

THE STORY OF

Lily's Fund



by Anne Morgan Giroux

One in 100 Americans has epilepsy. One of them is my daughter—a beautiful blue-eyed teenager named Lily.

Like every new mom, I anxiously awaited her first steps as a toddler. Like every toddler, Lily took her share of spills. Often, she would just drop to the ground with no apparent cause for her misstep ... like a marionette whose strings had been cut. But she quickly got up and went on her way.

Eventually, my mother's intuition kicked in and drove us to seek answers to the multiple falls. After many blood tests, MRIs, EEGs and no small amount of anxiety, we found ourselves traveling down an unexpected path—living with a condition called epilepsy.

Over the years, Lily has failed several medications. A vagus nerve stimulator, surgically implanted into her chest, proved futile. And a rigid high-fat, almost-no-carb seizure-controlling diet did nothing.

But today, the right medication cocktail seems to be working. Lily, now 15, has not had a seizure that we know about for three years. I hesitate to brag about it, though. The memories of days when we witnessed dozens of seizures per minute remain painfully vivid.





Lily, opposite in lei and grass skirt, looks on as guests at the 2010 luau enjoy themselves and also raise \$40,000. From left, Robert Golden and Sarah Carlsson; Colleen Penwell, Anne Giroux and Sabrina Frey; and Avtar Roopra. Opposite bottom, Grace and Lily gear up for softball.

THE START OF LILY'S FUND

Lily and millions of others who live with epilepsy deserve more. They need new diagnostic tools, improved seizure-controlling medications and better surgical options. They need a cure. They deserve hope.

One day in 2006, a glimmer of hope showed up in our local newspaper—in an inconspicuous story on a study in *Nature Neuroscience* about a possible epilepsy treatment. We had seen similar stories about new breakthroughs in faraway laboratories, but this one came from an SMPH lab one mile from our home.

Two of the lead researchers, Avtar Roopra, MD, professor of neurology, and Thomas Sutula, MD, PhD, chair of neurology, met with us for coffee. With great passion, and a few scientific words we could not possibly understand, they described their work and the exciting research being done right here at the medical school.

That was the genesis of Lily's Fund for Epilepsy Research. Working with the UW Foundation, we made a personal investment in this life-changing work, establishing a fund to "celebrate and support" epilepsy research at UW-Madison.

What began as a private gift became a public groundswell. When others heard about the fund, they felt empowered to share their personal stories. "My aunt has epilepsy." "My mother died of epilepsy." "My brother suffered from epilepsy." I knew how many people were touched by epilepsy, but I didn't realize how many of those people were so close to me and my family. They are all around us, coping silently with a health

condition that has been relegated to the shadows for too long.

Epilepsy affects more people than multiple sclerosis, cerebral palsy, muscular dystrophy and Parkinson's disease combined. However, research dollars spent on epilepsy pale in comparison.

LILY'S LUAU

With strong encouragement from a circle of friends, we put Lily's Fund—and epilepsy—squarely in the public spotlight. In January 2009, "Lily's Luau" was held at the UW Memorial Union, raising money and awareness. Neurologists, scientists, business leaders, family members and friends came together in their grass skirts and Hawaiian shirts for a common purpose.

Shortly after the first luau, we received an email from Bruce Hermann, MD, an SMPH neuropsychologist.

"I have been in academics for 30 years and have never seen an event like Lily's Luau," he wrote. "We deeply appreciate all you are doing to help us in the fight against epilepsy."

Two guests at the first luau were Colleen and David Penwell, who were invited by mutual friends. Their 11-year-old daughter, Grace, was diagnosed with a severe form of epilepsy when she was two. After multiple medications, combinations of medications and brain surgery, Grace continues to suffer from tonic-clonic seizures on a weekly basis.

Like us, the Penwells needed hope that a new discovery was somewhere around the corner.

"Epilepsy affects my everyday life. I need to know that there's someone right here, right down the street, who is devoted to epilepsy research—someone whose job it is to crack the code," says Colleen.

In January 2010, with the help of the Penwells, we transformed the Memorial Union into a tropical paradise once again. A sold-out crowd of 450 raised \$40,000 for epilepsy research at UW, giving hope to people living with the disease.

FUND A FELLOW

At the second luau, we announced our new goal for Lily's Fund: funding a new research fellowship at the SMPH. A "Lily's Fund Fellow" will work exclusively on epilepsy research and can help the university leverage outside funding, position the school as a leader in epilepsy research, attract new talent into the neurology field and keep the momentum going.

SMPH Dean Robert Golden says, "Lily's Fund is very focused, very effective with a grassroots feel to it. You know that every penny raised is immediately going to be put to good use. We are now on the threshold of a major series of breakthroughs, so the timing is perfect to roll up our sleeves and become rededicated to an enhanced effort to tackle epilepsy."

 Visit lilysfund.org to learn more.

