Morgan Bartel plays with her 4-month-old son, London Crowne Bartel, recently at Blue Bonnet Park. It was discovered shortly after his birth that London was born with a condition known as MCADD — medium chain acyl-CoA dehydrogenase deficiency — and is unable to store energy from the food he consumes.

MCADD a silent killer for many

Story and photos by Rachel Coleman

At the age of 4 months, London Crowne Bartel looks like the flourishing, healthy baby he is. Yet when his parents, Colton and Morgan Bartel, look at their son, they know that only hours after his birth, he was a pinprick away from death.

Born with a condition known as MCADD — medium chain acyl-CoA dehydrogenase deficiency — London is unable to store energy from the food he consumes.

“His body is unable to fast,” said Morgan, “and that means he has to eat every three hours. Everything he eats, his body burns. He can't convert stored fat into energy. If he doesn't eat, his body goes into crisis.”

Luckily for London, a routine pinprick blood test performed at Southwest Medical Center alerted his pediatrician, Nargis Husainy, to the possibility of MCADD.

"Morgan was still in recovery from childbirth, and I was in the nursery when our pediatrician said, 'There's something you should know. I think there might be a problem,'" recalled Colton. "When Morgan heard that —"

" — I was a basket case," she said.

The parents' panic at the news quickly turned to gratitude.

"Our baby could have died," said Morgan. "If they hadn't noticed and done further testing and we had just gone home, he could have died. Finding out saved our baby's life."

Although a simple set of blood tests is conducted for all newborn babies, the unusual results that showed up in London's lab work required an additional test, which cost the Bartels "about $25," said Colton. That test confirmed what Dr. Husainy suspected: London had inherited a recessive or "hidden" genetic disorder carried by both parents.

"MCADD is one of those silent things that can kill a child without anyone ever realizing what was wrong," Morgan said. "A lot of babies who died from SIDS (Sudden Infant Death Syndrome) turn out to have had one of the types of MCADD."

MCADD's symptoms are difficult to distinguish from ordinary infant behavior: the body's inability to store energy can result in extreme sleepiness, irritable mood and poor appetite, often

interpreted by parents as a baby simply being fussy. But the collection of seemingly innocuous symptoms can set off a metabolic crisis, in which the child with MCADD develops breathing problems, organ failure, seizures, coma and possibly death.

"London could have died within a week," said Morgan, "and we wouldn't have even known anything had been wrong."

Some children with MCADD avoid death, but the disorder exacts a high price. Repeated episodes caused by the metabolic crisis that result from the body's inability to store and use energy can cause permanent brain damage that may lead to mental retardation, learning problems or damage to muscles, known as spasticity.

That won't be the case for London, whose parents tackled the challenges of life with MCADD with a fiercely positive commitment.

"I was upset about it, yeah, for a few days, maybe a week," Morgan said. "It was not exactly a grieving process, but just asking why this happened and not feeling sure how to make our way." Through consultations with specialists at University of Oklahoma, the Bartels learned the details about how best to care for London.

"At first, it was really scary, but then I realized it's simple," Colton said: "Feed him. A lot." Unlike many parents of newborn babies, who long for a night of uninterrupted rest, the Bartels are committed to limiting sleep. Colton takes the night shift, waking every three hours to feed his son.

"At nine months, we'll be able to stretch that out to four-hour shifts," he said, "but I'll still do all of the feedings at night. The longest he'll ever be able to go (without eating) is probably six hours."

Neither parent resents the limitations imposed by MCADD.

"When I was pregnant, we talked about getting the test for Down Syndrome, and decided not to do it," said Morgan. "It wouldn't have made any difference. We were going to have our baby and love our baby, no matter what."

Now, she said, they still consider themselves "so lucky," she said. "You go to the children's hospital and see all these kids with braces and wheelchairs and disabilities … all London is going to need is a sturdy fork."

Online networks brought further companionship and comfort to the Bartels, enabling them to reach a place of thankfulness rather than grief.

"Thank God for social media," Morgan said. "We haven't met anyone, in real life, with MCADD, but I have all kinds of friends online who share their experiences with me. It makes the process easier."

The abundance of information online, however, was a mixed blessing, said Colton.

"Dr. Husainy told us right off, 'Don't go on the Internet and start reading,'" he said. "Of course, that's the first thing we did, and it turned out that half of what we found was incorrect."

The impulse to do research was natural for the couple. Throughout the pregnancy, Morgan gave in to her impulse "to be overly safe," she joked.

"It was just one of those things that I've come to expect," said Colton said with a laugh. "We'd be driving down the road and she'd be rattling off these random facts about pregnancy and babies. I'd just listen."

Once MCADD became part of the family's story, Morgan applied the same zeal to understanding and adjusting to the disorder. Since London's condition dictates that he must consume a steady supply of fat and energy, it's important that he stick to "heart healthy" foods.

He will have to follow that protocol all his life, so his parents decided to start early.

"We're learning to eat the way he is going to have to eat," said Morgan. "I'm a major junk food and sweets person, I have never liked vegetables, and I just ate my first mushrooms ever yesterday. I'm going to learn to eat healthy."

It's amazing, she added, "that this little 4-month old baby is already teaching our family to live healthy, without even knowing he's doing it."

Not everyone understands the delicate balance dictated by MCADD. If London gets sick, for example, "He can't wait in the emergency room for long periods of time, just because he looks like your average sick baby," said Colton. The couple carry emergency protocol letters with them at all times, in order to communicate the urgency of quick treatment.

"Everyone goes to the ER thinking their child is the number one priority," said Colton, "But I actually have a letter that says he is."

Fortunately, the Bartels have not had to pull out the emergency protocol letters. London's physical condition matches his happy, high-energy spirit. He loves being outdoors. He displays a fascination with giraffes — the live kind at the zoo, and the stuffed variety as well. He has begun to teethe "and he gives us these big, gummy smiles," said his mother. "There's not a day that goes by that we don't feel thankful to our doctor and to the hospital for catching this. They did, so now we get the joy of getting to hold our baby and watch him grow up."