# Community

COLUMNS
FEATURES
TOWN NEWS
OBITUARIES
BIRTHS

## Seizure-Free, Thanks to a Special Diet

Story by Amy Simcik Williams



The Kristals, all for one and one for all. (Left to right) Evan, Jeff, Emma, and Jynell.

Photos by Ralph Stewart

ith seeming non-stop energy Evan Kristal, a rosycheeked six-year-old, runs in place in his family's living room. "I'm doing my exercise right now," he says without slowing down or skipping a step.

Moments later he and his younger sister Emma drag in the dining room chairs and arrange them in rows. Then they invite their parents to a make-believe movie theater.

Evan's parents, Jynell and Jeff Kristal, owners of the Crocker House Inn in Vineyard Haven, look on, smiling appreciatively. Not too long ago their

son wasn't able to play like this. In fact, Evan couldn't do much on his own. For a period of three years he suffered frequent seizures that were so intense and unpredictable that his parents were afraid to let him out of their arms or walk around without wearing a helmet.

Last spring, Evan was having four types of seizures and as many as 50 a day. Today, remarkably, he is seizure-free because he follows a Ketogenic diet.



## Diagnosis and Beyond

Evan was hardly a year old when he had his first seizure. At age three and a half he was hospitalized for a month and diagnosed with Doose Syndrome, a rare form of epilepsy. Although Evan was under the care of a competent doctor at Children's Hospital in Boston, Jynell and Jeff sought a second opinion at Massachusetts General Hospital and continued to learn as much as they could about their son's disorder.

For the next three years, Evan was on various medications to control the seizures. "We tried seven to ten different medications," Jynell says. "One worked for a little while."

Accompanying the minimal success of the medicines were harsh side effects. Jeff remembers one occasion when Evan passed kidney stones; he shudders to think of the pain his son experienced. "It was hours and hours. It was terrible. The pain of trying to pass a stone would make him vomit."

Evan was also groggy much of the time and had trouble with speech and coordination. "He was very medicated and there was nothing we could do at that point," Jynell recalls.

Between the seizures and the side-effects of the medication, Evan had a lot of ups and downs at school. "He needed a great deal of support with kindergarten tasks," says his teacher, Kate Tynan. "Evan was still having seizures. Although small, they were still significant enough to be affecting him."

By last spring, Evan's seizures had increased in frequency and severity.

### The Diet

The Kristals called Mass. General and were referred to a new doctor there, Dr. Elizabeth Thiele, director of the pediatric epilepsy program. She recommended the Ketogenic diet and gave them two other options: a chest implant, which would send impulses to Evan's brain to counteract seizures when they occurred, or brain surgery. The Kristals decided to try the diet first.

According to Dr. Thiele, the Ketogenic diet was developed in the 1920s after doctors noted the ameliorative effect that fasting diets had on some young patients with epilepsy. The name "Ketogenic" comes from "ketones," chemicals that the body produces to metabolize fat for energy

when insulin levels are low.

It is not clear how the diet reduces seizures in many children and teenagers — in some cases the diet actually prevents childhood seizures — or why it seems to work best on young children.

Nonetheless, Jynell and Jeff were hopeful.

Jeff thought that if Evan's seizures reduced from 50 a day to 25, that would spell success. "We never thought in our wildest dreams that we'd go from 50 to zero in four days," he says.

Motivated by Evan's swift and surprising improvement, the Kristals continue to adhere to the diet even though it is rigorous to maintain.

"If you get sloppy or lazy, it could trigger a seizure," says Jynell. "We stick to what the nutritionist tells us and the food products that she recommends. Evan sticks to it and I think he understands that he feels better because of the diet."

The Ketogenic diet is a high-fat, low-carbohydrate regimen. Unlike other popular low-carbohydrate diets, the Ketogenic diet is prescribed by a physician, individually formulated, and initiated under medical supervision. Nutritionist Heidi Pfeifer formulated Evan's diet and the Kristals work closely with her in administering it.

Evan has three meals and two snacks per day, but his calorie intake is limited. "We measure and weigh everything to the gram," Jynell says.

Evan's food choices include meats and cheeses, butter, vegetables, and fruit. He drinks cream with every meal. Also, he drinks lots of water to stay hydrated; his level of hydration

and ketones are monitored regularly.

Shortly after Evan began the diet last May, he was weaned off his medication.

## **Progress and Support**

Evan is now experiencing life in a new, exciting way and his progress is noteworthy. "He's reliving a lot this past year that he hasn't been able to do," says Jynell.

"He was in Kindergarten last year but he's repeating it this year," Jeff says. "He has the same teacher and it's great because she sees the amazing results from last year to this year."

"Evan is articulating much better and his energy level has increased," reports Ms. Tynan. "He's right in there with the rest of the kids."

Jynell and Jeff know there is a chance that Evan will outgrow his seizures.

Whether that happens for their son or

not, they have found support in sharing their experiences with other parents who are part of the program at Mass. General.

"We felt that it might be nice to have a support group and that's when we decided to do a 'Keto-Parent Weekend," says Jeff.

The Kristals arranged for their invitations to be sent with a newsletter from the hospital and seven couples were able to stay with them at their inn last November. "It was wonderful. Everybody needed a break first of all, and then just to

body needed a break first of all, and then just to be able to talk," says Jeff. He and Jynell are planning another Keto-Parent weekend this spring.

Having experienced different approaches to medical care, Jeff feels that awareness of the Ketogenic diet is critical. "The diet was never an option. It was only meds. That was it."

"The diet was never brought up because a lot of doctors don't believe in it," adds Jynell.

But from the time Evan started the diet, the Kristals can hardly believe what they have seen.

"Evan started walking up and down stairs, foot over foot about eight months ago," says Jeff. "And he just started writing his name several weeks ago. Every day it has been something new."

"There is nothing holding him back," Jynell says. "He's 100 percent."

For more information about the Ketogenic diet, visit  $www.epilepsy.com\ or\ www.epilepsyfoundation.org.$