

Summary – 2012 Mito Town Meeting

Mito 411

Parents and family members need your help! **Please, be a Mito 411 volunteer this year.** Mito 411 volunteers respond to phone calls from patients, parents and family members who need support throughout the year. As a volunteer, you will go through a training (by phone) and take calls two or three months out of the year. Both adult patients as well as parents/family members are needed!

Please email our volunteer coordinator Wendy at mito411@mitoaction.org and see the website for more info and to set up your training.

<http://www.mitoaction.org/mito-411>

The Marcel's Way Family Fund

MitoAction is proud to announce that we will continue the legacy of assisting families in need with the costs of living with mitochondrial disease by carrying forward the Marcel's Way Family Fund. At this time we are NOT taking need-based applications, but are seeking dedicated volunteers to serve on the MWFF committee. An volunteer application will be posted this month here:

<http://www.mitoaction.org/marcel-s-way-family-fund>

Rare Disease Day, February 29th



Wear "**Jeans for Genes**" on Wednesday February 29th! Thanks to our friends at the Global Genes Project, organizations, patients, families and medical providers around the world will unite on Feb. 29th to show support for rare diseases!

- 1) Start this idea now at work, for your child's school, at your church or with a club that you belong to by organizing a "**Wear Jeans for Genes Day**", to be held on February 29th, 2012.
- 2) Raise money to support the 2012 Awareness Kit Campaign by asking company employees, teachers, friends, etc. to donate \$5 as part of a "dress-down" day. If you are planning to raise money this way as part of the "Wear Jeans for Genes" day, please let us know so we can send you complimentary Mito pins to share with your colleagues or classmates! The funds raised for this day will go toward funding the production of and shipping of hundreds of Mito Awareness Kits in 2012.
- To learn more about **Rare Disease Day, Feb 29 2012**, visit <http://www.globalgenesproject.org/wrdd.php>

Awareness Week Initiatives

Mitochondrial Disease Awareness Week 2012 is September 16-23

Kick off the week on September 16th by attending the Boston Energy Walk & 5K Run. Save the date and plan to attend! <http://mitoaction.org/walk>

Are YOU ready to be a part of awareness week? Let us help you plan a mini-walk or community awareness event - we will help you! Please email Susan at events@mitoaction.org for more info

The Lilly Pulitzer Mito Tote



Do you look stylish while raising awareness for Mito? The perfect accessory and the perfect gift for every lady - the exclusive **Lilly Pulitzer Mito Tote**. Limited edition - get yours while they last! <http://shop.inthepinkonline.com/product/6585-mito-tote?tab=>

EVENTS_

Fundraisers, Walks, Runs, Conferences & Awareness Events:

CureMito Half Marathon

CureMito! - Pasadena Half Marathon February 19, 2012

Research, Treatment, Cure

DEADLINE TO SIGN UP TO PARTICIPATE IS FEBRUARY 5TH!!!!



CureMito! is helping children with mitochondrial disease and dysfunctions by improving their quality of life. Our mission is to establish and support a local center of excellence for the innovative research, treatment and education in mitochondrial disease and functional disorders. <http://www.active.com/donate/curemito/teammitoaction> and www.curemito.org

Rina's Magic Bracelet Premiere

Follow the incredible story of a dream coming true <http://www.facebook.com/magicbraceletevent>

Plan to watch the hometown premiere on March 1st in Philadelphia, then again in June for the **Red Carpet Premiere for Rina's film, "the Magic Bracelet" in Hollywood**

Celebrate the Kentucky Derby in style this year at the SKR Derby Day Benefit for Mito, Saturday May 5th



At the gorgeous waterfront Boston Harbor Hotel

Cocktails courtesy of Grey Goose Vodka. Auction, Derby games, appetizers and ladies hat parade. Tickets online now!

<http://www.mitoaction.org/derbyday>

Plan to attend the UMDF conference this summer:

Mitochondrial Medicine 2012: Capitol Hill

Capitol Hill UMDF Advocacy Day: June 14, 2012

Scientific Sessions: June 13-16, 2012

Family Sessions: June 15-16, 2012

Bethesda North Marriott Hotel & Conference Center

5701 Marinelli Road, Bethesda, MD 20851

More info: www.umdff.org

Camps, Socials and Support Groups

Mito Socials



Want to meet other people in your area who are also living with mitochondrial disease? Join or host a Mito Social!

<http://www.mitoaction.org/mito-patient-and-family-socials>

Coming soon

Sunday, Feb. 26, 2012: My Gym Children's Fitness Center, Brewer, Maine, 1-3 p.m.

RSVP to support@mitoaction.org

February (date TBA): Houston, TX stay tuned for details.

Hole in the Wall Gang Camp Metabolic Family Weekend



For kids with Mito along with their siblings and parents
Metabolic Family Weekend is April 20-22 in Ashford, CT

<http://www.holeinthewallgang.org>

Camp Korey is now accepting campers and volunteers for Mito Week!



Mito Week is July 23-27 at Carnation Farm in Washington. Camp Korey serves children ages 7 and up living with serious and life-threatening conditions, and hosts the only dedicated camp week for mitochondrial disease in the U.S. as a partnership with MitoAction.

Applications for campers now available online:

<http://campkorey.org/camper-programs/apply>

MEDICAL VOLUNTEERS NEEDED!

<http://campkorey.org/ways-to-help/volunteer/medical-staff>

and for more volunteer information:

<http://campkorey.org/ways-to-help/volunteer/camper-program-volunteering>

Questions? cweed@campkorey.org.

MitoCamp.org in Houston, Texas open to all ages

Mito Camp will be November 2-4, 2012 at Camp 4 All. This year, there is opportunity for 150 people to attend, free of charge! Campers attend from as far away as Washington and Florida in 2011. MitoAction is a proud sponsor of Mito Camp. Please direct questions to Charles or Melody Wilds via www.mitocamp.org

Speakers & Teleconferences
1-866-414-2828 code 017921#

Support groups by phone offered every Friday at noon EST/9amPST - all encouraged and welcome.

Autism-Mito group every 2nd Tuesday at 12:30 pm EST

Details can be found at <http://www.mitoaction.org/news-and-events>

Upcoming speakers (check www.MitoAction.org/blog for details)

February 3rd - Jonah and the Whale Foundation regarding medical child abuse accusations in families with mitochondrial disease

March 2nd- Dr Richard Haas, "practical aspects of the diagnosis"

April 6th - Dr. Mark Korson, interpreting and understanding lab findings