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## Rare condition makes life challenging for 7-year-old, family

By [Bethany Fuller](#) | Statesville R&L

Kimberly Herrera waited at the end of the Sloans' driveway for the school bus doors to swing open. She heard it coming up the road before it reached Four Winds Drive.

Being at the end of the driveway to meet Gabe every day was an important part of their daily routine.

Herrera leaned forward to pick up the Kleenex box that fell down the steps when the doors opened and handed it up to the driver as they talked about the trip home from N.B. Mills Elementary School.

As the bus monitor leaned over the leather partition in the front to add something else, a small blond boy with thin eyebrows that met in the middle of his forehead, bright brown eyes and a huge smile held onto the handrail and made his way down.

Seven-year-old Gabe Sloan's head barely came up to his caretaker's waist when he hugged her, making him look a couple years younger. A pair of blue hearing aids surrounded his ears.

Herrera, a support service specialist with M&M of the Carolinas, signed a greeting.

"Can you say hi?" Herrera asked Gabe, as they walked down the driveway.

He turned his face away and pressed his small body into her side before she took his hand and they walked the rest of the way.

"He's very much a you got to stick to the routine," Herrera explained. "You are such a good boy."

Inside, Herrera quickly started to take off his shoes to start their play time. It's quiet for a Thursday afternoon. Big brother Ben and little sister Addie were at their grandmother's for the afternoon.

"What color is your shirt?" Herrera asked.

Gabe quickly signs something back. "Your shirt is red," Herrera said.

"He fell asleep again," Herrera tells his mother, Margaret, who was behind the counter.

His mom doesn't look surprised. Learning to live with Gabe's limitations and the disabilities associated with congenital Cornelia de Lange Syndrome has been an ongoing process since he was born.

The Sloans have worked hard to adapt Gabe into their normal life.

Gabe and Herrera disappeared into his room to change his clothes and prepare for his afternoon lesson.

When he reappeared from his room, his "Tater" truck from the Pixar movie "Cars" was tucked under

his arm.

Herrera lifted him up to one of the stools next to the counter and pulled out yogurt and a chocolate pudding pack out of the refrigerator.

"Which one do you want?" she asked. Gabe pointed to the yogurt.

"To be so little, he will out-eat my other two," Sloan said.

The routine Herrera goes through every day is a part of their plan. The exercises they go through help Gabe, who has a moderate mental disability, to learn the basics.

"She's been my friend for a year now, and Gabe loves her," Margaret Sloan said.

It takes a special person to fit into the position, Sloan said. Not only does the person have to help Gabe cope with his moderate mental disabilities, but she also has to help him learn to communicate with the world.

He has a pair of hearing aids, but he's been known to take them out. Herrera tries to engage him into speaking, but often times he sighs or grunts.

"It can be very frustrating since he is nonverbal," Sloan said. "He doesn't sign like everyone else does."

Gabe needs to use both of his hands to make certain gestures. If he tries to sign the color yellow, which requires his thumb and pinky fingers to stick out, he has to hold up his small finger.

Not all children born with CdLS go through the same problems. Gabe is in the exceptional children's class at N.B. Mills, but his friend Grace Dixon, who lives in Salisbury, is in a regular classroom.

Like Gabe and Grace, other children can have a small stature, hands, feet and head. A lot of times their facial characteristics are defined by unibrows, long eyelashes, an upturned nose and thin downturned lip. Around 25 percent of these children are born without limbs.

Sloan said Gabe has adored Grace since their families befriended each other at a CdLS conference in New Jersey in 2006.

The two families planned to meet at the East Lincoln Speedway on Saturday for a Checkered Dreams event. Sloan said her son loved racing, but she thought he was looking forward to seeing Grace more.

"Gabe has no boundaries," Sloan said. "He goes every where we go."

Sloan and her husband, Scott, once had every reason to believe the energetic child the members of Yadkin Baptist Church and N.B. Mills have come to know wouldn't walk or sit up on his own until he was 3.

Margaret and Scott, like many people, had never heard about Cornelia de Lange Syndrome before their 5-month old son was diagnosed.

Sloan's blood work during her pregnancy indicated Trisomy 18, which could suggest serious birth

defects. The couple went for an ultrasound to see if their baby had a cleft pallet or webbed fingers.

Sloan said the baby clearly smiled and spread apart his fingers, so her doctor concluded the test was incorrect.

The couple went through the rest of their pregnancy expecting Gabe to be developmentally normal.

In his baby pictures, Gabe's clothing engulfed him. He was six weeks early and weighed four pounds one ounce.

Low birth weight was a sign of CdLS, but his parents didn't know that yet. Their first indication that anything could be wrong with their infant was when their pediatrician said she had reason to believe something was wrong with Gabe and recommended further testing at Wake Forest University Baptist Medical Center.

"He looks a lot like Scott, so we thought she was crazy," Sloan said.

