



Annette Reed and her daughter, Madison, who suffers from spinal muscular atrophy (SMA), share a laugh as they prepare for a promo shot that Madison, 4, would do for WDRB-10TV. They were promoting "Madison's Angels at the End Zone" fundraiser.

Circle of love keeps Madison Reed alive

By CANDACE L. PRESTON
Villager Staff Writer

The bond between a mother and her child is strong. With the first flutter in the womb, an attachment begins that will forever tie the woman to the child.

A mother gives life, with the birth of that child, and she also gives love. Annette Reed knows about love. She also knows about life. Now, she knows about death.

By concentrating on the first two, she works feverishly every day to ward off the latter.

Annette is the mother of four-year-old Madison Reed. She and her husband, Carl, and nine-year-old son, Kenny, live in Dublin. Carl is a social studies teacher at Dublin Coffman High School. Kenny is a fourth-grader at Scottish Corners Elementary. Annette is an OB nurse at Doctors Hospital West.

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Angels at the End Zone out to raise funds for SMA research

The Buckeye Hall of Fame Cafe is once again the site for the major fundraiser for the Miracle for Madisons Fund, which supports research into spinal muscular atrophy (SMA) at The Ohio State University Medical Center.

From 11 a.m. to 3 p.m. on March 10, families are invited to play games at the "Madison's Angels at the End Zone" fundraiser with a portion of the proceeds going to the foundation. There will be entertainment and a sports general store section, including autographed photos of OHSU players and other sports personalities, gift certificates and sports equipment. Attendees can also have their picture taken with current and former OHSU players. There is no admission charge for the day's events.

At 6:30 p.m., the evening event begins with a silent auction, followed by dinner from 7:30-9 and a live auction.

Reservations are required for the evening portion with patron tickets \$75, couples \$140 and a table of 10 \$675. Corporate sponsorships are also available. Call the event hotline at (614) 718-6220 to make reservations. For more information, go to the organization's Web site at www.miracleformadison.org.

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neck control and swallowing. Most deaths come from lung problems, Annette Reed said.

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prove Madison's quality of life, her mother said. Some were "convenience items," like a special chair to help her sit up. Others, such as a nighttime breathing machine, and a feeding tube, kept her alive.

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"Annette's constant devotion and care is certainly the key to making Madison's life better and longer," Carl said.

The devotion comes with a price, though. Madison needs 24-hour care that only medical professionals trained in the treatment of SMA patients can give. While nurses come in one or two days a week to 12-

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That devotion comes with a price, though. Madison needs 24-hour care that only medical professionals trained in the treatment of SMA patients can give. While nurses come in one or two days a week in 12 hour shifts, the rest of the time that duty falls to Annette, a registered nurse. Madison doesn't like to be alone, and can't be left alone because breathing problems could prove deadly in a matter of seconds.

Annette sleeps in Madison's room. She's there when she wakes up, and begins the morning routine that takes several hours, removing secretions that build up during sleep, and feeding her through a stomach tube.



After her bath, where the water gives Madison the buoyancy that gives her more movements, Annette carries Madison downstairs, where she watches her favorite shows on Disney and Nickelodeon.

"Then I get dressed," Annette said.

There are a few mini-breaks during the week when speech, occupational and physical therapists come to the home. And, Madison is tutored by a teacher from the special needs preschool in the Dublin school district.

While some people would head to the mall, a movie or a spa when they got the infrequent 12-hour break,



Above: Nine-year-old Kenny Reed shows his sister, Madison, the tooth he lost the previous night. Madison, 4, who has spinal muscular atrophy, couldn't wait for Kenny to get home. She asked so that she could see the tooth. She had that the tooth fairy would leave Kenny a dollar. He actually received \$5.

Right: Madison celebrates her fourth birthday at Dublin Coffman High School, where her father, Carl, teaches social studies.

