

Beyond Cosmetic

Surgical advances make repairing facial abnormalities easier

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Journal Staff Writer

Nurse Krista Sullivan held herself together as best she could, but when she saw Dr. Luis Cuadros, an Albuquerque plastic surgeon, in the hall, she broke down.

After eight years working with Cuadros on facial deformity surgeries, Sullivan had an ultrasound revealing a cleft lip on her unborn son.

She consulted Cuadros for the rest of her pregnancy and, when the time came, he repaired the boy's cleft lip and palate. "I always had a passion for these kids," she says, "but never anticipated being one of his patients."

Her son, Cody, now a wild child 3-year-old, is the beneficiary of plastic surgery advances that have made it easier to repair some facial abnormalities like cleft palate. Other New Mexicans with cranial and facial conditions are benefitting from access to resources and education that was previously impossible.

"A lot of people don't know things can be improved," says Cuadros, who does most of the cleft repair surgeries in New Mexico. He also operates a traveling clinic that visits communities across the state.

Often, he says, parents of these children in small communities feel isolated until they find themselves in a clinic with 20 similar families.

"They're not alone," Cuadros says. "Their child is special; we want them to have as normal a life as possible, which they can have."

Cuadros says facial reconstructive surgery is delicate, and techniques have improved now to where the only outward appearance of a cleft is a single thin scar along the upper lip. Sullivan also notes that, with speech therapy, a child born with a cleft palate can learn to speak normally.

Across the board, plastic surgery in the past 25 years has improved greatly, and with it the lives of these children, says Charlene Smith,



GREG SORBER/JOURNAL

Cleft lip and palate are the most common craniofacial conditions in the state, according to the state Health Department and Dr. Luis Cuadros, a plastic surgeon who performed surgery on 3-year-old Cody Sullivan, above, of Rio Rancho. Cody's mother, Krista Sullivan, had been a nurse working alongside Cuadros for eight years before an ultrasound revealed the clefts on her son.



COURTESY ISABEL CLEMENTS

Some craniofacial conditions, like Pfeiffer Syndrome, are extremely rare and require a series of complex surgeries. Gabby Clements, 2, of Roswell, has undergone seven surgeries, her mother, Isabel Clements, says, including four to her skull that allowed her brain to keep growing.

executive director of the Children's Craniofacial Association based in Dallas.

Part of the association's mission — in addition to providing financial support to some families, organizing retreats and public advocacy — is

connecting families to one another.

For parents with these children, the largely Internet-based association is a godsend, says Isabel Clements, a Roswell mom whose 2-year-old daughter Gabby has Pfeiffer Syndrome, a

For Information

Contact Dr. Luis Cuadros of the New Mexico Cleft Lip and Palate Center at 243-7670 or the Children's Craniofacial Association at cckids.org or 1-800-535-3643.

condition that prematurely fuses the bones in her skull. Clements says the association has helped Gabby travel to Dallas for surgery and a retreat with other families.

The association also has been an advocate for requiring insurance companies to cover reconstructive surgery, Smith says, and successfully lobbied Gov. Bill Richardson to name Sept. 15, 2009, as "Craniofacial Awareness Day" in New Mexico.

Causes are unclear

Clefts are the most common of the 35 to 40 major craniofacial conditions, Cuadros says. According to the state Department of Health, fewer than 50 are reported

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annually in New Mexico.

Microtia, which inhibits outer ear growth, is the next most common in his practice, Cuadros says.

Other conditions, like Pfeiffer Syndrome, are very rare and are not fully repairable with plastic surgery. Cuadros says he usually sends these children out of state for treatment.

Despite being a toddler, Gabby has had seven surgeries, four of which were major operations on her skull that allowed her brain to grow.

Clements says she expects Gabby to have three more major surgeries, including one to remove the breathing tube she now uses because her facial bones are underformed.

According to the association, the causes of most of these conditions are unclear but are likely, at least in part, genetic.

Arranging for corrective surgery can be difficult, says Matilde Merriken, whose son, Jerry, now 12, was born with microtia. After moving to the Albuquerque area when Jerry was about 6, she says she heard about Cuadros from another parent.

For most children with microtia, Cuadros says, corrective surgery involves taking cartilage from the rib cage when a child is about 8 years old, and using it to fashion a new ear or ears.

"The first time I saw him, I was shocked," Merriken says of the bandages and tubes protruding from Jerry's head. "I didn't expect him to look like that."

Now, Merriken says, "he looks just like an almost normal kid," not exactly the same as his brothers "just because his ears are really small."

Cuadros may do a touch-up of one of the ears, Merriken says, but for



COURTESY KRISTA SULLIVAN

Cody Sullivan at 4 days old, when both cleft lip and palate were apparent.



Cody Sullivan at 8 months old, after the surgery to repair his lip but before one on his palate.

now Jerry seems happier and more confident than he ever has before. He's a fan of the Beatles who, despite being a bit hearing-impaired, loves to sing and has a guitar and drum set.

Cuadros usually repairs cleft lips when babies are about 3 months old, and palates at about 9 months. The surgeries are delicate but generally very successful. In Cody's case, Sullivan says that after some speech therapy, the only remnant is a minuscule scar and a slight puff on his lip.

Recovery from the lip surgery was fairly easy,

Sullivan says. After Cuadros fused the tissue in Cody's palate, however, he was eating through a syringe and in a lot of pain for about a week.

The surgeries can cause families some hardship, Cuadros says, but the cost of these procedures is often far less than their benefits. That's true for Gabby, who needs them to grow, as well as Jerry and Cody.

"It's not cosmetic. Even though it's done to make it look better, it's to make it look normal," Cuadros says. "The appearance of your face has a social function in

terms of acceptability and integration into society."

Parents' fears

Even with the resources available to parents, Smith says many grieve having a child who looks different from what they imagined.

Sullivan says she was anxious for Cody before he was born but her husband wasn't ("That's it? He'll just grow a mustache"). But when he was born, she says, "he was perfect."

The biggest obstacle she faced was feeding: Cody required a consistent schedule and a specially designed bottle.

Merriken found out about Jerry's diagnosis after she delivered him.

"From my side, it was a lot of guilt," she says. "I felt like I did something wrong."

Those feelings, too, disappeared after speaking with doctors who explained that these conditions frequently appear after normal pregnancies.

Strangers provide the most discomfort, the mothers say. Other children and even adults can be cruel.

Clements has stopped worrying, resolving instead to give Gabby enough strength to stand up to shallow people.

"She may look different," Clements says, "but I want her to be proud of herself."

And while the surgeries aren't perfect — Gabby will always bear the effects of her condition, Cody will always have a scar on his lip and Jerry's ears seem small for his head — they go a long way to lessen these children's suffering.

"He's so proud of his big ears," Merriken says of Jerry. "He's so happy."