“Speak up for those who cannot speak for themselves”

Proverbs 31:8

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SPLAD CLUB ANNOUNCEMENT:
Be on the lookout for our upcoming SPLAD events. Like our Andrews SPLAD Facebook page for announcements. Club officers will be stopping by your classes to invite you to events and we will keep you posted with posters hanging around campus!
Why won’t she talk? One mother’s journey to find her daughter’s voice

Raleigh, N.C. — By age 3, most children can say Heather Waite’s daughter can say seven.

At 3½, Rebecca Lynn Waite communicates mostly through grunts – repetitive “ah ah ah” sounds her parents and 6-year-old sister have learned to embrace. When she does speak, the few words she can say, like “mama” and “dada,” sound more like baby talk. Rebecca Lynn isn’t delayed. She doesn’t have a learning disability or autism. And, no, she won’t simply talk when she’s ready, her mother explains to curious strangers and well-meaning friends.

"She wants to be ready. She just can’t," said Heather Waite. Waite says she first suspected something might be wrong when Rebecca Lynn was 6 months old.

"Someone said to me, 'Oh, she’s the quietest child. You never hear a single word from her,’” Waite recalled. "I thought to myself, ‘Interesting. Most babies are kind of loud, if you think about it.’"

As a baby, Rebecca Lynn never babbled or made a sound, other than crying. By age 1, when other children in her preschool were calling out for their mothers and fathers, Rebecca Lynn was silent. She’s just delayed, Waite thought.

By 18 months, when Rebecca Lynn still hadn’t said her first word, her mother sought help from an early childhood program. "They assessed her and said, ‘Yeah, she’s definitely delayed. We’ll start speech therapy sessions right away,” Waite recalled.

Four speech therapists later, Rebecca Lynn still wasn’t talking. At preschool, her classmates surged ahead, quickly adding new words to their growing vocabularies. Rebecca Lynn remained silent, often playing alone in the corner.

After turning 2, Rebecca Lynn was finally paired with a speech therapist who figured out why she wasn’t talking. Waite vividly remembers the therapist’s words: "I really think she has apraxia. Don’t look it up on the Internet ... You’ll get scared.’’

What is apraxia?
Childhood Apraxia of Speech, known as CAS or apraxia for short, is a neurological speech disorder. Children diagnosed with it struggle to say syllables and words because their brain has trouble directing the muscles in their mouth to move.

It’s not a matter of muscle strength or intelligence. Children with apraxia understand language and want to respond, but their lips, tongue, jaw, face and other muscles struggle to get the message from their brain to make the necessary movements for speech.

Researchers estimate one or two out of every 1,000 children have apraxia, but not much data about the disorder exists. There are also varying levels of apraxia, from mild to severe, and getting the correct diagnosis can be difficult.

"The way it works in the brain is very, very complex," said Cindy Crockett, a speech/language pathologist at Wake Pediatric Speech Therapy in Cary. "It’s something rare we don’t see a lot.”

Crockett has spent more than 20 years helping people with speech disorders. She started treating children with apraxia two years ago and can count the number of apraxia clients she has on one hand. One of those is Rebecca Lynn.
"She's really trying. She's working at it," Crockett said. Since they began working together earlier this year, Rebecca Lynn has added five more words to her vocabulary. In addition to mama and papa, she now can say purple, blue, sissy, ball and bubble. Her pronunciations are a work in progress – for example, bubble is "buh-boo," ball is "bah" and purple is "pur-puh" – but any progress is welcomed and celebrated.

"The most important part is to repeat, repeat, repeat," Crockett said. "We're forging those neurological paths to make it easier and more automatic."

Mild, moderate or severe?

Children like Rebecca Lynn who undergo frequent, intensive therapy can make improvements, but how much depends on the child and the severity of their disorder.

"If you catch it around 2 or 3 (years old), you're looking at three to five years of therapy," Crockett said. "It's a marathon. It's not going to happen quickly."

Children with a mild form of apraxia can have occasional problems pronouncing words but otherwise sound normal. In some moderate cases, children struggle with sounding robotic because they pronounce each syllable one at a time, with equal stress. In severe cases, they have to rely on sign language or other ways to communicate.

