

Matthew & Ryan

“It was more difficult the first time; we didn't know what to expect. But with Ryan it was a whole other ballpark.”

– Walter Carpio, the boys' dad

Matthew sits quietly and plays with superhero action figures. His little brother, Ryan, never stops moving. “Only when he's sleeping,” says his dad, Walter Carpio of McFarland.

Even with opposite personalities, the boys share a mysterious genetic link that could have robbed them of normal lives. Matthew, age 4, and Ryan, age 2, were born with a missing suture down the middle of their skulls. The condition allows the head to grow longer but not wider, with pronounced bulging at the forehead and back of skull.

“When children grow up with physical deformities it affects their entire life,” says Dr. Mimi Chao, the pediatric plastic surgeon at Valley Children's who repaired the boys' skulls when they were a few months old.

“When Ryan was born I noticed right away,” says the boys' mom, Alma. “I thought, oh no, it's the same thing again.”

“For siblings to have a missing sagittal suture just by chance is extremely rare,” says Dr. Chao. “There must be a genetic connection, but as of yet, no one has identified the gene.”

Dr. Natalie Hauser, a pediatric geneticist at Valley Children's, is working with the Carprios to assess the risk of recurrence, which could be as high as 50 percent. “There are options to keep you from passing on a genetic trait, but first you have to identify what it is,” says Dr. Hauser. “That's what we're here for, to prevent things from recurring.”

“We want to try for our little girl,” says Walter. Alma agrees. Will she be more like Matthew or their “little tornado,” Ryan? If by chance she inherits the same mysterious gene, the Carprios will know what to do.

“We're very comfortable with Valley Children's,” says Alma. “They've been good to us.”

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