



December 2006 Newsletter

A Note from the Executive Director

2007 is fast approaching, and for MDAC we are sure it is to be year of positive growth and change.

In 2006, MDAC welcomed Mary McQueen, ANP, as Executive Director. The Board was solidified and committees were formed that would help MDAC better achieve our mission of helping improve the daily quality of life for patients and families affected by mitochondrial disease. Over \$70,000 was raised at the 2nd annual MDAC “MitoAction Family Fun Walk & Auction” in Boston. Those monies have been set aside to fund projects and programs submitted by both parents and professionals in the coming year. Time and resources were delegated to Margaret Klehm, a nurse practitioner working with Dr. Mark Korson at Tufts-NEMC, to develop a mitochondrial disease management manual for physicians. This manual, which will soon be available to all patients mid-2007, will be a tremendous resource for patients in any medical community as they collaborate with their primary care physicians and advocate for their children and family members affected by Mito. Keeping our mission goals of support, advocacy, awareness and education in mind, MDAC also funded the creation and future publication of “When Jeremy Jones’ Stomach Stopped Working”, by Anne Reckling, PhD. This loving and informative children’s book addresses some of the feelings and real concerns felt by children who have gastrointestinal difficulties which result in placement of a g-tube, a common phenomenon for children living with Mito. Additional projects include a “Living with Mito” series to be published on the web, and an awareness campaign including the Massachusetts governor’s declaration for “Mitochondrial Disease Awareness Week”.

For the group of patients, parents and health care professionals that founded this organization, perhaps the greatest accomplishment has been increased recognition and support within the general community of both our mission and mitochondrial disease.

The end of 2006 is exciting, for as the year comes to a close, MDAC welcomes new executive leadership and renews an emphatic commitment to involving and linking patients, families and volunteers from all over the United States. I am thrilled to step in as the new Executive Director and build on the excellent foundation started by Mary. My background in community health nursing and my experiences with my daughter Eva (Leighs disease) complement the mission and vision of MDAC perfectly. We are so excited to have Mary’s continued involvement on the Board, and we are equally excited to welcome Susan Zelenko as our newly appointed Media and Public Relations Director. Susan is a multi-lingual, multi-cultural mother of a child living with

mitochondrial disease, and she brings passion and her journalism experience to the organization that will help us promote awareness of Mito and our mission in 2007.

Stay tuned in January for the announcement of several new and very exciting projects which will be funded and carried out in 2007. If you have ever considered sharing your time, talents or energy, now is the time to join us! MDAC is an organization that was started by patients, parents, nurses and doctors who, just like you, want to energize each day to the fullest, and help others who are living with mitochondrial disease. You can become a volunteer or supporter by visiting our website www.mitoaction.org, or by emailing me directly at director@mitoaction.org. I am always so happy to hear your suggestions, ideas, or thoughts about how we can better support you.

Thank you for the opportunity to step in and be a part of your family.

Happy Holidays!

Cristy Balcells RN, MSN

Executive Director, Mitochondrial Disease Action Committee

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IMPORTANT HOLIDAY SHOPPING ANNOUNCEMENTS!

Do you shop online for gifts or books during the holidays?

You can help MDAC earn a portion of your holiday purchases when you shop on Amazon.com.

Simply visit the MDAC website (www.mitoaction.org) and link to Amazon by clicking “**Give Back to MDAC when you shop on Amazon.com**”

If you can't find what you are looking for, don't stop shopping! Link through MDAC (www.mitoaction.org) to the **GoodSearch** search engine and designate MDAC as your charity of choice. We can earn hundreds of dollars from your search for the perfect fruit cake (or whatever you might be looking for...)!

Finally, many of us struggle with the choice of a **perfect gift** for teachers, partners, associates and neighbors. Why not make a **gift donation to MDAC**? Beginning December 5th, you can **choose “Give a gift that makes a difference”** on our website, and through ActiveGiving.com, you can make a donation in any amount in honor of or on behalf of a person of your choice. MDAC will then send an acknowledgement to you, the donor, and a special holiday card to the gift recipient, recognizing your support in their behalf. Your gift of appreciation is not only a meaningful holiday gift, but is also an avenue to increase awareness of mitochondrial disease and fund programs which will directly help patients and families.

Go now to www.active.com/donate/holidaygifts !!!

IMPORTANT DATES TO REMEMBER!

First **Mito Family Social** to be held December 10th, 2006 in Needham, MA.

- Snacks, drinks, crafts and games for all ages!
- 4:30-6:30 p.m. at the First Parish Unitarian Church, 23 Dedham Ave
- RSVP to Kim Lorimier simkue@comcast.net

day of questions call Kim at (413) 320-2579- more directions and details at www.mitoaction.org

Next **General Meeting: January 5th** at noon at Tufts-NEMC Floating Hospital 3 Conference Room (conference call-in available 866-414-2828, participant code 017921)

Project Proposal deadline extended to January 15th, 2007! Project ideas accepted from anyone – please fill out the proposal form at www.mitoaction.org/projects.html and email it directly to director@mitoaction.org

“Let’s Get Energized!”