

SUPER SARAH

Before her third birthday, Sarah had endured 23 episodes of status epilepticus - long, drawn-out epileptic seizures that last from 30 to 75 minutes. Those, however, were just a prelude to No. 24, a relentless five-hour barrage that left this beautiful little fighter in a coma with a relatively small chance of survival.

"The doctors said she had a '1 in 5' chance of surviving," says her mother, Sandy.

Sarah and her family were accustomed to beating the odds. Despite a myriad of ailments and struggles associated with multifocal intractable epilepsy, Sarah was keeping pace developmentally.

"Through those first 23 episodes, she never suffered brain damage," Sandy says. "Prior to this last seizure, she was about six months behind a typical child her age in speech and physical development."

The 24th, as Sandy calls it, occurred on March 28, 2004. During the massive seizure, Sarah suffered collapsed lungs and was on an oscillating ventilator for a week. She remained in a coma for more than three weeks at a local hospital.

Sarah finally opened her eyes on April 22, a day before the birthday of her father, Dave.

"How's that for a birthday present?" Sandy says. "We really couldn't think of anything better than that for his birthday."

Following the most recent seizure, Sarah was diagnosed with hypoxic ischemic encephalopathy (HIE) resulting in cortical visual impairment and quadriplegia. After spending nearly four months recovering at the hospital and pediatric rehabilitation center, she returned to her Crestwood home. Her regular routine includes physical therapy, occupational therapy, speech therapy, and developmental therapy.

To further enable Sarah in her progression, St. Louis Variety has provided a wheelchair from its recycled equipment pool.

"We really, really appreciate it," Sandy says. "Once you get through something like this, the reality of bills sets in. There's so much necessary day-to-day medical equipment that we hit our insurance ceiling pretty quickly. At the time, you don't really think about mobility needs - like a \$5,000 wheelchair."

Your donations to St. Louis Variety could provide a new wheelchair for Sarah. She also needs a feeder seat; a neck support brace to allow her to ride in a car seat; and a special therapy back brace to help support her trunk while she's building her neck strength.



Sarah (in wheelchair) continues to recover from a massive seizure that left her in a coma for more than three weeks. Above right: Sarah before the latest episode. Right: Sarah's father, Dave, received the ultimate birthday present when his sleeping angel opened her eyes.



"This equipment is so important," Sandy says. "If Sarah can get to the point of holding her head up by herself all the time, it really increases her life expectancy."

Life, for now, literally consists of one day and one victory at a time for Sarah and her family. "I thought I pretty much knew what was important in life before this," Sandy says. "But now the important stuff is *really* important."

Activities once considered normal or even mundane have taken on added importance for Sarah and her family. Vital equipment provided by St. Louis Variety can lead to mobility and an enabling independence that makes every day count.

"I thought I pretty much knew what was important in life before this," Sandy says. "But now the important stuff is *really* important."

"Just having the mobility to go places is so nice," Sandy says. "I think it's important that she gets outside her own house and experiences sights and sounds. We went to a restaurant recently. Dave was so nervous about how it would go. About

halfway through the meal, we realized everything was going fine. We all relaxed and it was such a relief. It was so normal and so strange at the same time. We were back to doing something *normal* for the first time in a long time."