

Norah

“This hospital is like home. We know Norah is going to be welcomed here with open arms.”

-Amanda Kerr, Norah's Mom



There isn't much that can keep Norah Kerr down.

Cheerful and energetic, Norah lights up the room, whether she is practicing for her pageants, performing a new cheer or showing off her pink wheelchair.

When Norah's mom, Amanda, was 18 weeks pregnant, Norah was diagnosed with Dandy Walker variant and congenital heart defects. Before Norah was even born, the Valley Children's genetics team was working to determine the extent of her diagnoses.

As soon as Norah was born, she was sent directly to Valley Children's neonatal intensive care unit (NICU) in Madera. During the first few weeks of her life, Norah was also diagnosed with spina bifida.

According to the Centers for Disease Control (CDC), spina bifida is a neural tube defect and "when the neural tube doesn't close all the way, the backbone that protects the spinal cord doesn't form and close as it should. This often results in damage to the spinal cord and nerves." Spina bifida can cause many complications in the body, including problems with mobility, the excretory system, the gastrointestinal tract and learning disabilities.

With additional genetic testing and advancements in genetic medicine, Norah was diagnosed with Joubert Syndrome, a rare genetic disorder, and Emery Dreifuss Muscular Dystrophy, a rare inherited muscle disease, along with her diagnosis of spina bifida. Norah also experiences challenges with her gastrointestinal system, kidneys, heart, urinary system and intestines.

"We pretty much see everybody except for oncology at this hospital, knock on wood. So I feel like we've been everywhere. It's not just one clinic for us. This is home. We know Norah's going to be welcomed with open arms," says Amanda.

Despite the multiple diagnoses, Norah is happy and active. She is already planning for her future: "I mostly wanna be a doctor at Valley Children's . . . MOSTLY! I also wanna work at Disneyland," says a smiling Norah.

"It might take her a little longer than most kids to reach those milestones, but she's doing it. Our hope is that she continues to do things in her own time, and that she is happy and healthy and does things to the best of her abilities," says proud mom Amanda.