

Madison Reed, 10, beating the odds

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Angels are everywhere in the Reeds' Dublin home -- on walls, over doors, on side tables and kitchen cabinets. All are there for one purpose: to watch over a little girl who lives life to the fullest, even though it could be snatched away at any moment.



Photos by Lorrie Cecil/Villager

Madison Reed takes time out from cruising around her house in her power chair so she can watch her fish. Reed has spinal muscular atrophy.



Kathy Alexander, Madison's teacher, helps Madison with her reading.

Carl and Annette Reed are the parents of 10-year-old Madison Rose Reed and 16-year-old son Kenny. Carl is a social-studies teacher at Dublin Coffman High School. Kenny is a freshman at Coffman. Annette was an obstetrics nurse at Doctors Hospital West but only goes in occasionally as her days are full taking care of Madison, a fourth-grader at Wyandot Elementary School.

Madison is a bubbly little girl who loves angels, princesses, Hilary Duff and computer games. Her daily life includes her family, friends, tutors and a multitude of strangers.

Her life's partners also include a team of doctors and researchers who work every day to keep the little girl with the big brown eyes alive.

Madison has SMA Type 1 (spinal muscular atrophy), the leading genetic killer of children under the age of 2.

The disease destroys nerve cells known as motor neurons, which control voluntary movements such as crawling, walking, head and neck control and swallowing. Most deaths come from lung problems, Madison's mother said.

When Madison was 1 year old, doctors dismissed the idea of providing special equipment to improve Madison's quality of life, and told the Reeds to take their daughter home and enjoy what time they would have left with her.

Annette and Carl dogged the physicians, convincing them Madison was not "the textbook SMA child," and had the right to anything that would prolong her life.

Through their advocacy and the constant care she receives from her mother, nurses and other trained volunteers, Madison celebrated her 10th birthday on Feb. 4.

Madison needs 24-hour care only medical professionals, trained in the treatment of SMA patients, can give. Several times a day, a tube removes accumulated mucus, which would choke her if not removed. Her disease also leaves her susceptible to what would otherwise be minor ailments, said her mother, and she hasn't attended school since last October, when colds and flu spread among her classmates. A tutor works with her at home four or five days a week.

Madison knows she's sick.

"She hears and knows," said her mother.

Madison was hospitalized in January 2006 for 10 days with a severe respiratory virus.

"We almost lost her," Annette Reed said. "This was the worst illness she has been through, and it really took a toll on her emotionally. ... She didn't sleep for days because she knew she stopped breathing."



The Reeds' cat sleeps while Kathy Alexander works with Madison.



Kathy Alexander works with Madison in the family's kitchen.

If her own health problems failed to remind Madison how precarious life is, the deaths of several friends, some who were not as sick as she is, bring that reality to her.

It's not all doom and gloom in the Reed household, however. In fact, the opposite is true.

Madison sleeps until noon, a routine that began during last year's illness, then it's time for a bath, teeth brushing, hair detangling and breathing treatments. Then mother and daughter do a little role playing, with Madison playing Michelle from the old TV series "Full House" and her mother playing one of Madison's friends.

Madison then takes a spin around the house in her electric wheelchair, then settles down to watch a video, work on her computer or talk to Hannah, a friend in Florida who also has SMA, via computer on a daily basis. The girls' both have programs so they can see each other as they talk, Annette said.

The research into SMA1 treatments is promising, Carl Reed said, for children in the early stages of the disease or those who have been diagnosed but show no symptoms.

Ohio State University and several medical centers around the country are in clinical drug trials.

During the study, those with no symptoms remained symptom-free and those with minimal problems showed progress, with many getting out of their wheelchairs and walking.

Because of the advances they see in these children, Reed and other SMA1 parents and researchers are lobbying the National Institute of Health to get the disease included in the newborn screening program.

The news for children like Madison, who have had the disease for a while, is not as promising but research continues, she said.

The Reeds have never questioned the decision they made to do everything they could to keep Madison alive.

"She brings so much joy to us ... the look on her face when she accomplishes something, the ordinary miracles, the things we take for granted," Annette said.

"When you meet these children, especially Madison, they're worth fighting for and helping," said Karen Muraski, a Powell resident and 8-year volunteer with the Angels in the End Zone fund-raiser for SMA research.

When asked about Madison's life expectancy, Annette said matter-of-factly, "Two years old. ... Anything more is a bonus."

Miracle for Madison fund-raiser scheduled:

The Buckeye Hall of Fame Cafe again will be the site of the major fund-raiser for Miracle for Madison Fund, which supports research into spinal muscular atrophy (SMA) at The Ohio State University Medical Center.

From 11 a.m. to 3 p.m. March 10, families are invited to play games at the "Madison's Angels at the End Zone" fund-raiser, with a portion of the proceeds going to the fund.

The highlight for many attendees is the photo booth, where they can have their picture taken with former OSU players Craig Krenzel, Tim Anderson and Simon Fraser. The daytime event will have no admission charge.

At 6:30, the evening event will open with a silent auction, followed by a buffet dinner and live auction.

Reservations are required for the evening portion, with patron tickets \$80 and a table of 10 for \$750.

Call (614) 805-4603 to make reservations or visit the organization's Web site at www.miracleformadison.org to RSVP.

-- Candace Preston-Coy