



Camp Korey changes lives of kids with mitochondrial disease

Camp Korey's week for campers with mitochondrial disease is being held Aug. 8-12 at Carnation Farm in Carnation, WA. Boston-based support organization MitoAction sponsors the week in partnership with Camp Korey. Camp Korey's Mito Week is the only dedicated week of camp in the country for children with mitochondrial disease ... and it changes their lives forever.

Addison Woods came back from Camp Korey's 2010 Mito Week a changed boy. He was more confident and independent. He took the initiative more. "I was blown away by what [Camp Korey] did with the kids," said his mom, Angie Woods, of Tacoma, WA.

Heather Wright-McNair's three children returned from camp with "big beautiful hopes and dreams." Chance, Madison, and Abigail came back with a "rejuvenated spirit. It's truly and completely been a life-changing experience," said the Dallas mom.

It's stories like these that fill Gordon Russell's heart with joy. He can't wait for Mito Week. The Wellesley, MA, resident, owner of In the Pink stores, and a MitoAction Board member has been a camp counselor during Mito Week since its inception three years ago. Last year his son Jonathan joined him as a counselor and he'll be back with his dad again this year.



"I've heard parents say they can't believe the change in their children. It's really stunning," Russell said. "One mom said, 'My child came out of camp with hope.'"

Hope, dreams, confidence. These are feelings that children with mitochondrial disease don't often experience. For 51 weeks a year, they spend their lives being different from everyone else. During Mito Week at Camp Korey, "normal is what they are," said Russell, who lost his wife, Sandra, to mitochondrial disease.

"They don't have to explain their droopy eyelids, being shorter than everyone else, their seizures," Russell said. "All these kids understand it."

"Mito" occurs when the mitochondria of the cell cannot produce enough energy for cell or organ function. The incurable disease affects 1 in 4,000 infants, children, teens, and adults. Symptoms vary and may include profound muscle weakness, extreme fatigue and pain, and ultimately organ failure. Mitochondrial disease in children can be very stressful because often they cannot participate in typical childhood activities.

Camp Korey's mission is to provide children facing life-threatening illnesses with a safe, friendly, medically sound environment in which to have fun and just be kids. MitoAction's mission is to improve the quality of life for everyone affected by mitochondrial disease through support, education and advocacy initiatives. Both nonprofits honor the courage and strength of these children and their families.

Camp Korey allows kids to safely enjoy traditional camp activities, such as painting, dance parties, talent shows, and swimming. "We provide children with experiences they may not be able to have otherwise," said Hillary Carey, the executive director of Camp Korey, which offers its programs to families at no cost to them. "Everything is universally accessible. We meet the needs of every child."

Carey said one of the many highlights of Mito Week for her is watching children do something for the first time, like horseback riding or fishing.

"As a camp counselor, you understand your duties are to allow these kids to be normal," Russell said, noting that every other week of the year they are dealing with their illness and countless doctor appointments. "Our role is to, as much as possible, let them have a week of camp and not let their medical condition be the primary focus."

With a full team of doctors and nurses on hand, the medical component is very strong but it's in the background, Carey said. In a happy role reversal for the campers, the doctors and nurses go to them, so if a child needs his medications, the nurse brings them to him.

The friendships the campers make last a lifetime. Oftentimes, they don't know any other Mito families in their hometowns. Camp Korey lets them know they are not alone. "They make connections and bond with each other," Russell said. Since the camp draws kids from all over the country, Carey cherishes the excitement as kids proudly proclaim they have made friends from other states. And with Facebook, they stay in touch all year and look forward to seeing each other at camp.

Russell chronicled camp activities on Facebook last year, posting photos and updates every day. He plans to do that again this year. His postings charted the growth of the campers, from being tentative, cautious, and timid on the first day of camp to flourishing at the end. "The growth is phenomenal," Russell said.

Addison Woods was apprehensive about going to camp last year because it was his first time away from home. At the end of camp? "He didn't want to come home," his mom, Angie, said.

For more information about Camp Korey, please visit www.campkorey.org. For more information about MitoAction or to help send a child to Camp Korey, please visit www.mitoaction.org or call Cristy Balcells, Executive Director, at 888-648-6228. Please note donations "Mito Camp" to earmark them for this special opportunity and mail to MitoAction, 14 Pembroke Street, Medford MA 02155.