

2024 Kids Day Ambassador

Jeremy

“I am grateful to all the staff at Valley Children’s who continue to help us – they are the lifeline that my kids depend on and for that, I will forever be grateful.”

-Kong, Jeremy’s dad



Meet Jeremy, a young hero whose imagination knows no bounds. He finds joy in constructing vibrant cities with magnetic tiles, creating a world of adventure for his beloved superhero action figures, led by his favorite, Spiderman.

But Jeremy’s life is more than just play. He faces a formidable foe called Hemoglobin H Constant Spring, a type of alpha thalassemia, a challenge he shares with his younger siblings, Tinsely and Ryser. This condition was an unexpected adversary, diagnosed through newborn screening, and Jeremy’s first blood transfusion came at just six months old.

Today, eight years later, Jeremy’s appointments are frequent and lengthy, lasting three to five hours every three to four weeks. Yet, it’s during these moments that Jeremy’s boundless imagination shines, helping him endure the challenges he faces.

Although Jeremy has an inherited condition, it was a surprise to both his parents who later learned through genetic counseling support that they were both carriers. Despite their shared diagnosis, each child’s unique needs are addressed with care. They rely on regular transfusions to maintain a good quality of life

“Jeremy comes to every appointment with his younger siblings. All three of them are transfusion

dependent which means they HAVE to be transfused every three to four weeks to maintain an adequate quality of life,” explained Dr. Latha Rao, Valley Children’s pediatric hematologist/ oncologist. “Each appointment starts with getting labs drawn and having an IV placed either by the RN or the vascular team who use an ultrasound machine. These chronic transfusions have side effects including iron overload which needs regular monitoring – yearly ultrasounds of the abdomen, echocardiograms, MRIs, measurement of iron in the body and audiology and endocrine evaluation. All three of them have different iron levels so are being managed slightly differently.

Jeremy is a superhero unlike any other.

Just as he conquers the uncertainty of his genetic condition, he stands as the central hero in his magnetic city, inspiring hope and resilience. Jeremy’s father, Kong, attests to the journey’s challenges but also celebrates the remarkable progress in medical care that has positively impacted their lives, nurturing trust and resilience in their family’s heartwarming story.

“Our entire experience required a lot of heart and trust and I have been able to confidently get to that place because I have witnessed medical progress and the positive impact that care has had on my kids’ lives,” shared Kong, Jeremy’s dad.

Futures Worth Fighting For.

valleychildrens.org/kidsday