Children's Mercy KANSAS CITY

KETOGENIC DIET SHOWS PROMISE IN REDUCING SEIZURES

Approximately 35% of pediatric patients with epilepsy continue to have seizures, despite treatment with multiple medications. A wide range of treatment strategies is necessary to help this subset of patients, such as the medically supervised ketogenic diet. Children's Mercy Kansas City provides advanced care for refractory epilepsy patients and is a designated Level IV Comprehensive Epilepsy Center. The center is led by Ahmed T. Abdelmoity, MD, FAAP, Division Director of Child Neurology, who is triple board-certified in child neurology, epilepsy and clinical neurophysiology. The center offers one of the largest ketogenic diet programs in the country, treating approximately 300 children.

NUTRITIONAL STRATEGIES HELP PATIENTS REDUCE MEDICATIONS

Patients whose seizures are not controlled by multiple medications are candidates for the ketogenic diet. This is determined after consultation in the ketogenic diet screening clinic, led by Tara Myers, RN, CPNP and Erin Fecske, DNP, APRN, CNRN, CPNP-PC. As they begin the new diet, these children continue their medications. In three to six months, seizure frequency is reassessed, along with quality of life. As many as 80% of patients are able to reduce their medications. Children's Mercy program participants have fared better than national averages, seeing a 72% improvement after one year and 90% after two years.

The multidisciplinary care team takes a holistic approach to monitoring ketogenic diet patients. The team quickly addresses their medical, social and psychological needs, including diet side effects. Team members include board-certified epileptologists, epilepsy nurse practitioners, epilepsy nurses specifically trained in ketogenic diet, neuropsychologists, ketogenic dietitians, a ketogenic diet chef educator and social workers.

IMPROVING ADHERENCE TO THE KETOGENIC DIET

The ketogenic diet can feel restrictive, making compliance difficult. Children's Mercy hired Chef Rachel Finn to work with its registered dietitians, Lindsey Thompson, PhD, RD, CSP, LD and Rhonda Sullivan, MS, RD, CSP, LD, and program coordinator Megan Gustafson, MSN, RN, CPNP-PC, as well as physicians and patients. Using complex ratios and macro requirements, Chef Rachel developed kid-friendly recipes for pizza, peanut butter sandwiches, sushi, cupcakes and more. She also began holding keto cooking classes, teaching families and kids how to cook together.

Chef Rachel's work has helped increase adherence to the ketogenic diet. Patients on the diet have experienced improvements in academic performance, attention, alertness and overall well-being.

KETOGENIC DIET DECREASES EPILEPSY-RELATED ER VISITS AND HOSPITALIZATIONS

Dr. Abdelmoity led a team that assessed the impact of the ketogenic diet on reducing seizure-related emergency department visits and hospitalizations in children with refractory epilepsy. The team conducted a retrospective review of children treated with the ketogenic diet in one tertiary center between 2009 and 2013. Study cohort criteria:

- Epilepsy was diagnosed and treated by a pediatric neurologist or epileptologist for ≥12 months prior to starting the ketogenic diet.
- Patients failed to respond to conventional pharmacological therapy before starting the ketogenic diet.

- Patients were treated with the ketogenic diet for ≥12 months.

They reviewed the number of ED visits, hospitalizations and hospital days, along with their associated charges. Thirty-seven patients (57% male) were included. Their ages at time of diet initiation were 4.0 ± 2.78 years. At the conclusion of the data review, the team identified specific reductions:

- Total number of ED visits was reduced by 36%, with a significant decrease of associated charges ($p = 0.038$).
- Hospital admissions were reduced by 40%.
- Hospital days were reduced by 39%.
- Cumulative charges showed net cost savings after nine months when compared to the pre-diet baseline.

TREATING INFANTS WITH THE KETOGENIC DIET WHILE MAINTAINING A BREAST MILK DIET

According to the International League Against Epilepsy, the ketogenic diet was reported as possibly effective as the treatment of choice for epilepsy in infants with glucose transporter type 1 deficiency syndrome and pyruvate dehydrogenase deficiency. This recommendation prompted Dr. Abdelmoity and colleagues to design a protocol for initiating the ketogenic diet in breastfed infants. They conducted a cohort study of infants with drug-resistant epilepsy who received ketogenic diet therapy at Children's Mercy between May 2005 and January 2016.

The infants were between the ages of 1 and 13 months. Each was treated with the ketogenic diet while being maintained on breast milk. Data from the first two patients was gathered retrospectively while the other seven were studied prospectively.

The study showed that all nine infants achieved and maintained ketosis effectively. One infant had no change in seizure frequency, while three were seizure-free at the first follow-up visit. Four had a burden of seizure reduction greater than 50%.

TREATING INFANTS WITH DRUG-RESISTANT EPILEPTIC SPASMS

Epileptic spasms, one of the most severe forms of epilepsy, can lead to drug resistance and developmental disability. About 20% of children will continue to experience spasms, despite drug treatment. Children's Mercy's research into the efficacy and tolerability of the ketogenic diet in these highly fragile children showed significant improvement in seizure burden and a high percentage of seizure freedom.

SOURCES

Kayyali HR, Gustafson M, Myers T, Thompson L, Williams M, Abdelmoity A. Ketogenic diet efficacy in the treatment of intractable epileptic spasms. Pediatr. Neurol. 2014 Mar;50(30):224-7. dio: 10.1016/j.pediatrneurol.2013.11.021.

Desai AA, Thompson LM, Abdelmoity AT, Kayyali H, St Peter SD. Management of symptomatic cholelithiasis while on ketogenic diet: a case report. Pediatr Neurol. 2014 Sep;51(3):439-40. doi: 10.1016/j.pediatrneurol.2014.05.013. Epub 2014 May 21.

Kayyali HR, Luniova A, Abdelmoity A. Ketogenic Diet Decreases Emergency Room Visits and Hospitalizations Related to Epilepsy, Epilepsy Research and Treatment, vol. 2016, Article ID 5873208,4 pages, 2016. https://doi.org/10.1155/2016/5873208.

Le Pichon JB, Thompson L, Gustafson M, Abdelmoity A. Initiating the ketogenic diet in infants with treatment refractory epilepsy while maintaining a breast milk diet. Seizure. 2019 Jul;69:41-43. doi:10.1016/j.seizure.2019.03.017. Epub 2019 Mar 26.

Thompson L, Fecske E, Salim M, Hall A. Use of the ketogenic diet in the neonatal intensive care unit-Safety and tolerability. Epilepsia. 2017 Feb;58(2):e36-e39. doi: 10.1111/epi.13650. Epub 2017 Jan.

BEST CHILDREN'S HOSPITALS U.S.News & WORLD REPORT NEUROLOGY & NEUROSURGERY 2019-20

LEARN MORE ABOUT THE KETOGENIC DIET AND TREATMENT OF REFRACTORY EPILEPSY.
Ahmed Abdelmoity, MD FAAP
Division Director, Child Neurology
aabdelmoity@cmh.edu • (816) 302-3331
transformpeds.childrensmercy.org

Children's Mercy KANSAS CITY

For consults, admissions or transport call: 1 (800) GO MERCY / 1 (800) 466-3729.

November 2019