

Girl

Concert is planned to raise funds

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revealed stroke-like damage. Sarah was left with brain damage, cell-level swelling, muscle stiffening and difficulty breathing. She was placed on a ventilator and received nitrous oxide gas to ease the pain.

Doctors predicted that she would not survive her first week in the hospital.

"For the better part of 30 days, she could have left us," said David Smith, who recalled that returning home to pick up extra clothes was the most difficult part.

"The absence of Sarah in that house — with the thought that we were going to lose her — was completely unbearable."

Although they had never dealt with a situation so serious, this was not the first crisis the Smith family had faced.

About five months after Sarah was born on April 10, 2001, she suffered her first seizure, which lasted about 30 minutes. Doctors told her parents that the seizure could have been triggered by a fever from a common sickness in babies and that it could be treated with medication, which was prescribed after a second attack hit. But the pattern became a concern when she didn't outgrow it. Sarah had developed epilepsy.

The Smith family began working with neurologist Dr. Glen Fenton at Cardinal Glennon. When David and Sandra decided to enroll Sarah at Casa Dia Montessori in Crestwood in the fall of 2001, her stay was cut short after only four months because of concerns about Sarah's daily exposure to such a large group of children. This environment could make her more vulnerable to common childhood illnesses, which could then lead to more fevers.

In January 2002, they decided to move her to a more private setting, despite the worry that it would slow her educational development. Cathy Goldberg, a mother who baby-sits small groups of children during the day, was put in charge of Sarah while her parents worked. Though during her stay Sarah suffered three seizures, she continued to take part in her favorite activities, which included swinging, walking outside, playing tea party with her friend Aleah and playing with dogs such as her own Dalmatian, named Forest.

"You couldn't find a nicer family ... (they're) exceptional people," Goldberg said about the Smiths.

David and Sandra Smith, self-employed for the past 26 years, shared both the responsibilities of parenting and managing their business, Smith-Lee. Their company, which they own along with Barry Lee and Kerry Brown, designs video, audio, Web site and multimedia productions for marketing and training at corporations; it also creates television and radio broadcast spots. In addition, Sandra Smith is an Emmy award-winning music composer for the company.

The costs of managing their business, combined with Sarah's trips to the hospital, presented a financial challenge for the family. In 2002, a neighbor recommended Missouri First Steps, the state's early-intervention program that serves children younger than 3 with special needs.

After a consultation with First Steps, the Smiths were assigned to a team of therapists that included developmental therapist Leslie Elpers. Coincidentally, Elpers is the president of Ability Network, which since 1989 has provided services and support for children with disabilities, ranging primarily from birth to age 3, though they accommodate all ages and levels of abilities. About 70 percent of her business is devoted to First Steps.

Through this program, Sarah's team of therapists focused on all aspects of child development, including what the parents could do to help. Said Elpers, "(We) show the family what they can do ... during their natural routine of the day. It's not the time that we're there doing the therapy ... but the time that we're not there that's important."

During her weekly 90-minute sessions with the family, Elpers had the chance to become close to Sarah and her parents.

"They're just very talented, very unique people who will do anything for their daughter," she said.

Elpers served as Sarah's behavioral therapist for nine months. She initially was called upon when her parents became concerned about Sarah's



Sarah Jane Smith on Christmas Day, 2003.

on our two feet; it felt incredibly important to pray." A prayer service June 6 at Maplewood Christian Church helped to show support for the family and to collect donations.

Through her company, Elpers established a trust fund to help with some of the costs. So far, \$10,300 has been raised. The donations have helped the family afford items that Sarah needs, such as a special chair. Checks can be made payable to the Sarah Jane Smith Charitable Trust Account and mailed to Allegiant Bank, 7801 Forsyth Boulevard, St. Louis 63105.

While hospital bills, therapy and equipment generate a large cost, there also is a cost of a different kind. Said David Smith, "There isn't a lot of time for anything but work and Sarah at this point, but we wouldn't have it any other way ... except that if she had never had this."

Doctors predict that if she recovers, Sarah will have cortical blindness, which refers to brain damage near the back of her head. Her vision seems to come and go; she responds to lights and noises only sometimes.

Therapy proved too difficult initially, as Sarah's back muscles were too tense to transfer her from a hospital bed to a wheelchair. This led her parents to decide to make use of a baclofen pump. This instrument, often used by children who have cerebral palsy, pumps the drug baclofen into the patient's spine; it helps to loosen intensely tightened muscles for purposes such as improving posture.

Although they believe she is conscious, Sarah can express herself only with limited communication, such as slight neck movements, crying and becoming attentive and quiet when her parents speak to her. She is beginning to use her little finger and responds to a lollipop by sticking out her tongue.

Said her father, "She's alive, she's stable, and a lot of the pain has been controlled."

Sarah's progress has been slow, and she will improve only with continued treatment and therapy, a costly process.

The band Sh'Boom will have a benefit concert to raise money for Sarah on Nov. 14 at Orlando Gardens Banquet Center on Watson Road. The event will last from about 6 to 10 p.m. and will include dancing, dinner and a silent auction.

For more information on helping to organize the event, corporate sponsoring or donating items to the auction, call Candace Bingham at 984-0768 or e-mail her at cbingy@hotmail.com.

Reflecting on the past few months, David Smith said, "It's been a long path, even to now. My best recommendation is for all parents to hug their children."

Benefit concert

What: An evening of music by Sh'Boom, dancing, dinner and a silent auction to raise money to help Sarah Jane Smith, 3

When: 6 to 10 p.m. on Nov. 14

Where: Orlando Gardens Banquet Center on Watson Road

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showing signs of aggression and head banging, which may have been related to the seizure medication she was taking.

They worked mostly toward her educational development, identifying colors, practicing types of grasps, matching shapes and colors and using both hands together.

"Before all this happened, she was just full of life," said Elpers. "To me, she was getting so close to getting ready to discontinue the services."

Since her major seizure, Sarah has been receiving treatment from doctors at Cardinal Glennon and pediatric therapists at the Ranken Jordan Home for Convalescent Crippled Children in Creve Coeur.

Sandra Smith said she believed prayer had played a major part in Sarah's improvement. David Smith agreed that religion "played a significant part in allowing us to stand

"It's been a long path, even to now. My best recommendation is for all parents to hug their children."

David Smith, father of Sarah Jane Smith

First Steps

To qualify for assistance through Missouri First Steps, children must be evaluated and have at least a 50 percent delay in one of five developmental areas: communication, learning, self-help, physical and social-emotional. A doctor's diagnosis of a disorder such as Down Syndrome or cerebral palsy also may qualify children.

To learn more about the program or whether your family qualifies for assistance, check <http://dese.mo.gov/divspeced/FirstSteps/index.html> or call toll free 866-583-2392. The program is under the Missouri Department of Elementary and Secondary Education's Division of Special Education.

■ Information about epilepsy also is available from the Epilepsy Foundation of the St. Louis Region at 314-645-6969.