

LOMA LINDA: Cleft lip, palate patients rejoice at reunion

By **SANDRA STOKLEY** | Press-Enterprise
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When Margaret and Glen Thronson learned they were expecting a baby with a cleft lip, they began researching the condition to prepare themselves.

But no amount of research could have prepared Beaumont resident Margaret Thronson for the complex emotions she felt as she held Noah for the first time after his birth on June 6, 2010.

The boy had a cleft lip and palate – a birth defect in which the upper lip and the palate, or roof, of the mouth do not grow together properly before birth.

“When he was first born, it was hard for me to accept that my child wasn’t whole,” Thronson said this week. “That he was missing a part of him.”

Those anguished moments were a dim memory Friday as the couple watched Dr. Jung-Wei “Anna” Chen greet Noah, now a lively 4-year-old, at a reunion of cleft lip and cleft palate patients treated by the Loma Linda University School of Dentistry’s craniofacial team.

The only reminder of Noah’s birth defect is a pink, nearly-invisible scar over his lip. “Hello, Noah. Look at you,” Chen said delightedly.

She greeted each patient, hugging some and taking “selfies” with others. The festive reunion included balloons, face painting and children’s games, tables decorated with pumpkins, and healthy snacks and drinks. A woman in a pink tooth costume interacted with participants.

The reunion brought together Noah and dozens of other tiny patients and their families to mark five years of cleft lip/palate surgeries at the school using an advanced technique involving a pre-surgical nasoalveolar molding, or “pnam.”

A pnam is a retainer-like device fitted into an infant’s nose and mouth and held with tape. It moves the separate parts of the lip and palate closer together, reducing the number of surgeries needed to repair the lip and palate. Scars are minimal.

Loma Linda’s dentistry school is one of three medical facilities in Southern California, and the only one in the Inland area, that uses the device, Chen said. The others are St. John’s Health Center in Santa Monica and Children’s Hospital in Los Angeles.

Under Chen’s direction, the school’s craniofacial team has performed 84 cleft lip and palate repairs.

The reunion was designed to let patients and their families interact and also to raise awareness of Loma Linda’s program.

Riverside resident Alexis Carreno, who brought her 2-year-old daughter Chassity, said she felt a sense of community.

"Seeing all these other parents, you don't feel so alone," Carreno said. "We can talk and support each other."

Chen said she also wants to tell as many new parents as she can about the rare procedure because treatment should begin as early as possible.

"This device has so many advantages," Chen said. "After three to four months, surgery can close the nose, the lips and the palate at the same time."

But the device must be fitted in the first weeks after birth, she said.

"At seven months, it's too late because the babies are grabbing and pulling," she said.

Chen said the biggest challenge for parents is removing the device every day, cleaning it and then refastening it with tape. Infants cry, scream and squirm when the device is being reinserted and taped.

"I'm not going to lie. It was very tough," parent Sergio Granda said about his son Andrew. "He would fight me."

Granda, a Rialto resident, said he spent the first days after his son's birth in shock. A sonogram had missed the birth defect.

"I was scared," he said. "I didn't know how he would eat. What would his life be like?"

"I've worked with special-needs kids in the past," he said. "But it's different when it's your kid." Margaret Thronson said Noah was fitted with the device when he was a month old.

The baby would sometimes cry and squirm, but other times was OK, Thronson said. The tape would cause his skin to peel.

"Our son needed us to make the decision for him," Thronson said. "We didn't cave." She said the result is better than she could ever have imagined.

"You would never know he had a cleft lip/palate," Thronson said. "They do amazing work."



Dr. Jung-Wei "Anna" Chen takes a photo with Chassity Carreno, 2, during a reunion for cleft lip/palate patients at the Loma Linda University School of Dentistry on Friday. Loma Linda University School of Dentistry hosted a reunion of patients who have benefited from use of a retainer-like device.



Brilynn Thornton, a 3-year-old Norco girl, high-fives Dr. Amanda Zenthoefler, after having her teeth checked during a reunion for cleft lip/palate patients Friday at the Loma Linda University School of Dentistry.



Aaron Sanchez, who is 1 month old, sleeps in a baby carrier during a reunion Friday for cleft lip/palate patients at the Loma Linda University School of Dentistry.



Panchito Loustaunau, a 3-year-old Bartsow boy, holds still as he gets a pumpkin painted on his face during a reunion for cleft lip/palate patients at Loma Linda University School of Dentistry on Friday.



Dr. Jung-Wei "Anna" Chen pinches the cheeks of a 10-month-old patient, Esmeralda Sotelo, who lives in Montclair, while in the arms of her grandmother Mayra Balmaceda. They attended a reunion Friday for cleft lip/palate patients at the Loma Linda University School of Dentistry.



Pediatric coordinator Magda Lavergne, reunites with Levi Andrade, a 1-year-old Ontario boy, as his father Jose Andrade and grandmother Tracy Montalvo watch during a Friday reunion for cleft lip/palate patients at the Loma Linda University School of Dentistry.



Registered dental assistant Ebony Reece watches as Micah Cooper, a 5-year-old San Bernardino boy, signs his name on a picture frame during a reunion for cleft lip/palate patients Friday at the Loma Linda University School of Dentistry.



Noah Thronson, a 4-year-old Beaumont boy, appears behind a picture of a large smiling mouth while playing a game during a reunion for cleft lip/palate patients Friday at the Loma Linda University School of Dentistry.



Andrew Granda shortly after his birth in 2012.