

Summary – 2013 Town Meeting

Importance of Community: Philip Borden, MitoAction Board President



For MitoAction, community is the center of our mission. Community takes several forms: We are a community of patients, a community of families, a community of medical professionals and caregivers, and a community of volunteers. In 2012, MitoAction helped more families than ever before. “We had a terrific 2012,” Borden said, “but as we look forward, I’m even more excited.” During 2013 we will continue to build, expand, and broaden our scope with even more opportunities to make a difference and educate people about Mito. For more information, email us at info@mitoaction.org

Camp Korey Summer Camp: Cora Weed, MSW, Camp Director



This summer, Camp Korey in Seattle WA will offer three sessions for campers with mitochondrial disease. Camp Korey gives children ages 7-15 with serious medical conditions a summer camp experience. The Mito sessions will be held July 15-19, July 29- Aug. 2, and Aug. 5-9. Applications are available online and will be accepted on a first-come, first-served basis. Go to www.campkorey.org for the application and more information. We are so excited to continue our partnership for the fourth year with Camp Korey. If you have questions, please email Cora at cweed@campkorey.org.

Awareness Events, Susan Stover, MitoAction Events Director



You should be a part of MitoAction's awareness event lineup for 2013! We will kick it off with the ***"Wear That You Care"*** campaign on Feb. 28. Thanks to our friends at the Global Genes Project, we will unite to wear jeans and show support for Rare Disease Day!

On May 4, join us at the annual Sandra K. Russell Derby Day Benefit for Mito at Fenway Park.

Don't miss our largest community gathering, the annual Boston Energy Walk & 5K Run on Sept. 8, 2013.

In 2012, a few families hosted their own awareness event, and we want to help you create such an event in your community! For more information on all these events, email Susan at events@mitoaction.org.

EPI-743 Clinical Trial: Dr. Guy Miller, Edison Pharma



"EPI-743 is obviously a highlight for us," said Dr. Miller. "Clinical trials of EPI-743 so far have been incredibly successful." Patients with Leigh Syndrome are urgently needed to participate in the Phase 2B phase of this trial. For more information, visit www.mitoaction.org/epi743, email info@edisonpharma.com or call the EPI-743 hotline at 1-800-243-0254.

New Memories Group: Maggie Orr, Medical Advisory Committee



As a group of parents who have lost a child to Mito, we saw the need for a specific support group for people who are grieving the loss of a loved one from mitochondrial disease. "It's helpful to have a place to share and to feel that you are not alone," says Maggie. Our webpage, www.mitoaction.org/memories, offers a list of resources, a link to share your photos and memories, a link to our forum, and more. Please contact us at memories@mitoaction.org.

Marcel's Way Family Fund: Mary Summers, Family Ties Director



The Marcel's Way Family Fund committee invites you to apply for support or donate in order to give a gift to those in need. The Marcel's Way Family Fund offers one-time grants of up to \$500 for expenses related to mitochondrial disease. To donate, apply or learn more, please visit www.mitoaction.org/marcel-s-way-family-fund.

Mito 411 Support Hotline: Mary Beth Hollinger, Volunteer



1-888-MITO-411 is a support group for patients and families provided by families. Anyone is welcome to call the hotline and speak with a volunteer who is either an adult patient or parent of an affected child. In addition, we are seeking volunteers to help provide vital one-on-one support. Mito 411 allows a person to talk to someone who understands what they are going through. It's not about medical advice; it's about helping, supporting, and offering a shoulder to lean on. For more information or for support, call us (1-888-MITO-411) or email mito411@mitoaction.org

ThriveRx iThrive: Melissa Pariseau, RN



ThriveRx offers a monthly online educational series of webinars on topics surrounding GI motility especially designed to help patients who rely on tube feedings or TPN. Topics vary and webinars are free. For more information, please find Thrive RX on Facebook or visit <http://www.thriverx.net>.

UMDF Conference: Cliff Gorski



This year's UMDF Mitochondrial Medicine conference will be held in Newport Beach, CA from June 12-15. The four-day scientific and clinical program runs from June 12-15; the two-day family conference is June 14-15. Registration opens soon. For more information, email connect@umdf.org or click [here](#).

Mito Socials & Mito Marketplace: Ginger DeShaney, Support Coordinator



Mito Socials



bring families together in the

same community for support, friendship, and camaraderie. We are always looking for volunteer hosts. It's easy and super fun. For more information, check out www.mitoaction.org/mito-socials. We've also started the new Mito Marketplace to showcase people who make Mito awareness items (www.mitoaction.org/mito-marketplace). If you're interested in hosting a Social or are a crafter interested in the Marketplace, please email Ginger at support@mitoaction.org.

Stay in Bed Day: Vicky Spadoni, MitoCanada



In cooperation with the AMDF (Australian Mitochondrial Disease Foundation), MitoCanada held its first "Stay in Bed Day" on Sunday, Jan. 27. People signed up at www.mitocanada.org/2012/11/27/stay-in-bed-day-2013. Participants collected pledges to stay in bed, hold a pajama party, hold a brunch, do a bed relay! For more information, email Vicky at info@mitocanada.org.

CureMito Half Marathon: Claudia Boles, CureMito.org



The Pasadena [Rock 'n' Roll Marathon](#) will be held Feb. 17 at the Rose Bowl in California. Join supporter and actress Chandra Wilson, whose daughter has cyclic vomiting syndrome. Last year's run raised \$50,000 for research! Get involved, start a team, join a team, run or walk on your own, or donate to someone who is participating. For registration/donation, click: <http://curemito.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=500>. For more information, check out www.curemito.org. or email contact@curemito.org. And check out this video: http://www.youtube.com/watch?v=s3Vsyj_XeKE&feature=youtu.be