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Families who got help for kids with cleft palates gather to share experiences

By **MICHELLE SHELDONE**
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Maryann Spasaro of Palm Beach Gardens didn't fully experience the overwhelming joy most new mothers feel at the miracle of birth.

Her son, Connor Cozzoli, was born with Kabuki Syndrome and had a cleft lip and palate known to accompany this rare disease.

"I was in shock," Spasaro said. "It was not a good scene."

With a cleft lip, one or two sides of the top lip appear to stretch up toward the nostrils. A cleft palate is marked by a gap on one or two sides of the roof of the mouth.

"It can be pretty overwhelming when (a child) is born with a condition like this," Children's Medical Services pediatrician Dr. Philip Colaizzo said.

"Everybody wants a perfect baby — and they're perfect, with a small defect."

The birth defects occur during early pregnancy, seemingly because of genetic and environmental factors, according to the American Cleft Palate Foundation. Often, they accompany other disorders and, because eating becomes so difficult, patients with cleft lip and palate can end up with an aversion to food, CMS Registered Nurse Specialist Carol Winig said.

Connor, now 5, has undergone two surgeries and five ear procedures and has only just begun to eat through his mouth. A team of Children's Medical Services specialists helped him at no cost.

The clinic, funded by the Florida Department of Health and located near St. Mary's Medical Center in West Palm Beach, serves those with cleft lip and palate regardless of the ability to pay.

Spasaro, homebound while feeding little Connor through a tube 24 hours a day, turned also to craniosacral therapy at the Palm Beach Gardens-based Upledger Institute.

She has just returned to full-time work and enrolled her son in elementary school.

On Sunday, they attended a Carlin Park Civic Center picnic with about 150 others who are a part of the Craniofacial Family Network of Florida. The Quarterdeck restaurant of Jupiter catered at no cost. Families came from Miami to Fort Pierce to socialize, share their experiences and offer each other support.

Chris Sapp of West Palm Beach was among them. He was born with Apert Syndrome and, in addition to cleft lip and palate, had fused fingers and an artery protruding from his left arm.

He is 18 years old and has just as many surgeries under his belt.



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Carol Winig, a registered nurse specialist at Children's Medical Services, spends time Sunday with Connor Cozzoli, 5. The Palm Beach Gardens boy was born with Kabuki Syndrome, and Children's Medical Services provided corrective surgery for his cleft lip and palate at no cost.

Children's Medical Services staff members Winig and Network liaison Peggy Larson, a speech pathologist with the Palm Beach County School District, provide comfort and hope.

Winig was preparing to accompany Sapp into his next surgery, for a jaw alignment, while Larson herself was born with cleft lip and palate.

"There are a lot of issues when you're a kid," Larson said, citing questions like "Why did God make me look like this?" and "Why am I so ugly?"

"You have to go through the living process," she said. "Now it's what makes me what I am. It defines me and my experiences ... and how I deal with other people."

"She gives other people inspiration," Sapp's mother, Patti, said. "I think the kids can dream and realize anything can be accomplished, because they see what Peggy's doing."

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