

THE DAY ADAM'S SEIZURES STOPPED

By Hannah Sutherland - Peace Arch News - May 31, 2008



Adam Martell. Brian Giebelhaus photo

To this day, it still hurts Arlene Martell to look at baby pictures of Adam. The round-faced, beaming youngster with plump cheeks and bright, hazel eyes reminds her of the way her son once was, before the nightmare of his later years. Martell began to lose Adam when he was two. The toddler would line his toys up and build things in perfect symmetry. He liked puzzles. Martell thought he was just smart for his age, not realizing Adam was exhibiting autistic tendencies.

He had his first seizure when he was four. Martell and her husband James returned from a night out to find Adam in bed drenched in sweat, his body contorted to the left. They took him to emergency where they were told Adam had had a seizure, a common experience among young children. But it happened again three months later. This time, Adam underwent an EEG (electroencephalography), a test that measured his brain's electrical activity. Adam was diagnosed with Lennox Gastaut Syndrome, characterized by different types of seizures that attack frequently. He would have hundreds of 'absent' seizures a day, which Martell describes as someone turning a light switch off and on. Adam would suddenly look glazed over, as if in a daydream. They lasted 10

seconds to 20 minutes. Up to four times a week, Adam would suffer full-blown attacks called tonic clonic (grand mal) convulsive seizures. He would sometimes have up to 25 in a row, so quickly that his body would be unable to recuperate before the next one hit. Because he was having so many different seizures, the condition was difficult to treat. From age four to eight, Adam was given various medications – six different ones over a two-year period, and usually two types at one time.

The effect on his behaviour was drastic. Sometimes, he would have violent outbursts and physically hurt other children. Other times, he became lethargic, unable to concentrate in school or follow directions. His teacher kept a couch in the classroom for when he could no longer stay awake. Two of Adam's younger siblings – born within three years of him – couldn't have friends over because of his erratic behaviour. Martell couldn't leave her youngest daughter, just a baby at the time, in his presence, because Adam was likely to step on her. Martell had to lock him in the house, because he would lose his way if he got past the door. On a night Adam did manage to get out, a neighbour found him at 5 a.m., walking barefoot in his pyjamas in a ditch. He was seven years old. No matter what the family was doing, one eye always had to be on Adam. Everything else took a back seat. Between raising three other children and trying to tend to Adam's demanding needs, Martell began to hit her breaking point.

Adam's neurologist suggested he wear a crash helmet and be institutionalized. Martell cried and prayed. She couldn't imagine giving him up, but was desperate for help, for answers. Two days later, she found something that gave her hope.

Right when Martell reached her wits' end, she came across a television program on the effects of a high-fat diet on epilepsy. Called the ketogenic diet, it mimics aspects of fasting by forcing the body to burn fat rather than carbohydrates. To this day, experts don't understand the link between the diet and epilepsy. When Adam was eight, he began to eat only whipping cream, butter, cream cheese and eggs. His seizures stopped.

"It's like he woke up," Martell said. "It was like getting Adam back again." With his medications and seizures out of the picture, Adam's autistic characteristics surfaced, including his obsessive compulsive disorder. When he went to bed, he had to walk the same route through the house to get to his room. In the grocery store, he would turn all of the soup cans so the labels faced out. Martell could never change the Thomas the Tank Engine sheets on Adam's bed. But none of it mattered – she had her son back.

Martell spread the word about the alternative treatment, and helped found the Fraser Valley Epilepsy Society, to provide resources for other families dealing with the condition. Adam continued eating high-fat foods for five years, however, it was too unhealthy to continue – most people only follow the diet for two years.

Every time Martell tried to slowly wean Adam off, he suffered a seizure. She was then approached by Dr. Paul Swingle, who treats brain disorders, and she took Adam in to receive neurotherapy. While Adam concentrated on playing a video game, Swingle used brainwave biofeedback to retrain his brain and bring his brain waves back to normal. Within three sessions, Adam's teachers were asking Martell how he had improved so drastically. After 40 sessions over several years, Adam was off the diet, reading, writing and learning. His autistic tendencies reduced by 90 per cent.

He became more social, remembering 200 of his peers' names at Elgin Park Secondary, and making a point of saying 'hi' whenever he passed them in the halls. It was so amazing to actually see the changes in him and get our lives back to normal," Martell said.

Now 21, Adam even has a girlfriend, who he met through Semiahmoo House Society, an organization that supports people with developmental disabilities. He's still a whiz with puzzles, enjoys punching in numbers on his calculator and is a fan of all sports.

Most of all, he likes trains. He knows when the Amtrak will pass through White Rock, has a collection of train DVDs and loves to visit the Art Knapp Plantland trains display in South Surrey. ADAM leans against the railing to get a closer look as a G-scale Burlington Northern train snakes through a railway on a miniature country hillside. With a large build, short, spiky blond hair and the beginnings of a moustache, Adam is now a gentle young man. However, he still has the same plump cheeks and bright eyes he did when he was eight. "They also have Canadian Pacific engines here," he excitedly tells his mom. She smiles and patiently watches the trains with him.

With Adam seizure-free for 12 years, Martell believes he is ready to live independently and hold down a part-time job. Although she knows he'll always need support, she is confident he can make a life of his own – one Adam insists on having with two dogs and a cat. "He's so happy," Martell says, looking over at her son as he points at the caboose of a particular train. "We can learn from him so much by the attitude he has every day."

Martell is no longer angry it took so long for Adam to receive helpful treatment. But she can't help but wonder what her son would be like if he started the ketogenic diet or neurotherapy earlier. "You still grieve for the loss of a child you would've had." In hopes of making others aware of the options, Martell wrote a book, *Getting Adam Back* (gettingadamback.com), three years ago.

She has also started a website, www.epilepsymoms.com, in her campaign to provide information for other parents of children with epilepsy and autism. "We can't rewrite our story," she says. "I'm not mad about what happened anymore. I'm at peace with it. I just accept him the way he is. "I want to help other parents. Just by telling my story – that's all I need to do. And let them decide for themselves."

Although Adam's childhood was a difficult journey, Martell knows it's important to remember all of the trials and triumphs so others can learn from her experiences. It's one of the reasons she keeps baby pictures of her children hung on the wall of her den – and why Adam is in every one of them.