## Britton student lobbies for friendly fund-raiser

Thursday, March 8, 2007 By CATHY WOGAN ThisWeek Staff Writer

Tears misted Lisa Ford's eyes as she listened to her daughter, Chandlar, share a story of

friendship with members of the Hilliard City School District Board of Education in an attempt to help raise funds for the Miracles for Madison and Friends Fund.

"I'm so proud of her," Lisa said of the 10-year-old who walked to the microphone and lowered it to her height after giving each board member a copy of her presentation.

Chandlar, a student at Britton Elementary where her mother works as a long-term substitute, asked the board if fellow students and staff members could read a book and donate at least \$1 to the fund.

It is Hilliard student's dream to help find a cure for spinal muscular atrophy (SMA) so her cousin and her best friend might live.

A SMA event is coming up on March 10 when a Family Fun Fest is held from 11 a.m. to 3 p.m. at the Buckeye Hall of Fame Cafe followed by the Believe in Miracles dinner and auction from 6 p.m. to midnight, in honor of Madison Rose Reed and her friends.

Chandlar met Madison, of Dublin, through her cousin Sarah Elizabeth Bellish, of Worthington, when the girls were about 3 years old. Now 10, they have all been close friends since preschool.

Madison and Sarah both have SMA.

While Sarah has Type 2, Madison suffers from Type 1.



By Adam Cairns/ThisWeek

Ten-year-olds Madison Reed (front), Chandlar Ford (back, right) and Sarah Bellish have been friends since preschool. Ford has been leading a push for school fund-raisers to benefit research for spinal muscular atrophy, a condition suffered by both Reed and Bellish.

"Everyone with her condition is diagnosed as an infant and most don't survive," Chandlar said. "She is special because she is the only person with Type 1 SMA in Central Ohio."

It is a miracle that Madison is alive, according to Chandlar and Madison's mother Annette Reed.

"Her doctors said that she would not live to see her second birthday," said Chandlar.

Annette said she has been blessed to have her daughter five times longer than the doctors predicted.

"They told us to take her home and make her comfortable," said Annette.

As a mother and a nurse, Annette had no intention of accepting the prognosis. Instead, she has fought to preserve her daughter's life.

When Chandlar came along, Annette said, the girls hit it off right away.

The Fords were asked if Chandlar could come over one day a week and be a peer for Madison so she could have a school-like setting and be challenged by another child.

"She takes her under her wing," Annette said of Chandlar's relationship with her daughter, "and finds things Madison likes to do and they do it together. She is really cute with her. She pays so much attention to her and cares about her a lot."

Rather than viewing her friend as a victim of a fatal disease, Chandlar sees her as a little girl who likes to play on the computer, read and is a lover of cats.

Sarah also works into the friendship equation as they all play together.

Sarah, according to Chandlar, has difficulty walking but is "amazing with her hands."

She said her cousin could probably knit a horse blanket.

"Although we are alike in so many ways, we do have some differences," Chandlar said as she spoke of Sarah and Madison. "For instance, I am a healthy girl who only has to wear glasses and I get to attend school every day. Sarah spends half of her time riding in an electric chair because walking makes her tired."

Every three months, for three days, Sarah is hospitalized for testing and she is involved in a drug study at the Ohio State University.

"Madison can only move her finger tips, a little bit in her arms and legs, and barely her mouth," said Chandlar. "It is sometimes hard for other people to understand what she is saying when she talks, because she can't swallow."

Machines help keep Madison alive.

"The one most often used is the suction, it clears her throat and nose," Chandlar said. "She sleeps with a bipap on her face to get enough oxygen so that she will not stop breathing at night. She has a feeding tube in her belly, because she cannot eat with her mouth. She gets aerosol treatments daily. She has a machine to help her cough."

Annette has to stay close by in case Madison gets choked, but she tries to give the girls a little space so they can play.

She said Chandlar does the things for Madison that Madison expects of her, such as moving her hand if it falls or brushing a loose hair out of her face.

"Chandlar is an old soul," said Annette.

While other friends come over to visit Madison, she said, Chandlar anticipates her daughter's needs.

"She cannot dance, but when I sleep over at her house, she makes me get up and dance for her, I always make her smile," said Chandlar. "She doesn't like it when my parents come to pick me up, she yells at them and tells me to hide so I won't have to leave. We think this is so funny."

Lisa and Annette said battle ensues when the Fords try to collect their daughter.

"It's an ordeal when I pick her up," said Lisa. "It takes half an hour to get her out of the house."

A couple of close calls with respiratory problems and whooping cough have nearly claimed the life of Madison.

"Most people with SMA die of respiratory illnesses," said Lisa.

Neither Annette nor Madison are ready to give up and they take every precaution against illness.

"But we can't live in a bubble," said Annette. "She does not want to be sick, it is scary for her. She wants to live. She will tell you 'I don't want to die. I just want to have fun.'"