

# Health

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## A Mother's Loss Brings Her Face To Face With Baby She Helped Save



(Staff Photo By Jaime R. Carrero)

Mary Lingle holds 7-month-old Jessie Neal, who was diagnosed with MCAD just weeks after birth. Jessie's mother, Christena Neal, looks on after meeting Ms. Lingle for the first time in Flint.

By LAUREN GROVER  
Staff Writer

Two-year-old Candice Lingle painted with watercolors, did cartwheels and tumbled with her sister on a Sunday in early November 1993.

But that evening she went to bed early with a cold, not feeling well enough to eat dinner.

On Monday her parents took her to the pediatrician, and then to a Longview hospital for fluids where she suddenly had a seizure.

By 7 p.m. Candice was dead.

The Lingles were shattered. But more, they didn't know what had happened. Neither did the doctors.

For three months they were given no answers. Then doctors told them Candice had died of a rare fatty-oxidation disorder called MCAD, or medium chain acyl-CoA dehydrogenase deficiency.

"That blew us away," mom Mary Lingle said. "We had both contributed one defective gene, and hadn't known it."



(Staff Photo By Jaime R. Carrero)

Mary Lingle, of Tyler, holds a picture of her daughter, Candice, who died at age 2 from an undiagnosed case of MCAD, or medium chain acyl-CoA dehydrogenase deficiency, in 1993. Ms. Lingle fought for awareness and legislation toward expanded newborn screening in Texas, which passed in 2005 and began in December 2006.

MCAD patients lack an enzyme crucial for breaking down fats in the body - they rely solely on glucose for energy and are prone to hypoglycemia and metabolic crisis.

If treated, people with MCAD can live normally by monitoring their fat intake and sugar levels.

If undiagnosed, the story is crushing: Like Candice, a seemingly well child can suddenly suffer seizures, respiratory failure, cardiac arrest, coma and death.

### **Undetected Killer**

Still in shock over her daughter's death, Ms. Lingle desperately wanted to know whether Candice could have been diagnosed.

Through newborn screening, doctors told her, a simple blood test can check babies for disorders. But in 1993 all states mandated newborn screening to a different extent - some required it for a handful of disorders, some for dozens.

In Texas, newborns were screened for only seven disorders, Ms. Lingle was told. MCAD wasn't included.

"It's something you just want to scream from the mountain tops," she said. "Why don't we have uniform newborn screening across the country?"

Ms. Lingle didn't wait for an answer. Just months after Candice's death she began a crusade to spread MCAD awareness around the nation - and, more specifically, to push for the expansion of Texas' meager newborn screening panel.

She wrote Reader's Digest, Oprah and Montel. She made calls and composed articles telling her story and warning parents about undiagnosed MCAD. She joined the Fatty Oxidation Disorder Family Support Group where she networked with hundreds of other families who had lost a child to MCAD.

And she learned that MCAD was being misdiagnosed as Reye's syndrome and Sudden Infant Death Syndrome, that most families find out they are MCAD carriers after the death of one child and that some 280 babies are born with MCAD in the U.S. each year.

But it wasn't until 2004 when her mission was rocketed by a call to the March of Dimes. The organization had taken up the newborn screening expansion fight in Texas and Lingle was ready to gear up beside them.

"I butted my head against the wall for years," Lingle said. "But it was the March of Dimes that came in and swooped down and did it."

March of Dimes took up the expanded newborn screening cause after the American College of Medical Genetics released a study saying MCAD and 28 other disorders were being detected either post-mortem or when children were very ill - and all 29 were treatable.

With some 400,000 babies born in Texas each year, and screening for only seven disorders, too many abnormalities were going undiagnosed, said Morgan Walthall, Texas' March of Dimes public relations director and a registered lobbyist.

"If we had been screening newborns for MCAD, we could have prevented a lot of mental and physical disabilities, even deaths," she said.

Bill-crafting and discussion began in 2004. Lingle wrote letters to senators and lobbied in Austin. Families who suffered child deaths to MCAD and other disorders testified to state House and Senate lawmakers.

Finally, in April 2005, health bill 790 passed. It allocated \$3.1 million for the equipment and staff to process newborn screening for 27 disorders. Texas newborns would be screened for all of them - first at birth and again at 2 weeks.

March of Dimes and families around Texas rejoiced; their heartbreak eased knowing newborns with disorders might no longer slip through.

"That was a huge step for a state as large as this," Walthall said. "Honestly we have one

of the largest and best newborn screening labs in the country."

### **A Changed Life**

Expanded newborn screening began in Texas on Dec. 6, 2006.

On Dec. 7, state officials tested the blood sample of Jessie Neal, a 2-week-old born in Marshall - just 23 miles from the hospital where Candice had died 13 years before.

Mom Christena Neal received a call from her pediatrician on Dec. 11.

"He said, 'Something's wrong with his blood - I don't know what it is - wake him up and feed him,'" Ms. Neal said. "I was shocked - I got off the phone with him and broke down."

Jessie went in for testing that day. Within two weeks he was diagnosed with MCAD.

Ms. Neal recalls her realization that Jessie's extreme sleepiness as a newborn was a quiet sign of metabolic crisis.

"I pushed and pushed and pushed Jessie - dipped him in water, stripping him down. He wouldn't get up for nothing. I was determined he was going to eat," she said. "If I hadn't force fed him there's no doubt he would have died."

Now 7 months old, Jessie is a smiling, giggling baby. He's limited to 30 grams of fat a day, has regular blood sugar checks and can't go without food for more than four to six hours.

But he's healthy and alive.

Last week Ms. Lingle met Jessie and Ms. Neal for the first time; they had been in contact through the online FOD support group, but had never met in person.

"It gives me just cold chills," said Ms. Lingle, smiling, as she looked over at Jessie, the first child in Texas to be diagnosed with MCAD through newborn screening.

Ms. Neal said it was amazing to find the person who pushed for expanded newborn screening in Texas and saved her baby's life.

"If they hadn't caught this he would have died within a month," she said to Ms. Lingle, as Jessie bounced on her knee. "I would have been right there beside you - trying to get the word out."