Town Couple of Son With SCAD Advocates Screening of Newborns

By CHRISTIE STORMS
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WESTFIELD – When Westfield residents Lauren and Michael Hammer first welcomed their son, Evan, into the world last year, he appeared to be completely healthy. He had his blood drawn, as is required for all newborns under the state mandated newborn screening, which checks for at least 20 known disorders, according to the New Jersey Department of Health website.

Because the Hammers had friends whose children had a rare metabolic disorder, they decided to pay an additional $70 to have a more comprehensive screening that reportedly tests for approximately 30 additional disorders done simultaneously.

Six days later, they were shocked to learn Evan had tested positive for Short Chain Acyl-CoA Dehydrogenase Deficiency.

The Hammers had never heard of SCAD, a fatty acid oxidation disorder. According to the New Jersey Department of Health, children with this deficiency have trouble using fat for energy. This is because a special enzyme, which converts fat to energy, may either be missing or not working properly. If someone with the disorder fasts or goes without eating for too long, medical crises can occur, including vomiting, low blood sugar or even more serious problems such as coma.

The state sent the Hammers to a specialist in Bergen County, who simply told them to feed Evan every 12 hours and he would be fine.

"She really minimized the disorder," Mrs. Hammer said. "But, if you go online and read stories about other kids with it, some of them have died or ended up retarded."

This led the family to pursue second opinions from metabolic genetic specialists Dr. Joan Pellegrino of St. Peter's Hospital in New Brunswick and Dr. Mark Korson of New England Medical Center in Boston.

"Dr. Korson really broke down what Evan had into laymen's terms we could understand," Mr. Hammer said.

The Hammers reported that both doctors took the disorder very seriously and put Evan on a strict regimen of eating every four hours around the clock.

This was reportedly no simple task for the busy Hammer family, which also includes a three-year-old daughter, Alexis. Mr. Hammer works long hours in ad sales for CNN in New York City, while Mrs. Hammer practices clinical social work in Summit and Westfield.

"The first year was tough. We were exhausted. We used to literally write down the time and how much he ate to the half ounce every four hours," Mrs. Hammer said.

Christine Storms for *The Westfield Leader*

ADVOCATING SCREENINGS…Michael and Lauren Hammer of Westfield are shown here with their 18-month-old-son, Evan, who was diagnosed with Short Chain Acyl-CoA Dehydrogenase Deficiency, a rare metabolic disorder detected early by a newborn blood screening, and three-year-old daughter, Alexis.

"Every parent is usually trying to make their newborn sleep through the night," Mr. Hammer added. "So if we didn't know that he had this, we would have, too. And we'd be high-fiving each other not knowing that we could possibly be killing him."

In addition to SCAD, Evan also suffered from several unrelated ear infections and Pyloric Stenosis, which causes projectile vomiting.

"Of all the kids to have a problem keeping food inside him, did it have to be one who has to monitor every ounce of intake?" Mrs. Hammer said.

Evan had to have surgery at seven weeks old to correct the Pyloric Stenosis, and then another surgery at 16 months old to place tubes in his ears. He had to be admitted to the hospital the night before each surgery to take the extra precaution of stabilizing his glucose for several hours intravenously.

The Hammers later learned that Mr. Hammer unknowingly has an asymptomatic version of SCAD, while Mrs. Hammer is only a carrier. After DNA testing, they found that Evan's gene mutation was different than his father's. Therefore, they would never know for sure whether he might also be asymptomatic, but felt they could never take that chance.

Evan is now 18 months old and becoming capable of going without eating for longer intervals. Dr. Korson, who now has him on a schedule where he eats every four hours during the day and is permitted to sleep eight to 10 hours at night, monitors his progress. The American Medical Association's Heart-Healthy Diet is also recommended.

However, according to Mrs. Hammer, whenever Evan gets sick, he must go back to the every-four-hour feeding regimen.

"When he has a fever, his body is breaking everything down faster, and he is at greater risk," Mrs. Hammer reported. "It could just be a cold, but if we can't get him to eat, he would have to go to the hospital just for the IV sugar drip."

When Evan eventually goes to school, he will wear a medical alert bracelet, and the Hammers always keep SCAD protocol literature handy in the car and everywhere they travel in case of an emergency.

Although having a child with SCAD hasn't been easy, the Hammers consider themselves lucky be-

CONTINUED ON PAGE 10

SCAD Screening

CONTINUED FROM PAGE 1

cause they know he has it, and, therefore, been able to prevent serious crisis by taking the aforementioned precautions.

"Unfortunately, not everyone is as lucky," Mrs. Hammer said. "There's a theory out there about Sudden Infant Death Syndrome possibly being related. They're finding out that if a family that lost a child to SIDS now has a kid with one of these disorders, it may not have been SIDS. Maybe the babies had some kind of metabolic disorder and the families didn't know the babies were basically dying just by sleeping through the night without eating."

The Hammers are hoping the state expands its funding to incorporate all of the disorders in the expanded screening into the state mandated one.

According to the Hammers, SCAD is now part of the New Jersey mandated screening, but many other disorders are not.

For more information on SCAD, visit www.fodsupport.org or e-mail laurenhammer@comcast.net.