



MitoAction Walk energizes mitochondrial disease patients

Dalia Flaggert could very well be the sweetest child on the face of the earth. Anyone who has met her will say so.

The 6-year-old cutie from Framingham, MA, is thoughtful, kind, caring, and charming. She's a total cuddlebug. And she's a real trooper.

When Dalia was 4 years old, she was diagnosed with MERRF Syndrome, an extremely rare form of mitochondrial disease. She has balance issues, hearing loss, speech, motor and developmental delays, and difficulty walking.

"She has a huge number of challenges and she faces each one with courage and a smile," said her mom, Jessie Fein. "It's really impressive."

When Dalia was first diagnosed, Fein and her family felt isolated. When Fein heard about MitoAction's Energy Walk & 5K Run for Mitochondrial Disease last year, she was excited and relieved to be able to meet other families dealing with similar issues. So she gathered friends and family and created a team, Dalia's Dynamos, for the event.

"For people who are touched by Mito, the walk is a way not to feel so helpless. There's a sense of healing in being able to do something," Jessie said. "There's so much thrown at you with this kind of diagnosis that you are constantly in a reactive mode. Here's an opportunity to be proactive."

This year, MitoAction's seventh annual Energy Walk & 5K Run will be held on Sunday, Sept. 18, at Castle Island in South Boston, MA. Registration is open at www.mitoaction.org/walk. The Boston-based nonprofit's mission is to improve the quality of life for everyone affected by mitochondrial disease through support, education, and advocacy initiatives.

Nicole and Will Dalton and their family and friends will be walking in memory of Emma, a sweet little redhead who died of Leigh's Disease on April 17, 2011, just shy of turning 7 months old. "They told us she had a year to live, but the disease was so aggressive that she passed away a week later," Nicole Dalton said.

"We had never even heard of [mitochondrial disease]," said Dalton, a Franklin, MA resident. "Most doctors haven't even heard of this, know what to look for, or how to treat it. It's heartbreaking that there is so little information out there. There are also so few Mito specialists, and even they are learning about this."

The family didn't have much time to get support or information in the hospital. "We desperately needed people to lean on or to ask questions to, but we didn't even know where to go or what questions to ask," Dalton said. "That is why MitoAction is so vital."

Emma brought so much joy and happiness to those around her. "She was a true gift to us in every sense of the word," Dalton said. "We are better people because of her but we miss her terribly. She left us too soon but she will forever be in our hearts."

Team Ladybugs is walking for Emma and everyone else with Mito. "In her memory we want to be very active so hopefully there comes a day when no one has to go through this," Dalton said.

Sheridan Johnston was working as a child life specialist at St. Jude Children's Research Hospital when she became sick and disabled in 2006. In 2010, she was finally diagnosed with mitochondrial disease. The first walk she attended after her diagnosis had a huge impact on her.

"I was somewhere where no explanation was needed. I knew that everyone 'got' me," said the Gorham, ME resident. "No one looked at me funny because I was in a wheelchair. There's a real feeling of community."

Before last year's walk, Johnston, the captain of the Mito Maine-iacs, was not feeling well and had to watch as others made posters and prepared for the event. "But when I got there, I was surrounded by all the energy in the world. I can't wait for that feeling again."

Lisa Parker mentioned the energy, too. Mito is an energy disorder, but the walk is energizing and electric. "The energy there is incredible," said Parker, who became sick in 2004 and was diagnosed with mitochondrial disease at the end of 2006 at age 26. Prior to getting sick, Parker was working full time and going to graduate school.

When Parker was first diagnosed, she didn't know anyone with Mito. She didn't even know what it was. "The walk is important because it brings the Mito community together. But it also spreads awareness and raises money," said the Burlington, MA resident.

Mitochondrial disease is a genetic, neurodegenerative disorder that affects 1 in 4,000 infants, children, teens, and adults. Symptoms commonly include muscle weakness, extreme fatigue, seizures, gastrointestinal dysfunction, developmental delay, vision and hearing loss, and organ failure. Mito is seriously under-recognized and often misdiagnosed. Mitochondrial dysfunction has been implicated in autism, diabetes, Alzheimer's and Parkinson's disease. There is no cure.

Wendy Helmka is excited to be attending her first walk, coming in from Michigan. "It's going to be significant," she said. "This will be the first time meeting other people with mitochondrial disease in person."

The team captain of Adults Get Mito 2 was an athlete, running marathons and taking 37-mile bike rides, when she became ill in 2002. The physical therapist wasn't formally diagnosed with Mito until 2006. "I represent MitoAction all over the world, but I've never met anyone," Helmka said. "The MitoAction community is like family."

Arthur Margolis, owner of America's Compounding Center in Newton, MA, and Saad Dinno, owner of Acton Pharmacy with his brother Raied (Ray), have been longtime sponsors of the walk. Both pharmacies have many Mito patients and each owner wanted to support something that helps his patients. And each pharmacist views the walk as an opportunity to spend time with patients.

Margolis feels very close to the MitoAction community. "The majority of the money goes right back to helping families," he said.

Dinno's first Mito patient came to him in 2000 or 2001. "I had never heard about mitochondrial disease until that patient told me about it.

"Awareness is important," said Dinno, who noted that at one of the first walks he attended, there were maybe 200 people. "Last year, there were people everywhere. It's absolutely amazing."

Last year's event drew almost 1,000 people to Castle Island. "I've recognized how many of us there really are," Johnston said, noting that she doesn't feel so alone anymore. "You realize there are so many others with Mito."

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