Three to five months later, the couple sat with their son in a geneticist's office stunned at the results. The doctor told them Gabe would always have limitations. He wouldn't start talking when other children did or learn at the same pace.

Around one in 10,000 babies are born with the genetic syndrome, and there is no cure. According to the CdLS-USA Foundation, "the gene change that causes CdLS is sporadic, not inherited, which means the change occurs randomly during conception in 99 percent of the cases.

The disease's severity ranges from mild cases to severe, but all children have similar characteristics. The family feels pretty fortunate that they've been able to find doctors in North Carolina, particularly Chapel Hill, with the skills to treat their son.

In 2006, the Sloans saw an advertisement for a CdLS conference in New Jersey.

Wanting to know more about the disease, they traveled 10 hours to hear experts speak.

"It was weird because we felt normal," Sloan said. "It was a relief to know we weren't alone."

There they met the Dixon family and found out about CdLS children who suffer from malrotation of the intestines.

Since a young age, Gabe always had some form of projectile vomiting. The Sloans always attributed it to the reflux CdLS children are prone to having.

When another couple asked them if they'd checked for any kind of abdominal issues, the Sloans became worried malrotation was the source of their problems.

During one of the workshops, the couple was told malrotation could cause obstruction in the twisted intestine and even death to that part of the gut.

Shortly after returning home, the Sloans confirmed Gabe had the condition, but were able to find a surgeon to resolve the issue.

Gabe pressed his face into the chained link fence and clasped the wires in between his small hands.

Across the back parking lot of N.B. Mills, a large spray of water poured from the Statesville Fire Department's truck onto the playground.

Gabe and his classmates in Susan Williams' exceptional children's class at N.B. Mills were taking a mini-break after a fire drill interrupted their day.

One of his classmates ran toward an opening in the fence, and Gabe followed in order to get a closer look. The potential escapees were caught by one of the teacher assistants before they reached the end of the sidewalk.

Across the yard, Williams watched the teacher take Gabe to the playground to burn off a little more energy.

Gabe doesn't run at school often, she said.

"The classroom is very structured," Williams said. "He's all boy. He climbs everything he sees. He's a lot of fun to be around."

"If he runs down the hall, all I have to say is Gabe stop," said Iredell-Statesville Occupational Therapy Assistant Cyndi Trimble.

Williams said Gabe is the only hearing-impaired student in her class. She signs to all her students though.

In order to divert their attention away from the departing fire truck, she told them to go play out loud and accompanied it with the correct hand gesture.

The school uses every resource at its disposal to make sure Gabe learns the skills he needs, Williams said.

The N.C. Department of Public Instruction sent someone to observe William's classroom and give her feedback. A hearing-impaired specialist works with him at least once a week.

He's worn hearing aids for the past two years, but Williams said he still gets frustrated over not being able to communicate.

"He's come a long way," Williams said. "He's ahead of the rest of the class."

One of the teacher assistants came over and asked for the new code to get into the building. Williams pulled a yellow slip of paper out of her pocket and handed it to him. She said it was almost time to go in and get ready for the bus anyway.

She took Gabe's hand and walked with him down the hall. Sometimes when people aren't looking or Gabe doesn't think they are paying attention, he will start talking, Williams said.

Back in the classroom, Trimble pulled out the writing exercise she gave to Gabe earlier in the day out of his bookbag. She is trying to get him to trace his last name. He's the only student who can write his first name.

"Sometimes he will look at me and I don't know if he doesn't understand what I am saying or if he's being stubborn," Trimble said.

The pit area of East Lincoln Speedway was a mixture of people, cars and trailers.

The Sloans and the Dixons stayed close to the tent Checkered Dreams, a nonprofit organization based out of Mooresville, set up for them.

Ben Sloan stood on the hill holding his brother Gabe on his stomach. The pose seemed rather natural for the 8 year old, who had been looking forward to the race all week.

Just as his Margaret suspected, Gabe was more excited to see his friend Grace, who was a short distance away.

Sloan had arranged for Checkered Dreams to hold the event for Gabe, said Founder Sue Ziegler. The group said the family could bring a friend as well.

Grace and Gabe weren't far apart while the two families tailgated and caught up with what was going on in their lives.

They tried on race hats together, received souvenir items from their favorite driver (Ryan Newman), watched the race and got autographs.

"I gear the whole day toward the kids," said Ziegler, preparing to give the pair their helmets.

Gabe looked rather bewildered when they placed him into Ziegler's husband Zig's micro Sprint. He looked around and tried to figure out where he was.

"He had a ball," Sloan said.

Gabe let his mother pick him up when Grace was in the micro Sprint. His father Scott came over and said there is a lot that people don't understand about the CdLS or even handicapped children in general.

"I've actually gone up to people and asked them if their child had it," he said.

The family is more than willing to help others understand their son and his condition. They feel the knowledge they've gained over the years has helped them put Gabe on the right path for a normal life.