Jacksonville Child With Rare Blood Disorder Celebrates 100th Transfusion

At just 10 years of age, Cai Cammilleri is celebrating his 10^{h} – blood transfusion, that is. Surrounded by balloons, cake and a handwritten sign of well-wishes from his classmates, Cai hit a landmark milestone in his lifelong battle with beta thalassemia major.

"It's taken me a long time to get to my 10th blood transfusion," said Cai, in an interview with WJXT-TV. Every month, he endures a 4-hour blood transfusion, facilitated by a port in his chest.

"It definitely is hard," said his mother, Lynzie Cammilleri. "It is difficult for a child not to participate in activities at school. They miss more days than is allotted in a school year for blood transfusions and possible hospitalizations."

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Beta thalassemia major is a rare blood disorder in which patients do not produce enough red blood cells on their own and must get regular blood transfusions. Cai's doctor, Dr. Cynthia Gauger, is a pediatric hematologist-oncologist with Nemours Children's Specialty Care in Jacksonville. She said children with the major form of beta thalassemia must receive transfusions every 3-4 weeks.

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Cai is one of only five patients Nemours treats that have beta thalassemia major. His brother, Corbyn, is one of the other four. Corbyn, 10, was diagnosed with the disease at just 14 months old and has received more than 165 transfusions to date. The family's daughter, Callie, does not have the disease. After Corbyn's diagnosis, his parents looked into adoption, and upon meeting Cai, his mother said they just knew.

"We looked at him and said, 'That's our son."

The brothers often sit side-by-side through their transfusions, sharing typical sibling banter, but also an understanding that only the other knows.

"I think there is a special bond that we will be thankful for someday," said Lynzie.

About Nemours Children's Health System

Nemours is an internationally recognized children's health system that owns and operates the two free-standing children's hospitals: the Nemours/Alfred I. duPont Hospital for Children in Wilmington, Del., and Nemours Children's Hospital in Orlando, Fla., along with outpatient facilities in five states, delivering pediatric primary, specialty and urgent care. Nemours also powers the world's most-visited website for information on the health of children and teens, KidsHealth.org, and offers on-demand, online video patient visits through Nemours CareConnect. Nemours ReadingBrightstart.org is a program dedicated to preventing reading failure in young children, grounded in Nemours' understanding that child health and learning are inextricably linked, and that reading level is a strong predictor of adult health.

Established as <u>The Nemours Foundation</u> through the legacy and philanthropy of Alfred I. duPont, Nemours provides pediatric clinical care, research, education, advocacy and prevention programs to families in the communities it serves.

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