Below: Madison and her family and friends walk in the Coffman High School hall to be called into the lecture hall so that they can celebrate her birthday with the Coffman High School Student Senate, which has raised thousands of dollars for the SMA Foundation.

Photos by Kim Riesebeck

Madison's mom heads to Doctors, helping to deliver other women's children.

"It's a way for me to get out and continue to do something that makes me feel good," she said.

While she's had some excellent nurses for Madison's care, it's difficult keeping them, Annette said.

"Many find it hard to sit and watch Madison...It gets frightening at times. I find it hard at times when she has a medical crisis", she said.

Nurses get attached and quit because they don't want to be there the one time Madison does not come through a crisis, she said.

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

It is easy to see why people are attracted to the bubbly four-year-old who loves anything associated with princesses.

"She's so delightful and so much fun," said her teacher, Ann Loehrer. The two do art projects, read stories, sing songs and play games twice a week in Madison's home.

"She works so hard and asks lots of questions," she said.

"Every day with Madison is a wonderful day," Annette said. "She has no bad moods. She doesn't get mad...She gets frustrated sometimes, especially when I can't understand what she is saying."

She's also intelligent and knows her limitations, accepts them without question, and goes on.

"She constantly brings me back to reality", Annette said.

The interaction between the mother and child is continuous and a joy to watch, said "Annette's sister, Michelle Worrellia, who lives with the Reeds and helps out with the cooking, chauffeuring and some of Madison's care.

"It's hard for me to see all that Annette has to do," she said. "She's a very caring person and would do anything for her children...her family."

Madison's illness affects the entire family, especially her brother.

The bond between brother and sister is intense and evident. Madison's eyes light up when Kenny gets home from school. He kneels down in front of her chair, picks up a balloon and the two begin a game of catch.

"He's so good with her, despite the age difference and Madison's limitations," Michelle said. "He was so happy when she was born and extremely sad when she was diagnosed. But now he has accepted it and moved on."



Top: Annette Reed (left) and her daughter, Madison, are in a room in the living room, where she plays with some of the dolls. In the top left, Madison is sitting on the floor with her mother, Annette, and her brother, Kenny. Middle: Annette is reading to Madison in a room. Bottom: Madison is sitting on the floor with her brother, Kenny, and her mother, Annette.

"She's fun to play with," said Kenny, who admits the two sometimes have typical sibling altercations.

"She gets mad at me, and I get mad at her; then we play," he said. "I wouldn't trade her for anything."



Kenny said he worries about his mom and all the time she spends with Madison: "She's in the house for three weeks sometimes."

There are others who make the 4-year-old smile and dote on her.

Neighbor Gwen Dawson pops in several times a week and spends time with the youngster and her mother.

"Madison has her own little personality," Dawson said.

Then there are the people who have helped the Reeds raise more than \$200,000 during the past four years for SMA research at The Ohio State University.

And, said Annette, there are the students at Coffman and other Dublin schools who have made Madison a part of their lives. Each year, Coffman's Student Senate hosts a birthday party for Madison at the school and has collected thousands of dollars for the SMA foundation.

"Every year the party gets better and better," Senate president Meri Sulser said. "I like to think we helped her get to this point."

With all the love and caring, come trying times, too.

"It's hard for us to find time for each other," Annette said about her relationship with her husband. "We love Madison. She's here for us to love and is our main responsibility...Sure we make sacrifices, but I'm okay with it."

"Our lives have definitely changed...I can't go to the bathroom. Can't walk out the door. Can't take a break...But I wouldn't do it any other way. We have to go on."

With the care she's received, Madison "has blossomed," her mom said. The way her doctors wanted to proceed, her "life would be stagnant."

Looking at her daughter through mist-covered eyes, Annette said, "This is what God sent me and what he wants me to do. I used to question what I was put on earth for...This is it."

"When Madison is no longer here, it will be a whole different life, but she could be a teenager before we face that time," said Madison's mom, "or it could come tomorrow."