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Taking care of Brendan

Boy's rare disorder keeps his family busy

By Teresa Dunham
The Winchester Star

Winchester — The first time Michelle Rees called her baby's name, he didn't respond to her voice.

Even when she looked into his eyes, he didn't seem to connect with her.

"He wasn't bonding with me, and I was nursing him. It broke my heart," she said.

These weren't the fears of a first-time mother. Brendan was her seventh child.

"I knew there was something wrong. Mother's instinct," said Michelle, who lives off Senseny Road with her large family. "I noticed right away, but none of the doctors believed me."

As Brendan grew, he wasn't hitting his typical milestones — and he didn't look like her other children.


It wasn't until Brendan was 16 months old that a doctor diagnosed him with Cornelia de Lange Syndrome.


"He was diagnosed by physical features,"




Brendan Rees, 8, gives brother Bradley, 6, a piggyback ride. When he was 16 months old, Brendan was diagnosed with Cornelia

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she said.

In
Brendan's
case, the
physical
features

de Lange Syndrome, signaled by his physical features: prominent eyebrows, long eyelashes, upturned nose, and small hands and body.
(Rick Foster)

include prominent eyebrows, long eyelashes, upturned nose, and small hands and body.

He also had a characteristic degree of mental and behavioral delays, as well as limb problems, severe reflux, and bowel abnormalities.

"It was a whole gamut of emotions when we heard the diagnosis," Rees said. "There's a mourning process you go through. It took me about two months to stop crying."

Yet she's thankful to have a name for what's wrong with her son. The diagnosis helped her to understand why his feet are turned inward and why he bangs his head when he gets angry.

It also explained why Brendan, now 8 years old, has trouble communicating. At times, when he becomes overwhelmed, he gets down on all-fours and starts barking, she said. "He's playing doggie. That's him shutting down."

Brendan can write his name and little words, make a sandwich, dress himself, and ride a bicycle without training wheels — but he's still far behind his peers developmentally.

He fixates on items such as toy cars or keys. Or, on the opposite end of the spectrum, he sometimes becomes aggressive when he doesn't get his way — pinching, pulling hair, spitting, screaming, kicking, or throwing himself backward.

Michelle pointed to some scars on her arm.

"That's from him getting upset," she said.

Raising a special needs child keeps Michelle and her husband Mike Rees constantly on the go.

"This is a family effort," said Michelle.

Brendan is the seventh of eight children, so his siblings ages 6 to 16 are active in his life.

"It's very cool having him as a brother," said Danielle Rees, 13. "As a sister, I don't see any difference in him, but when we go in public I wonder if people see a difference in him."

For the eldest child, Ashley Rees, having Brendan insist on talking to her while she's chatting on the phone can be difficult at times.

"It's interesting," the 16-year-old said. "My friends



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Brendan Rees gets support from his sisters (from left): Emily, 10, Danielle, 13, Courtney, 13, Ashley, 16, and Brittany, 15.

(Rick Foster)

Michael Rees, 11, said it's not always easy sharing a room with Brendan. "It's fun, but he can be annoying sometimes. He never picks up his

stuff."

Sisters Courtney, 13, and Brittany, 15, and Emily, 10, agreed that living with Brendan has taught them patience.

"It's a blessing on our family to have him," said Brittany.

The youngest sibling, Bradley, 6, has a more challenging relationship with Brendan than the older children.

"Sometimes he kicks me and bites me, and sometimes he takes my [toy] car," said Bradley.

Brendan is probably more aggressive with Bradley since they're the closest in age, Michelle said.

"Brendan lashes out at him the most," she said.

After Brendan's diagnosis in October 2000 by the medical director of the Cornelia de Lange Foundation, the foundation asked if Michelle would like to be an awareness coordinator for CdLS.

"He's my son, and I'm his voice," said Michelle, who immediately accepted the foundation's request.

The CdLS Foundation, based in Connecticut, has 123 awareness coordinators such as Michelle in 41 of the 50 states.

Awareness coordinators are needed because so many children still go undiagnosed for the syndrome, said foundation spokeswoman Marie Malloy.

She estimates that 1 in 10,000 live births have CdLS — and statistically, about 20,000 children are undiagnosed.

Brendan went to several doctors before anyone diagnosed him, said Michelle.

"They've either never heard of it or or briefly studied it in medical school," she said.

The syndrome isn't hereditary, Michelle said, though differences in a set of three genes are believed to be connected to CdLS.

A Dutch pediatrician named Cornelia de Lange discovered the syndrome in 1933, she said.

To spread awareness, Michelle often posts fliers in doctors' offices and makes public presentations.

Meanwhile, she must keep up with Brendan's many doctor visits.

He sees a neurologist, gastroenterologist, internal medicine specialist, urologist, and ear, nose, and throat specialist at Washington (D.C.) Children's Hospital.

He also sees an orthopedist for his feet at Johns Hopkins in Baltimore.

Having the CdLS Foundation there to guide Michelle to the right doctors and answer her questions has proven invaluable.

"I couldn't parent Brendan without the foundation," she said.

On the Internet. . .
www.cdlsusa.org

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