invite” your family and friends. It’s all up to you whether you have a tea party or ask your friends and family to send a donation and drink the tea in the privacy of their homes.

SPECIAL EVENTS CALENDAR
In January, the UMDF launched its brand new webpage! The new design gives the website a fresh, clean feel and the navigation is more user-friendly. The UMDF homepage now lists upcoming events including meetings, fundraisers, and Grand Rounds in the right column. In addition, every Chapter and Group has its own calendar. Chapter calendars are accessible from the chapter’s homepage. All calendars are accessible from the UMDF National Calendar, linked on the UMDF homepage. This is one more way the UMDF is keeping its membership informed.

Contact the Special Events Department at events@umdf.org or 888-317-8633 to have your event listed on the calendar. Check it out regularly for upcoming events and meetings in your area!

ENERGY FOR LIFE WALK
As you know, our Pledge Based Fundraising initiative is well underway. The UMDF staff and volunteers participated in the last phase of training in Pittsburgh on January 9 and 10, 2010 with Biondolillo & Associates. Our volunteers returned home energized and ready to roll out our new walk model to their committees and we are all looking forward to a very successful fundraising season.

The UMDF headquarters is working with Breehl, Traynor & Zehe in Cleveland to design a new logo to support our Energy for Life walk branding initiative. All walk websites and collateral will have the same look and feel. The goal of this project is to give us the tools to attract national awareness, dramatically increase both volunteers and walkers which will raise additional revenue to fund research to find treatments and a cure for mitochondrial disorders.

If you have ever thought about organizing a walk in your area, now is the time to do it. The UMDF Special Events Staff will support your efforts by providing all of the one-on-one consultation needed to make it an organized and streamlined process. Please contact Carol Milsovic, National Events Manager at 888-317-8633 or email carol.milsovic@umdf.org.

SPECIAL EVENTS UPDATE

UPCOMING EVENTS
February 15-19, 2010 was the UMDF’s “Call to Action” Week across the nation. The goal of the week was to empower our members to take action on H.R.3502 and S.2858. Even though the bills have been introduced, we have a long road ahead of us in getting them passed into law. The goal of the “Call to Action” week was to secure additional co-sponsors for each measure. While we are still looking at the results of the week, our experts in Washington D.C. tell us that we need a minimum of 100 cosponsors in the House and 25 in the U.S. Senate. We are sitting at 25% of our goal for each chamber.

Additional co-sponsors are important. By gathering additional members of the House and Senate as co-sponsors, we demonstrate support for the bills. In demonstrating support, it is easier to move onto the next phase in the process – Committee Action.

H.R.3502 has been referred to the House Energy Committee. S.2858 has been referred to the Health, Labor, Education and Pensions Committee in the Senate. These committees have a great deal of power in deciding if the bills receive any attention. The more support a bill has, especially from congressional committee leadership of the President, the greater the bill has of receiving consideration. That is why we have asked our members to advocate for additional co-sponsors.

The next step is to secure a hearing before a House or Senate Subcommittee. Witnesses are called to testify about the merits of our bills. The hearings also give House and Senate members an opportunity to ask questions about the bills. After hearings, the committee members are able to offer their own views on a bill and suggest amendments. This is called a ‘mark up.’

When the mark up is complete, a final draft of the legislation is voted on for approval. If a majority supports the bill, it is sent out to be voted on by the full House and Senate. Prior to a vote, the committee prepares a report on the bill, describing the intent of the legislation and its impact on current laws and programs.

After this process, the legislation is put onto the House or Senate calendar for debate. When the debate concludes in each chamber, a vote takes place to approve or defeat the bill.

While our Day on the Hill in the summer of 2009 started this process, we need you to continue. How important is the legislation to you? How important is federal funding to help find better treatments or a cure? Will you let your voice be heard and become part of the cure? Visit www.umdf.org/advocate now!

