

Emoryi

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- Victoria, Emoryi's Mom



“She’s the family comedian – she can turn your frown upside down so fast,” says Victoria James about her 1-year-old daughter, Emoryi.

With her high spirits and positive attitude, one might not even know that Emoryi has a rare blood disorder. Emoryi received the diagnosis of Diamond Blackfan anemia at just weeks old. This diagnosis means that Emoryi’s body doesn’t produce enough red blood cells, as many of the blood cells she does produce die before they develop, leading to necessary specialty care and frequent blood transfusions.

However, Emoryi’s mother Victoria is no stranger to this diagnosis and treatment routine, as she was also diagnosed with Diamond-Blackfan anemia at just 6 months old and treated at Valley Children’s.

“It feels good knowing the nurses I grew up with are still here,” says Victoria. “It’s amazing how well these doctors know what they’re doing and it’s a comfort to know this team is here 24/7 for you, whether you have questions or not.”

Terea Giannetta, hematology nurse practitioner, treated Victoria as a pediatric patient and knows the concern parents might have when it comes to a rare blood disorder.

“Genetics are much better now than when Victoria was a patient,” says Terea. “So we did some genetic studies on Emoryi here at our genetics center, and then received approval to do the study on Victoria. We discovered they both carry a genetic mutation that has been known to cause Diamond-Blackfan anemia.”

Terea goes on to explain that while gene identification is still very new, the hematology and genetics teams at Valley

Children’s recognized the importance of it in the case of Emoryi and Victoria. While it is typically very hard to identify such a rare disorder in newborns, identifying the gene helped confirm Emoryi’s diagnosis.

“Because this diagnosis is so rare, if it isn’t recognized, it can be life threatening,” adds Terea. “If the patient doesn’t get transfused correctly as an infant, it can damage their physical and mental growth and inhibit their longevity. It’s so important these patients are seen at a qualified center where people educate the parents and even other providers. Because Diamond-Blackfan anemia is so rare, patients can have great providers who have never had experience with this disorder.”

This expert care is also the highest of priorities for Emoryi’s father, Kenneth Williams, Jr. After receiving Emoryi’s diagnosis, her parents knew instantly that at Valley Children’s, they would receive not only the best care, but also have the most compassionate staff who would welcome them to each appointment with smiles.

“I have to admit, I’ve never liked hospitals,” Kenneth shared. “But after working with Valley Children’s, it changed my whole perspective. After coming here, even the first time, each and every doctor and nurse changed my perspective of how a doctor is supposed to act. They treat me with nothing but kindness.”

Victoria explained why she is more than happy to come back every month to Valley Children’s: “When it comes to my daughter’s wellbeing and livelihood, especially when it comes to such a rare disorder, there’s no other option in my mind.”

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