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Cornelia de Lange Syndrome group is having a conference in the area.

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BY COURTNEY PERKES / STAFF WRITER

Published: June 20, 2014 Updated: 8:14 p.m.

Traci Weber has never met anyone who suffers from the same rare genetic disorder as her 4-year-old son, who still fits into baby clothes and can't speak.

That will change next week when Weber of Irvine attends a national conference for the Cornelia de Lange Syndrome Foundation in Costa Mesa. Her son, Jacob, was diagnosed a few days after birth with the condition, which is marked by traits such as small size, thin eyebrows that meet in the middle, and thin, down-turned lips.

"I was happy it was coming here," Weber said. "I will be bringing Jacob. I'm really eager."

The conference takes place Thursday through Sunday and will draw about 140 families. Speakers include UC Irvine professors Arthur Lander and Anne Calof whose infant daughter died of the syndrome in 2000. They collaborated on research that identified the causative gene in 2004.

The syndrome occurs in roughly 1 in 10,000 births. Children may suffer intellectual disabilities, gastroesophageal reflux disease, bowel obstruction, hearing loss and congenital heart defects.

Weber's son weighs only 21 pounds and receives nutrition through a feeding tube. He sees an array of specialists and goes to physical, occupational and speech therapy. He crawls and eventually will learn to walk.

"He's easygoing," she said. "He's super happy. He's just the sweetest thing. He loves music."

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Jacob was delivered 6 weeks early because he wasn't growing well in utero. Weber, 42, said she sometimes tells strangers he's a premie because it's easier than explaining a condition most people have never heard of.

Brenda Shepard, communications coordinator for the foundation, said more awareness is needed to ensure timely diagnosis.

"They may have some of the symptoms and some of the facial features but if their medical provider doesn't know about CDLS they could be missing serious medical issues that could be life saving," Shepard said.

For more information on the foundation, go to cdlsusa.org

Contact the writer: 714-796-3686 or cperkes@ocregister.com



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