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**ESTABLISHING A MITOCHONDRIAL DISEASE AWARENESS WEEK SEPTEMBER 19 - 25, 2010**

Let's work toward making Mitochondrial Disease a familiar disease to everyone. One of the ways you can do this is to lobby for a Mitochondrial Disease Awareness week in your state. In most states this can be done by proclamation for one year, with the potential for annual renewal. The best possible option is to have the third week of September permanently designated as Mitochondrial Disease Awareness Week. Our hope is to have this week permanently designated in every state.

How to accomplish this will vary from state to state so here are some general guidelines.

- **Start with your state government website, which can be located by conducting an online search using terms such as “state government” and the name of your state. On this site you can find information on the process for getting a bill passed in your state, who your local representatives are, how to contact them, and track the bill as it progresses. If you have difficulty finding your state’s government website, please contact the UMDF office and we will help you.**

- **Contact your local state Senator or Representative and enlist their help. You can send them a letter including your or your child’s story and request that they introduce a bill to permanently designate the third week of September, Mitochondrial Disease Awareness Week. It would be great to include a picture along with information about mitochondrial disease and the UMDF. A sample letter has been included in this packet.**

- **Follow up your letter with a phone call in about a week. Some states have offices that will draft the bill, or you can provide them with the sample bill from New Jersey that we have included.**

- **Please contact UMDF and update us on your progress.**

- **Once the bill is drafted and introduced, enlist friends, family, chapter and group members to write their representative encouraging them to support the legislation. Whenever you write, always include the child/adult’s story with a picture and the UMDF pamphlet. They need to put a face with the cause.**

- **Once the bill is introduced to the legislature, it will probably go to a committee for a hearing. When you learn that the bill has been “referred to committee,” find out who is on that committee and who the chair of that committee is. Then send them a letter asking them to move the bill quickly for a hearing and out of committee. Again include the story and UMDF literature.**

- **If you are invited to testify, take energy bands, yours or your child’s story and UMDF information. Testifying puts a face with the bill and makes it more personal to the legislators.**

- **After you testify, send the committee members a thank you note for moving the bill along and giving you an opportunity to testify. Include a picture.**

- **Track the bill’s progress on your state’s legislative page if that capability is available.**

Visit www.umdf.org/awarenessweek for more information!
as mentioned in this newsletter, the UMDF has urged our members to contact their Congressmen and Senators and ask them to co-sponsor H.R. 3502 and S. 2858. While the “Call to Action” week is over, we still need your help.

The most important thing that you, as an affected adult, have is your voice. You can talk to your representatives, you can tell them first hand how mitochondrial disease affects your daily life. Our affected children have their parents to describe the affects that mitochondrial disease has on their child. But in most cases, the child cannot talk for him/herself. You can! We urge you to help in this effort.

Here are a few ways in which your voice can be heard.

1. E-mail. If you have access to e-mail, why not use it to your favor? Send an e-mail to everyone in your address book urging them to contact their Congressmen and Senators to support H.R. 3502 and S. 2858. Explain the content of the bill, how it will affect you if it is passed and then provide them with the website (www.umdf.org/advocate) so they can advocate on your behalf. Not sure what to say? Go to the UMDF website for full details on the bills.

2. Petitions. How many petitions have you signed in your lifetime? How about starting one of your own? Get a copy of H.R. 3502 and S. 2858, attach a blank paper to the back, and ask your friends, family members, neighbors, co-workers, to sign and show their support. Don’t forget to ask everyone in your community, your pharmacist, clergymen, librarian, teachers, and anyone you have contact with. Then, send or take the signed petition into your Congressmen or Senator’s office. It is a great way to show the community support of the bills.

3. Calling Party. Reach out and have a virtual Calling Party! Invite 10 of your friends to set aside some time to call their Congressman and Senators and ask them to co-sponsor H.R. 3502 and S.2585. Then, ask those 10 friends to contact 10 of their friends to do the same! You could easily have 100 people contacting your Congressman and Senators in a short amount of time.

