Weekly transfusion at Women & Children's Hospital helps shrink girl's brain tumor

By Barbara O'Brien | News Staff Reporter on April 29, 2014 - 12:01 AM

Jennifer Reynolds thinks of Women & Children's Hospital as an extension of her family.

"The people there are just extraordinary," she said, adding that there is always someone there to lift her up when she's having a bad day.

Reynolds and her husband, Joseph, of Grand Island, have been bringing their daughter Caralyn to the hospital for two years, ever since she was diagnosed with pilocytic astrocytoma, a brain tumor.

Every Monday afternoon, the 9-year-old goes to the Hematology/Oncology Division for chemotherapy to shrink the tumor.

It used to take all day for the drug to be pumped into her body. After eight months, she developed an allergic reaction to that drug, and she now gets a different one, spending half a day for treatment and missing less school. The infusion takes just minutes, then she must wait for blood tests.

"During that time she keeps busy. The Arts in Residency program is phenomenal," Reynolds said, explaining that when Caralyn was recovering from surgery and confined to bed, therapists would stand over her bed while she painted.

"She's great. She is one of the most artistic kids I've seen," said Caralyn's physician, Dr. Lorna Fitzpatrick, chief of the Division of Medical Education and medical director of the Pediatric-Neuro-Oncology Program.

The fourth-grader at Huth Road Elementary School on Grand Island learned she had a tumor about two years ago. She was always large for her age, and her parents, worried about an endocrine problem, had taken her to various specialists, but tests were negative.

It was an off-hand conversation with another daughter's neurologist that led to the diagnosis. One of Caralyn's sisters, Emily, 11, is being treated for migraines. Reynolds said she happened to mention that Caralyn had always been large for her age and that Caralyn and Emily were often mistaken for twins. The doctor saw Caralyn on a Wednesday, she had an MRI on Saturday, and the family knew the diagnosis two days later.

"We feel we had to go through Emily's journey to get to the right place and right time," Reynolds said.

Caralyn had eight surgeries in seven weeks, most due to complications with a shunt in her head and an intravenous port in her hand.

"Those first seven weeks were tough. She was in the ICU, I would say, six weeks of that," said her mother.

Surgeons were able to remove about one-third of the slow-growing tumor, which is wrapped around a main artery in her brain. Chemotherapy is shrinking it further.

This type of tumor is not unheard of in children, but Caralyn's presented its own challenges.

"The location of hers is more rare," Fitzpatrick said.

"She's doing so very well," Reynolds said. "We're one of the few blessed with the kind of tumor she has."

Tests show the tumor is still shrinking, and chemotherapy probably will end in June. But it is likely the tumor will resume growing at some point.

"This will be a watch-and-see approach for the rest of her lifetime," Reynolds said.

In the meantime, they are grateful that Caralyn does not have headaches or other pain, and that she misses only a half day of school a week. She can't hang from monkey bars, but she's having a good year.

Ironically, all she has been through has enabled the shy girl to come out of her shell a bit, her mother said. And her quiet demeanor has helped her handle all that comes her way.

"We've always called her an old soul. She was just that quiet girl who could always relate better to adults," Reynolds said.

The entire family, including Caralyn's other two sisters, Samantha, 16, and Megan, 6, went to Hawaii on a spring break Make-a-Wish trip. In between the luau, sightseeing and playing on the beach, Caralyn really enjoyed swimming and learning to surf.

"It's a bitter sweetness, seeing the joy," Reynolds said, happy her daughter has the opportunity to see the world but hating the reason.

She is happy for the little things, the smiles, the family togetherness, the good days at school.

"This is our new normal, yet our normal is nothing short of extraordinary," Reynolds said.