

# Carrier fights disorder that took his daughter



**C**entral Iowa Merged Branch 352 member **Jason Berkley** of Indianola, IA, turned tragedy into triumph for children with a rare genetic disorder.

In 2006, Berkley brought his daughter, Jamie, then 7, who had Angelman syndrome, to a doctor for a checkup. Angelman syndrome is a genetic disorder that often causes delayed development, intellectual disability and severe speech impairment. It occurs in one in 15,000 live births. Most cases are caused by a missing or malfunctioning part of the 15th chromosome.

Like most children with Angelman syndrome, Jamie also had frequent seizures, so she needed regular neurological checkups to monitor her health.

“We had just been to the neurologist on a Tuesday, and they gave her a clean bill of health,” Berkley said. “Wednesday, she collapsed at school.”

Doctors thought that Jamie was sick due to complications of Angelman syndrome, but eventually diagnosed her with meningitis, an infection of the brain and spinal cord not caused by her genetic condition.

Jamie was non-verbal and could not tell doctors about her symptoms, Berkley said, so the meningitis went undiagnosed.

“Angelman syndrome was a contributing factor,” Berkley said, “because she wasn’t able to verbalize her symptoms. ‘My head hurts’—she couldn’t tell us those things.”

When the meningitis finally was detected, it was too late. On her third day in the hospital, Jamie died.

Berkley and his wife, Cindy, had been considering adopting another child with Angelman, a little girl from Texas named Rebekah, before Jamie died but, stricken with grief, Berkley gave up on the idea. He changed his

mind a few months later, when he happened to see another child with Angelman syndrome in the cafeteria at the school attended by his other children, Lucas and Madison. Disturbed that the girl seemed lost and isolated, Berkley and his children sat with her during lunch.

After lunch, Berkley called his wife and told her he was ready to resume the process of adopting Rebekah.

“There was a girl in Texas who would be lost her entire life unless someone steps in,” he said. After bringing Rebekah into their family, the couple didn’t stop there. They later adopted Mekayla, another girl with Angelman syndrome, as well as Jack, a boy who does not have the condition. Rebekah and Mekayla are now in their teens.

For Berkley, adopting two children with Angelman syndrome marked a transformation from the time when Jamie was born and he felt totally unprepared to be a father to a child with special needs.

“I wasn’t wired for it,” he said. “But you don’t have a choice. This is what you’re given and you have to handle it.”

At first, he focused only on the negatives of Jamie’s diagnosis and assumed the worst. “She’s never going to go to prom,” he said. “She’s never going to get married. She’s never going to have children of her own. I looked at all the things Angelman syndrome robbed her of.”

A trip to an Angelman syndrome conference where he saw other children with the condition changed Berkley’s perspective. He saw children with many different levels of ability and achievement and realized that the diagnosis of Angelman syndrome wasn’t a tragedy.

“There wasn’t a limit to what she was going to be able to do—the only limit was what we were going to help her accomplish,” he said. “It’s like



**Top: Jamie Berkley**

**Above: The Berkleys (pictured from l) are Madison, Jackson, Cindy, Mekayla, Jason, Rebekah and Lucas**

every other child. They all have goals that they eventually reach, and hers were just going to be different.”

Jamie’s needs changed their daily life, and she required extra care that took time away from her older siblings, Lucas and Madison. But Berkley is proud of how it developed their character and compassion. Both siblings escorted children with special needs at their school to a prom for kids with disabilities, and Madison, now in college, works part time as a caregiver and companion for a young woman with autism.

Jamie, Rebekah and Mekayla have changed Berkley’s perspective on work life as well. “I was always driven to make money and work, work, work,” he said. He saw money as an important way to provide for his family, until he realized his family needed his time, too. “I figured out that working all the time got me nowhere. I actually lost out. The time that I lost with Jamie—how much was that worth?”

Berkley has been a hero in other ways as well, including on his route—last May, he rescued a woman who had been attacked and left in a wooded area (see the December *Postal Record*).

After adopting Rebekah and Mekayla, Berkley began an effort to support research on Angelman syndrome by establishing a golf tournament held at the Bright Grandview golf course in Des Moines each year on or near Jamie’s memorial day, Sept. 23, that raises funds for the Foundation for Angelman Syndrome Therapeutics (FAST), a non-profit group that supports medical research.

Now in its sixth year, the Jamie Berkley Memorial Open has raised more than \$55,000 for research about the condition and for treatment of people with Angelman syndrome.

An avid golfer, Berkley began his work on the tournament by lining up a golf club and going to local businesses to ask for sponsors. After sharing Jamie’s story, he found that gathering sponsors was easy.



Letter carriers from the Des Moines area come out in force to support the tournament, he said—almost half the golf teams have letter carriers or family members of letter carriers participating to raise money for the cause.

After Jamie was born, Berkley and his wife had resolved not to have more children because they feared caring for a daughter with a disability would be too difficult with a larger family, he said. But by the time Jamie turned 5, he had learned that Jamie could live a relatively normal life and that the burden wasn’t what he had feared it would be.

Berkley urged others to consider adopting a child, whether with a disability or not. “There are so many children who need a home,” he said. “People should consider going outside their comfort zone and doing something they thought they couldn’t do.”

Children with disabilities who need a new home, he said, “deserve to have the same life that every other child has.”

FAST provides financial support to a group of doctors and researchers across the country seeking a cure for Angelman syndrome. It is the largest non-governmental funder of Angelman syndrome research, and has raised more than \$10 million for research since 2011. For more information about FAST and Angelman syndrome, go to [cureangelman.org](http://cureangelman.org). **PR**

**Above: Berkley raises money by asking individuals to sponsor holes along the course.**

**Below: The funds raised went to support the work of Dr. David Segal at the U.C. Davis Genome Center, where an imaging facility was dedicated in Jamie’s honor.**