These are just a few of the ways your voice can be heard. Be creative and use your voice to the best of your ability! We will be heard!
This year Mitochondrial Medicine 2010 will be held in Scottsdale, Arizona. With June quickly approaching, now is the time to start thinking about ways to raise money so that you can attend the meetings. The cost of one family member attending the symposium will include the cost of registration (approximately $225, which covers nearly all meals,) two nights at the Camelback Inn Resort (approximately $155 per night) and ground or air transportation. It can seem like a huge financial hurdle for some - But, there are ways to raise funds!

**DEVELOP AN “AZ OR BUST” PLEDGE SHEET. THEN...**

- **Day 1:** Sponsor yourself. Pay the fundraising ‘kitty’ $25
- **Day 2:** Ask five friends to contribute $20
- **Day 3:** Ask two relatives to sponsor you for $25
- **Day 4:** Ask five co-workers to sponsor you for $10
- **Day 5:** Ask five neighbors to sponsor you for $10
- **Day 6:** Ask your company for a contribution of $25
- **Day 7:** Ask two businesses you frequent to sponsor you for $25

Most people are happy to give when they are asked, especially if it will help you care for your loved one. People want to do something positive for you!

**LOCAL GOVERNMENT AND NON-PROFIT RESOURCES**

If you plan to contact state/local resources for financial support, you will need to get started as soon as possible. Many of these agencies have early deadlines for the upcoming year.

Start by searching the internet using goodsearch.com (don’t forget to use the UMDF’s code!)

Note: The IRS will allow parents to deduct some of the costs, such as registration and transportation costs, that are associated with attending medical meetings related to their children’s health conditions. See IRS Bulletin 2000-9 (May 8, 2000) for more information.

**Some keywords to try:**
- ARC of (enter your state)
- Legal aide
- Financial assistance
- Conference assistance
- Conference stipend
- Disability assistance
- Disability stipend
- Family assistance
- Disability resources
- Or any other creative combination of words!

Make sure to put the name of your state in each search you do. Different states have different names for programs, so you may need to do some research in your area.

**Applications can usually be made to:**
- Your state’s Early Intervention Office
- Your state’s Department of Human Services
- Your state’s Department of Public Welfare Disabilities Office
- Your state’s Commission on Disability
- Your state’s Medicare Waiver Program
- Your state’s Parenting Education Network (IEP or FSP program)

The following are state-specific organizations you can contact to see if they provide financial help for medical/disability conferences:

- Your state’s Parenting Education Network (IEP or FSP program)
- Your state’s Medicare Waver Program
- Your state’s Commission on Disability
- Your state’s Department of Human Services
- Your state’s Early Intervention Office
- Your state’s Department of Public Welfare Disabilities Office
- Your state’s Commission on Disability
- Your state’s Medicare Waiver Program
- Your state’s Parenting Education Network (IEP or FSP program)

- Georgia Council on Developmental Disabilities (www.gcdd.org)
- Illinois Family Assistance Program (via Illinois Legal Aide website: www.illinoislegalaid.org/index.cfm?fuseaction=home.dsp_content&contentID=218)
- The ARC of Illinois, Consumer Involvement Program - Consumer Stipend Funds
- Utah Governor’s Council for People with Disabilities, Empowerment Fund (http://utahddc.org/grants/empowerment/documents/Empowermentfundupdated709.pdf)
- Consumer and Family Participation Fund - Virginia/DC Area
- The Morgan Project - offers grants for individuals who wish to attend medical conferences. More information can be found at www.themorganproject.org
- United Cerebral Palsy (UCP) Conference Assistance Funds (not limited to those with CP. For more information visit www.ucp.org/ucp_channelsrv.cfm?94/14/30/1033

Remember! The total cost of attending the Symposium will need to include registration fees, transportation costs, hotel costs and some meals.

**UMDF SYMPOSIUM SCHOLARSHIPS**

The United Mitochondrial Disease Foundation has a limited amount of funds available for full and partial symposium scholarships. These scholarships are limited to members who are affected individuals and their immediate family members.

