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Straight from the heart

Couple opens home to man with Cornelia de Lange, a rare birth defect

By Michael Hines/Times Record News
April 29, 2007

Of all the things keeping Jeremiah Caudillo from enjoying life - his inability to speak, the chance of choking every time he eats, being 21 yet easily mistaken for a 9-year-old - a little thing like rain wasn't about to dampen his fun, if he had anything to say about it.

Caudillo has Cornelia de Lange Syndrome, a condition once considered rare. Researchers now believe the disorder occurs much more frequently than previously thought, and advocates want people to become more aware of that fact. Mickey and Barbara Galyean have joined the advocacy ranks.

"People look at Jeremiah, especially children, and I always try to smile and let them know 'It's OK. You're curious,'" Barbara said, explaining those are moments to teach people. "I try to put out as much information in the schools."

The Galyeans have taken Caudillo into their home. On a day like April 17, it was hard to keep him in the house.

As rain continued that morning, Caudillo grunted and shuffled from the patio and toward the downpour. He pulled on Barbara. His hunched stature made him seem like any other preteen dressed in khakis and a paper bag-colored Tony Hawk skateboarding T-shirt. But some differences were obvious.

His favorite foods include a mishmash of souffles, from carrot to pumpkin, partly because meat can easily choke him. When pulling wouldn't work, Caudillo at one point pinched Barbara to relay his displeasure at being kept indoors. Later, he erupted into a wail. Convinced he wouldn't be allowed outside, Caudillo began undressing as a sign he was ready to take a shower. Finally, Barbara took out a picture from a collection in a plastic container on her counter. The photos serve as reminders of the day's activities, and this picture showed Caudillo playing with toys. Thus prompted, he headed to his room.

The struggles to communicate and keep the 21-year-old on task can get frustrating, said Barbara.

But, her husband explained that Caudillo's determination to have his way is what's made him such a big part of their home and heart.

"He never gives up. If he wants to do something, if he sees something or wants to go outside, he will approach it from so many angles," said Mickey Galyean. "The little guy doesn't know anything but to keep going.

"Everything he does has to come from his heart."

The unique family arrangement was as much of a surprise to the Galyeans as anyone. Both admit that they're stumped as to exactly why they agreed to care for the young man for the next two years. That's when he becomes ineligible to go to school and will have to go into a group home.

What's not in doubt for them, though, is the importance of their work.

"The Lord is definitely in control here," Barbara said. "Sometimes in the



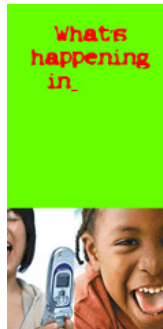
Jeffrey Haderthauer/Times Record News

Mickey and Barbara Galyean walk down a path near their rural Wichita County home with Jeremiah Caudillo, who has Cornelia de Lange Syndrome. Caudillo, who is 21, has the appearance of a 9-year-old because of the rare genetic disorder.



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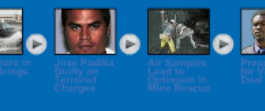
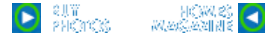
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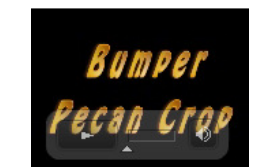
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midst when it can get tough and demanding, at no time have I ever thought this was not what I'm supposed to do."

In January, researchers at the Children's Hospital of Philadelphia announced the discovery of a gene that caused a milder form of CdLS. The form was so mild, in fact, that researchers concluded that physicians were probably misdiagnosing those with it as developmentally delayed or simply mentally retarded.

"It's not that CdLS happens more, it's that they're finding it more," said Marie Malloy, spokeswoman for the foundation.

It's now believed that 20,000 people have the disorder without knowing it, said Marie Malloy, spokeswoman for the CdLS-USA Foundation. The foundation serves about 2,300 families. There are 145 Texas families, with two in Wichita Falls. The Galyeans became one of those families in an unusual way.

Barbara, a former educator, and Mickey, principal of Kate Haynes Elementary School, already had one son who is now 40. While serving as an educational diagnostician in the Burkburnett Independent School District, Barbara came across Caudillo eight years ago.

Something impressed her, and she soon met his family. Barbara agreed to keep him overnight during weekends to provide some respite care. About four or five years ago, when Caudillo's father was transferred to an Air Force base in Virginia, the Galyeans visited and kept him at their home during the summer. Once his father retired this year, Caudillo's family was spreading across the country: a brother stayed in Virginia to finish school, another brother went into the Marines, his parents were going to Oregon.

"This was going to be such an upheaval for Jeremiah," Barbara said.

To counter the problems Caudillo would have endured, Barbara decided to bring the 21-year-old into her home.

"I said 'I'm going to bring a special-needs guy home.' My husband said 'OK,'" she said.

The decision came just three years after their last child had left the home.

"I wasn't sure what to expect," Mickey said.

Since bringing Caudillo into their home, the Galyeans have made many adjustments. Nights out are now out of the question, while schedules must be coordinated because it takes both guardians for any sort of trip. Caudillo still is not potty trained. He copes with a narrow esophagus as well as poor vision and hearing. Like many families dealing with the condition, the Wichita County couple faces many expenses.

"It's a new world for me," Barbara said, explaining the need to set up services such as Social Security as well as specialists for gastroesophageal reflux and eye problems.

And for all the work put into caring for him, the Galyeans know he likely won't recognize their efforts. That comes through just judging by his reaction to Barbara's chicken incubator. The plastic tub sits near the breakfast nook and has about a half dozen chicks clucking and chirping around under heat lamps.

"He could care less about them," she said. "He comes and looks in at them, but then that's it."

Regardless, though, the arrangement has been rewarding.

"We feel fortunate that we have a chance to maybe make a difference in his life," Barbara said. "This was so unique and unexpected. We didn't go out and say 'We have an empty nest, we need to fill it.' The way things happened, it just evolved. ... He's our life now."

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Background facts

Dutch pediatrician Cornelia de Lange first described the collection of features for the condition that would come to bear her name in 1933. Sometimes called Brachmann-de-Lange Syndrome, it affects about one in 10,000 births. Characteristics include low birth weight, slow growth and small stature, small head size. Facial features include thin eyebrows that can meet at the middle, short upturned nose and thin, down-turned lips, according to the CdLS-USA Foundation. Other frequent symptoms include excessive body hair, seizures, heart defects and developmental

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delay. A random mutation of genes causes the condition.



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