The severity of Rebecca Lynn's apraxia is still unknown.

"Usually, around 6, 7, 8, that's when you'll be able to tell what the future looks like for them speech wise," Waite said.

In the meantime, Rebecca Lynn has several outlets to express herself. She uses basic sign language to ask for things like milk or to say "please" and "thank you." If she needs to say more, she touches pictures on her iPad, which speaks the words for her. And then, there's the grunting.

"It's not easy hearing her 'ah ah ah ah ah,'" Waite said. "I mean, it's all day long. You get frustrated. You get annoyed. You just want her to say what's on her mind."

While it may be difficult to hear the constant grunting, Waite encourages family and friends to be patient with Rebecca Lynn and understand that she does want to talk. That advice even goes for her 6-year-old sister.

"In the car, Rebecca Lynn will be going, 'ah ah ah ah ah,' basically asking her sister how her day is, and Samantha's just like, 'Rebecca Lynn, I can't understand you. It's too much noise. Stop,'" Waite said. "I just have to remind her, 'Hey, remember, she really wants to communicate. She thinks she's communicating with you. Any noise coming out of her is appropriate. We shouldn't shut that off.'"

Dealing with careless comments

Since her daughter's diagnosis, Waite has found a community of support online and often chats with other moms in apraxia parenting blogs. There, they can ask questions, share what's worked for them and commiserate about the difficulties of dealing with apraxia.

Waite also lends her support locally and is helping to coordinate the 2015 Triangle Walk for Apraxia this Saturday in Apex.

One of the many difficult things about dealing with apraxia, Waite says, is that people can't tell Rebecca Lynn has a speech disorder by just looking at her, and they don't understand why she won't speak. Strangers, and even well-meaning friends and family members, can sometimes make careless comments or offer unhelpful advice.
One example happened last year as Waite and her daughter stood in line at a store. A clerk began asking Rebecca Lynn questions – “What’s your name? How old are you?” Waite quickly intercepted each question, answering for her daughter, but the clerk continued on. Finally, Waite had to explain the situation. “I was like, ‘Ma’am, she can’t communicate to you. She’s non-verbal,’” Waite recalled. “(The clerk said), ‘Oh, well it’s funny because I used to have this dog that was completely silent for so many years, and then all of a sudden it just started barking one day.’ I kind of looked at her, and I’m like, ‘Did you just compare my 2-year-old to a dog?’”

Another time, Waite watched in disbelief as a woman patted Rebecca Lynn on the head and joked, “You complain that she’s not talking now, but one of these days she’s not going to shut up.”

“I’m thinking to myself, ‘I will never complain when this child starts talking,’” Waite said. By far, the one comment apraxia parents hate the most, Waite said, is, “Oh, she’ll talk when she’s ready.”

A mother’s dream

Sharon Gretz can empathize. She created the Childhood Apraxia of Speech Association of North America, CASANA for short, after her son was diagnosed with the disorder at age 3. “There is almost nothing more distressing to a parent of a child with apraxia than to have their concerns dismissed by those people closest to them,” she said. “Unfortunately, I think at times it is hard for those around us to see us worried and upset and so they make comments like, ‘you are over-reacting,’ or ‘there’s nothing wrong,’ or ‘Einstein didn’t talk until he was 5.’”

Gretz encourages parents who are concerned about their child’s speech to get help from high-quality sources as early as possible. Speech therapy was able to help her son, who is now 23. “He has beautiful speech now, and you would never know that at one time he had a severe speech disorder,” Gretz said. “He has had the best possible outcome.”

Waite is hoping for a similar outcome for her daughter. Whether she’s driving Rebecca Lynn to weekly speech appointments or struggling to balance their exhausting work, speech and family life, Waite holds on to one dream, a vision for her daughter’s future. “I do have this vision that she’s going to be this grand speaker one of these days,” Waite said. “She’s going to be able to stand up in front of people and give amazing speeches. That is my vision.”

Reporter Kelly Hinchcliffe

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