You must be a member of the UMDF to be eligible for a scholarship; go to http://secure.umdf.org/join to become a member today. If you have received assistance in the past three years (2007, 2008, 2009) you may not be eligible for assistance this year.

Prior to applying for a UMDF symposium scholarship, please exhaust all other potential resources for financial support. Please check with state and local resources for assistance in subsidizing attendance costs before submitting your application.

2010 UMDF Symposium Scholarship applications are available online at www.umdf.org/symposium. If you have questions, please contact 888-317-8633 or e-mail symposium@umdf.org.

**If you have a resource you would like to see highlighted, please go to www.umdf.org/submitaresource and let us know!**
Mitochondrial Medicine 2010: Scottsdale, Arizona

Scientific Session - June 16-18, 2010
Family Session - June 18-19, 2010
Special Scientific/Clinical Autism Meeting - June 19, 2010

JW Marriott Camelback Inn Resort
Scottsdale, Arizona

Registration will open in March.
Registration brochures will be mailed out to all members and will be available on the symposium website.

www.umdf.org/symposium
**ANNOUNCEMENTS**

**COQ10 CLINICAL TRIAL**
The University of Florida is continuing to recruit patients for a clinical trial to investigate the safety and effectiveness of Coenzyme Q10 (CoQ10) as a treatment for children with specific mitochondrial diseases. CoQ10 is a mitochondrial cofactor and antioxidant in the process that cells use to convert food and oxygen into energy. To be considered for the trial, patients must be 12 months to 17 years of age and have a biochemical or molecular diagnosis of a deficiency of complex I, III or IV of the respiratory chain. For additional information contact Tracie Kurtz, RN, at Tracie.Kurtz@medicine.ufl.edu or 352-273-9016.

**LENNON PHOTO MOSAIC - SHINE ON FOR A CURE**
The UMDF is in the process of collecting photos for the Shine on for a Cure Photo Mosaic. We need 1,000 photos in order to make the mosaic a reality. Please visit www.shineonforacure.com for photo requirements or email photomosaic@umdf.org.

**UMDF MERCHANDISE**
The UMDF Store is open 24 hours a day, 7 days a week! Simply go to http://umdf.promoshop.com and let the shopping begin! UMDF merchandise is a great way to support the UMDF, gain awareness of mitochondrial disease and provide fundraising support. The store is currently running clearance specials on last season’s merchandise as we make room for new items! Don’t forget, Energy and Life Members receive a 10% discount on all merchandise. Simply follow the directions when ordering to receive the discount.

**LEAP AWARD AND HEARTSTRINGS AWARD**
The UMDF wants to recognize our champions and heroes, and we need your help! Nominations are open for the 2010 UMDF LEAP and Heartstrings awards. You can print and mail the forms or submit online at www.umdf.org/volunteerawards. You can also request forms by mail or fax by contacting us at info@umdf.org or at 888-317-8633. Submissions must be received by April 14, 2010.

**FACEBOOK, TWITTER, YOUTUBE AND RSS FEED**
Have you heard? The UMDF is now on Facebook, Twitter and YouTube! We also have an RSS Feed for our ‘Current News’ section of the website! Follow the corresponding icons on www.umdf.org to go to each page! Become a FAN of the UMDF’s page on Facebook, become a FOLLOWER of the UMDF’s page on Twitter, SUBSCRIBE to the UMDF’s page on YouTube so you can see all videos posted by the UMDF, and SUBSCRIBE to the UMDF’s RSS Feed so you can be the first to know about Current News! It is now easier than ever to receive up-to-date information from the UMDF. What are you waiting for? Go online today and connect with the UMDF in these new ways! Here are the icons you want to look for on the UMDF home page:

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**SUBMISSION DEADLINE FOR VOLUME 15 ISSUE 2 IS APRIL 30, 2010!**