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## Students put their hats on to raise \$11K

### 5-year-old with epilepsy in need of assistance dog

By **Bill Fortier** TELEGRAM & GAZETTE STAFF  
[wfortier@telegram.com](mailto:wfortier@telegram.com)

**AUBURN**— It all started July 17, 2006, when Alex LeBlanc fainted in a shoe store on a hot day.

At first, it was thought that the heat was the reason — but he had fainted in an air-conditioned location.

That was when Deanna LeBlanc knew something was wrong with her son, who had been healthy up until then.

“Little boys just don’t faint for no reason,” Mrs. LeBlanc said one day last week as Alex, now 5, and his 7-year-old sister, Jennifer, played with their dog, Brady, an 18-month-old bichon frisé, inside their home on Hampton Street near the Worcester line. Alex is in pre-kindergarten at Mary D. Stone Elementary School.

Doctors in August 2006 diagnosed Alex with a severe form of epilepsy called Myoclonic Astatic Epilepsy, also known as Doose Syndrome. Research indicates that MAE affects 1 percent to 2 percent of all youths suffering epilepsies up to age 9.

Alex has to wear a helmet because he can suddenly faint, sometimes 10 to 30 times a day. Since last summer, he has been experiencing potentially life-threatening tonic-clonic seizures, usually between 3:30 and 7 a.m., when his doctors at Children’s Hospital in Boston say he is experiencing his deepest sleep.

Deanna and her husband, Jeffrey LeBlanc, have been experiencing anything but deep sleep because Alex has to be watched closely 24 hours a day. Since the tonic-clonic seizures started, they stay awake during the night in shifts in case they have to take any action when Alex is having a seizure.

Doctors have treated Alex with nine medications in an effort to reduce the number and seriousness of the seizures he gets when he is awake, as well as a special high-fat, low-carbohydrate diet.

Almost 18 months since the first seizure, Alex has not responded to any of the treatments, Mrs. LeBlanc said. As for a prognosis, Mrs. LeBlanc said, she has been told by neurologists that the more severe the symptoms, the less chance a person with MAE has to improve as he grows older.

Because of his condition, Alex can’t do the things children do, such as ride a bicycle or a swing. Those activities could cause him to suffer a serious injury if he falls. His condition prompted the family to get a special brace that straps his body into the bathtub and holds his torso up in case he has a seizure.

There is no warning when Alex is going to have a seizure.

“Nothing tells you it is going to happen,” she said.

This is a story about Alex LeBlanc, but it also a tale about how students in town and other organizations have banded together to help the LeBlanc family raise \$11,000 to get a dog through 4 Paws For Ability, a nonprofit organization based in Xenia, Ohio, that trains and places service dogs. The LeBlanc family hopes an assistance dog will be able to sense when Alex is going to have a seizure and protect him when he does.

The local fundraising effort started at Auburn High School, where students paid \$5 to wear a hat in school for a week, according to Principal Casey J. Handfield. He said he became aware of Alex’s condition because he has two children who go to the Mary D. Stone school. In mid-January, he sent a letter to all the teachers in the school to let them know that if the students donated \$5, they could wear a hat for a week.

Mr. Handfield said that while there haven’t been any problems at his high school, students in other towns have been



Alex LeBlanc, 5, at center, needs an assistance dog because of his frequent seizures. Students at Mary D. Stone Elementary and Auburn High School have pitched in to help raise the \$11,000 needed to get the dog, and the Auburn Police Association is helping as well. At left is Alex’s sister, Jennifer LeBlanc, 7, with their mother, Deanna LeBlanc. (JIM COLLINS)

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caught bringing drugs and guns inside their hats to school. As a result, students are prohibited from wearing hats at both the middle and high schools.

"Hats for Alex" week was the main reason why about \$4,500 has been raised at the high school for the LeBlanc family as of late last week. Alex, according to Mary D. Stone Principal Elizabeth D. Johnson, was a big hit at the high school when he visited about 10 days ago.

"They loved him at the high school," she said.

Auburn Middle School Assistant Principal John J. Giordano III said a recent "Hats for Alex" week helped raise about \$1,100.

The Auburn Rotary Club has agreed to donate \$1,000 to benefit the LeBlancs in their quest for an assistance dog.

Mrs. LeBlanc said the Auburn Police Association has donated \$500 to help sponsor a benefit for the LeBlanc family that will be held from 7 p.m. to midnight March 22 at the Elks Club on Southbridge Street (Route 12). Tickets cost \$20.

Also, a spaghetti supper is scheduled from 5 to 7 p.m. Feb. 28 in the high school cafeteria. Tickets cost \$10, \$7 for students, and supper free for children younger than 5. The high school event will include a silent auction and raffle.

"We're halfway there," Mrs. LeBlanc said late last week about the effort to raise the \$11,000, adding that she hopes to have the entire amount raised by the time the fundraisers are done late next month. More money would be needed for transportation and lodging during a two-week training session with a dog, which Mrs. LeBlanc hopes would take place this summer.

Ms. Johnson said about \$200 had been raised as of Friday at the Stone school to benefit Alex.

"He's a real, real character," she said. "I think he's going to be in local lore. He's like a rock star, and he's handling his disability like a rock star, so it's not a disability."

Information on Alex can be found online at [www.4paws4Alex.org](http://www.4paws4Alex.org). Karen A. Shirk, executive director of 4 Paws For Ability, said she is familiar with Alex's situation. She said the organization works mainly with children and will be 10 years old in October. She said about 30 dogs have been placed with epileptic children and about 260 with children with other neurological disorders, such as autism. She said research has shown that a person having an epileptic seizure gives off a chemical scent that is recognized by the dog. She said the specially trained assistance dogs have about a 75 percent success rate with predicting seizures.

Ms. Shirk said that once the money for a dog and its training have been raised, the LeBlancs would send a T-shirt Alex is wearing when he has a seizure to the organization's headquarters, and a potential canine match for him would sniff it to become familiar with the child's chemical scent.

Ms. Johnson, who is retiring in October, said she looks forward to seeing Alex enter kindergarten at the start of the next school year.

"And he'll be coming with a dog," she said.

Mrs. LeBlanc said she wants her son to lead as normal a life as possible, and it is hoped the dog would keep him safe from serious falls and warn people around him that a seizure may be about to occur.

"I have to say, the fundraising and the efforts of all the people in town have been overwhelming," she said.



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