

PAID CONTENT

# Couple Partners with World-Class Neurosurgical Team To Give Girls a Better Quality of Life

By SIEVE MILANO

The day before they were to pick up their third adopted child, Tamera and Bryan Wong found an unexpected little gift.

The couple had traveled to China for the adoption of a son, and while they were waiting to finalize the paperwork they spent time volunteering at a local orphanage.

"We held Bella and fed her and fell in love with her ... and we wanted her," said Tamera, who learned the 4-month-old had a medical condition unfamiliar to the Wongs. They had no experience with or knowledge of her condition – spina bifida, a disease that affects the spine and spinal cord.

"I just started researching like crazy before we brought her home," said Tamera, a Clovis resident who is now a mother of 12, including eight adopted children from China, seven of whom have special needs.

During their research, the Wongs learned that with the right medical care, a person with spina bifida could look forward to an active and long life. They discovered that Sutter Children's Center and Shriners' Hospitals for Children, both in Sacramento, were well-regarded for the care they provided children with spina bifida. Tamera and Bryan decided to contact Sutter neurosurgeon Samuel Ciricillo, M.D., about the baby's surgeries and follow-up care.

"Everybody I talked to said Dr. Ciricillo was the best, bar none. At that time his practice was kind of hard to get into and so we wrote him a letter. We told him our little girl had no previous medical care and that we wanted her to have the best. We asked him, 'Will you be on our team?' and he said, 'Absolutely.' He's phenomenal," said Tamera. "He did a lot of educating and so did Shriners, and together their partnership is incredible."

Dr. Ciricillo has practiced pediatric and adult neurosurgery at Sutter for more than 15 years and has worked with Shriners since 1992. Based on the medical care, financial support and emotional help the couple received from various sources throughout the area, they decided to adopt another girl with spina bifida, 2-year-old Beka-Joy.

"The help from Sutter with Bella was absolutely a huge component of that decision," says Tamera.

Bella and Beka-Joy now have a team of medical professionals at Sutter and Shriners who monitor their progress in a wide variety of areas, including urology, orthopedic surgery, psychiatry and therapy.

"When we do have to stay at Sutter following a surgery, I feel like we have a whole team who really knows how to treat kids and make our stay more positive," Tamera says. "The Child Life specialists regularly check in on me and help keep the girls calm and entertained before and after surgery, and I feel like we've been on this journey with the same pediatric nursing staff for the past four years. And then there is the pediatric surgery team and physical therapists that are so good at building rapport and trust with the girls."

"Both of the girls needed surgery because they were coming from a Third World country that didn't have the proper means of caring for them," explains Tamera. "Both of them had spinal cord repair by Dr. Ciricillo. For Bella, that's when she started walking, after that critical surgery. Beka-Joy mostly uses a wheelchair, and Bella walks, runs and jumps and all that great stuff. Dr. Ciricillo follows up regularly with the girls checking for neurological symptoms."

Because spina bifida patients can have relapses, they need regular monitoring. Tamera and Bryan make the six-hour round trip from Clovis to Sacramento about once a month to make sure the girls are as healthy as possible. They may need additional surgeries, but their prognosis is good.

"Both of the girls are very bright," says their mother. "Bella is in kindergarten and she's already reading at the second-grade level. Beka-Joy is 3½ and is already beginning to read. Our goal is to help each of them reach their fullest potential. I could totally see Bella being a doctor one day. She's super bright and asks great medical questions. Beka-Joy is a super-smart, sensitive little girl, too. Her prognosis is really good. Had they been left in China without medical care, both would not likely have made it to their teenage years because of kidney failure and infection and all the things that happen when you don't have intervention."

Life expectancy is much longer for spina bifida patients than when it first came to public attention, says Tamera. "It's really about how well you manage the symptoms. Things can go downhill really quickly, that's why it's important to stay on top

of it all. I've met a 57-year-old with spina bifida who is in great health."

Tamera also wants people considering adopting a child with spina bifida, or parents who have a child with the disease, to know that, financially, the condition is manageable. The Wong family's health insurance covers most of the costs of the girls' medical needs, with

other agencies, such as California Children's Services, covering the gaps.

"The Spina Bifida Association is great for educating families, developing mentor relationships and connecting professionals with parents," says Tamera. "Both of our girls are able to participate in an adaptive sports program. That's been nice because they can meet people

with other disabilities and learn to do sports with adaptive equipment and have fun.

"When you look at spina bifida, you think it defines the child, but with all of the amazing medical care we have here in the United States, I know that with our girls, it does not define them, it's just part of their description and what they cope with. It's just a regular kid who happens to

have a birth defect that affects them. That's one of the things Dr. Ciricillo really showed me early on – spina bifida just happens to be a description, but it doesn't define who a person is or what they can accomplish. Once you get to know a kiddo with spina bifida, there's so much more."

Sacramento-area families who have a child with spina bifida, or

who are considering adopting one, can lead happy, fulfilling lives for many years thanks to the community's health-care facilities, state agencies, non-profit associations, support groups, parents and volunteers.

For more information about Sutter's Pediatric Neurosurgery Program, visit [sutterneuro.org](http://sutterneuro.org) or call (888) 287-2270.



Samuel Ciricillo, M.D., Medical Director of Neurosurgery and his patient Beka-Joy.

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