



□ *Editor's note: The subject of this story is also the grandson of the writer. This is a follow-up to a story that appeared in November, 2007.*

By Russ Pankonin

The Imperial Republican

Sunday, Nov. 22, represented a major milestone for six-year-old Austin Lutz of Ogallala.

Not only was it his birthday but it marked the first time in two years that Austin got to celebrate with a real birthday cake.

Since October, 2007, young Austin depended on a "modified" Atkins Diet to control epileptic seizures from a rare condition known as Doose Syndrome (pronounced doe-sa).

Since starting on the high-fat, low carbohydrate diet, cake, breads, pastas and other high carb foods became a thing of the past.

After Austin began suffering from constant drop seizures and several grand mal seizures by mid-2007, his mother, Brooke, began scouring the Internet for alternatives to seizure medicines that weren't working.

A neurologist at a children's hospital in Denver, Colo., told Austin's parents, Brooke and Jeff, the alternative would be to increase medications, which would likely leave Austin retarded. The diet would only be a last resort.

In her search, she came across a doctor at John Hopkins Medical Institute in Baltimore, Md., who specializes in using a ketogenic diet to control children's epilepsy.

Dr. Eric Kossoff began using the diet to control epilepsy in 2002 and currently sees about 1,500 patients per year.

Misdiagnosing Doose Syndrome

In October, 2007, Austin and his parents flew to Baltimore to see Dr. Kossoff, who diagnosed Austin with Doose Syndrome.

Kossoff said Doose Syndrome is often misdiagnosed as a much more serious form of childhood epilepsy, Lennox-Gastaut Syndrome (LGS).

LGS is a difficult-to-treat form of epilepsy that most often appears in children between ages 2 and 6. It is often accompanied by mental retardation and behavior problems.

Denver doctors suspected Austin may have had LGS, although he didn't show any of the developmental problems.

Within weeks of starting the modified Aktins Diet, Austin's seizures almost stopped completely. He suffered one setback but, as of his birthday, has remained seizure free for 700 days. On Dec. 22, he will be seizure free for two full years.

Brooke keeps a running calendar of Austin's seizure-free condition on her family's blog on the

web, jblutz.blogspot.com (no www.).

When Austin began the diet, he was limited to 10 carbohydrates per day. Over time, he was able to increase the limited number of carbohydrates in his diet and was able to eventually wean off anti-seizure medicine.

The diet forces the body to burn fats rather than carbohydrates. Normally, carbohydrates are converted into glucose, which fuels brain function.

In a ketogenic state with few carbohydrates in the system, the liver converts fats into fatty acids and ketones. The brain replaces glucose with ketones as its energy source, which helps reduce seizures.

Kossoff said the diet does not help all kids but it did the trick for Austin.

When Austin was first diagnosed, his brain waves from his first electroencephalogram (EEG) showed constant seizure activity. His latest EEG in June showed his brain function had returned to normal.

Weaning off the diet

After a visit to see Dr. Kossoff this past July, Austin was slowly weaned from the diet. Today, he can eat like a normal six year-old.

Kossoff said if Austin remains seizure free through November, he will most likely be cured.

If seizures return, Austin would have to restart the diet, adding that most kids eventually grow out of Doose Syndrome by age 8-9.

Brooke said she was always amazed at how fast Dr. Kossoff would respond if a problem developed.

Kossoff said he keeps his Blackberry with him all the time, and uses e-mail to quickly respond to his patients' needs.

Kossoff coauthored the book, "The Ketogenic Diet: A Treatment for Children and Others with Epilepsy." Information about the ketogenic diet and contact info for Kossoff can be found on www.epilepsy.com.

Answer to prayers

The Lutzes said Dr. Kossoff and the diet proved to be the answer to their prayers. "God is actually the miracle worker! He led us to Dr. "K" and the diet," Brooke said.

She doesn't know what they would have done if they had not found Dr. Kossoff.

She said Austin was really good about knowing what he could and couldn't eat. It was as if he knew the diet would make him feel better and not have seizures.

Even after he was off the diet, he was still cautious. The first day he was allowed to eat school lunch, he informed his mom he took the breading off the chicken because he thought he wasn't supposed to eat it.

While being seizure-free means the most to his parents, Austin said the best thing about being off the diet is "getting to eat anything" he wants.

The Lutzes just recently moved to Ogallala after living briefly in Red Cloud. For more than five years, the family lived in Imperial.