

Handled with care



Advocate staff photo by ARTHUR D. LAUCK Susan Heard Crawford gives daughter Mary Kate, 4, a kiss at Pediatric Health Choice. Mary Kate was one of the first children at the new children's health center, the first of its kind in the state.

Pediatric Health Choice provides skilled care for medically fragile children

By Ellyn Couvillion
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Mary Kate Crawford, 4, was born with a very rare illness, called Aicardi syndrome. "She's the only child known to be living in Louisiana with Aicardi syndrome," her mother, Susan Heard Crawford, said.

In the syndrome, which affects only girls, the structure that connects the two sides of the brain is missing, so that the left and the right side can't communicate with each other, Crawford said.

"Anything you consciously develop, any kind of coordinated effort that you have to learn" isn't possible, she said.

The life expectancy for children with this syndrome, also marked with seizures and blindness, is, on average, 8 years, Crawford said.

"At home we call her 'Kate.'" In medical situations, we call her Mary Kate," Crawford said. "It's a blessing to say the 'Mary' part."

It also helps differentiate Crawford's daughter for her doctors and their staffs — the name "Kate" became a very popular name about the time her little girl was born, Crawford said.

In addition to her family and team of doctors and other health professionals, Mary Kate is cared for by another kind of family, the caregivers at a new children's center in Baton Rouge, Pediatric Health Choice.

Pediatric Health Choice, the first children's health center licensed in Louisiana under regulations established in 2009, has been serving medically fragile children since shortly before Christmas last year.

Located on Drusilla Lane, the center serves children from birth to age 21 who have a skilled nursing need, said Donna Thomas, a speech pathologist and administrator of the center.

Based in Tampa, Fla., Pediatric Health Choice also has centers in Florida and Pennsylvania.

The children, teens and young adults the staff at the centers care for could have a tracheostomy, a surgically created breathing hole in the neck, be on oxygen or have a feeding tube or other medical needs, Donna Thomas said.

“Nothing is done without a medical order. Each child has their own team for the day that’s charting all day long and have a report for the parents each day,” Thomas said.

“We’re in constant communication with (the child’s) physician,” she said.

There are other, intangible benefits for the children.

“These children would not have an opportunity for socialization. They learn to interact with other children,” Thomas said.

Baton Rouge’s Pediatric Health Choice location is open from 7 a.m. to 7 p.m. on weekdays.

A Medicaid-paid center, it provides what private-duty nurses would at the children’s homes, Thomas said.

The children’s parents are experts, themselves, in their children’s care, she said, and Pediatric Health Choice is another source of support for the children’s parents.

Many times having the center means that a parent can go back to work or spend one-on-one time with their other children, she said.

“There’s stress, it’s hard on the parents, and it can be very difficult on marriages,” Thomas said of providing care for a medically fragile child.

“Lots of parents feel somehow responsible, guilty. This is not their fault. They didn’t ask for this; the kids didn’t ask for this. The parents need support; they can’t do this 24/7,” she said.

“We’re not a respite center, but we certainly provide a respite time for the parents,” Thomas said.

Decorated in bright colors, with rooms for physical therapy, “quiet” rooms with beds for the children, and learning labs for school-age children are located around a spacious central activity area in the center that’s staffed by nurses and other health-care workers.

There’s lots of natural lighting from plenty of windows, and an outdoor play area will be added soon.

“The idea is to be a totally normal setting,” Thomas said.

“We want them to maximize their potential, whatever that potential might be,” she said.

Parents bring the children to the center or the children can be picked up at their home in a medically equipped van.

Even that brings a sense of normalcy for the children, Thomas said. Their siblings get on a school bus, and they do, too, she said of the children cared for at the center.

Susan Heard Crawford, whose daughter Mary Kate attends the center, said that, in addition to providing the medical care her daughter needs, Pediatric Health Choice made it possible for her to continue in her job as assistant attorney general at a point when she thought she wouldn’t be able to.

Crawford, who also has an older son and a younger daughter, took unpaid leave for several months after Mary Kate was born, caring for her with the help of family and home-health nurses.

Crawford was eventually able to use flex-time to return to work, with her support system, and use one day a week to take her daughter to doctors’ appointments, she said.

As Mary Kate grew older, the board of a local church nursery voted to have Mary Kate attend there, Crawford said.

And, then, this school year, Mary Kate went to prekindergarten at the Southdowns Preschool Center, which serves children, ages 3 and 4, who have special needs.

Earlier this school year, Mary Kate came to Pediatric Health Choice after school, and will be at the new center now, Crawford said.

“It came to fruition just in the nick of time,” she said of the opening of the children’s health center.

“I love it,” said Jordan Washington, mother of Michael Skipper, who’s 9 months old.

Michael was born three months early and has some problems with breathing. He receives oxygen and is on an apnea monitor, Washington said.

She stayed home with him after his birth and had the help of home health nurses and family members, she said.

In March, Michael was able to begin coming to Pediatric Health Choice. His medical staff will be trying to wean him off of oxygen in the near future as he matures, said his mother, who’s been able to resume her career as a hairstylist.

Kiola Skidmore’s son, Durell Green, 2, underwent surgery and therapy as an infant to correct a part of his intestines that wasn’t functioning.

Today Durell, a friendly little boy, has a feeding tube, which he’ll have until the age of 5, his mother said. His parents are looking forward to his being able to enter school at the regular time, Skidmore said.

Of her son’s time at Pediatric Health Choice, Skidmore said, “It’s some kind of normalcy. He can develop like other kids, instead of being (overly) sheltered.”

When she brings him to the center every day, he just says, “Bye, mom!” and heads off to play, she said.