

# 2007 Foundation Awards

## Sandy and David Smith, Clemens Award

*The Foundation presents the Clemens Award, named for Samuel Clemens (Mark Twain), to people who make outstanding contributions supporting the independence of people with epilepsy. Samuel Clemens was devoted to helping his daughter, Jean, who had epilepsy, live as independently as possible.*

Sandy and David Smith are the parents of five-year-old Sarah who began having seizures when she was five months old. She has been on many different medications and the ketogenic diet, but has never had seizure control for more than a few months at a time. Sarah has experienced status epilepticus - prolonged and potentially life-threatening seizures - many times. Despite this, Sarah's development was nearly on track for her age. Sandy and Dave enrolled her in the First Steps Program, and she was expected to catch up by kindergarten.

Then in March of 2004 just before her third birthday, Sarah experienced a rare five-hour seizure. She was in a coma for 28 days and in the hospital for close to four months. She returned home with significant disabilities -

she could not see, move her body, swallow, nor communicate. She could not hold up her head and had no facial expressions.

Through Sandy and David's tireless efforts, Sarah has come a long way since then. She can now hold her head up, is able to eat pureed food, sees well enough to identify objects, smiles, laughs, sings and cries.

In addition to working with the First Steps Program, Sandy and David have used the services of the Regional Center and the Variety Club. They have participated in Epilepsy Foundation parent gatherings and invited Foundation staff to educate the staff at one of Sarah's pre-schools.

They have consulted with the experts at Cardinal Glennon Hospital, St. Louis Children's Hospital and the Cleveland Clinic.

They have taken Sarah to Chicago for 109 hyperbaric oxygen therapy treatments for her brain injury and have started neurotherapy - a type of biofeedback - for her seizures. Sarah will soon have eye surgery, and Sandy and David are considering the possibility of a

vagus nerve stimulator implantation for better seizure control. Last spring and fall, Sarah enjoyed riding horses at the Therapeutic Horsemanship program.

"Because she is so young and because she has already surpassed the prognoses she was given after the big seizure, we have a lot of hope for Sarah's continued recovery and progress. We are always learning about and trying new ways to help her. There are always new medical advances, and there are exciting new treatments in the works for both brain injury and epilepsy. Sarah's will and determination are probably even more important than what medicine has to offer - she really does try hard. Our biggest hope is that she is enjoying her life, and we think she truly is. We want to give her every opportunity to be as independent as she possibly can," says Sandy.

