

Superhero comes home after bone marrow transplant

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Content

Hayes Robinson got a superhero's welcome home from family, friends, church and community members in late June after a harrowing health journey ending in a bone marrow transplant.

Some in the parade at his home even donned superhero costumes and waved signs as Hayes sat and smiled at the passing cars.

Hayes, who is 5, was born with Fanconi anemia, a rare genetic blood disorder that affects bone marrow. The disease can cause delayed growth or development, certain cancers, fertility issues in women, hearing loss, anemia, infections and bleeding problems — to name a few.

Hayes' side effects have included underdeveloped kidneys, hearing loss, Chiari malformation of his brain and being born without thumbs. Both of his parents underwent genetic testing, and found they are carriers of Fanconi anemia, causing Hayes to inherit the recessive gene for it, which is an incredibly rare probability.

His mom, Kelsey Robinson, explained that his body was born with all of the platelets — red and white blood cells — that he would have in his lifetime, as he does not have the ability to generate new cells.

“Once his body uses (blood cells) ... his body does not know how to make them anymore,” Kelsey said. “We had to be super careful with him being sick, because you need white blood cells to fight off an infection. (Those) platelets (are missing), so he would always bruise because his body had a clot.”

Kelsey said that Hayes has had “a life full of infusions,” and has logged hundreds of hours in medical facilities in his lifetime.

Hayes traveled to Minneapolis, Minn., this spring for a bone marrow transplant. The transplant became necessary after his body was less and less able to sustain blood transfusions. He started getting a transfusion every six months, but eventually had to get one every week.

He was in M Health Fairview Masonic Children's Hospital for 30 days and in recovery there for another 70 days.

Kelsey said Minnesota is a medical hub for Fanconi anemia, and their family was able to stay at the Ronald McDonald House there during treatment and recovery.

"We had the best nurses; they took care of us and they loved on him, loved on us," she said. "I don't think we could have asked for a better team."

Kelsey said the highlight (maybe more for her than Hayes) was meeting Chris Pratt via video chat to hear about his new "Super Mario" movie. As Hayes' immune system was incredibly fragile, he lived in quarantine and was not able to leave or have many visitors.

Although he was locked in one place, Kelsey said the hospital and house made sure to keep Hayes entertained with a superhero week, bingo nights and therapy dog visits.

Kelsey said Hayes has never complained or had a bad day, and she admires his perseverance through the entire situation.

"I am so proud," she said. "In the thick of it, I felt like, in a way, no one wants to see their child go through a bone marrow transplant. I wanted to do something, to take it away, but there's really nothing you can do."

Hayes also has an 8-month-old little sister, Anniston "AB," whom Kelsey said he absolutely loves and gets to spend time with between treatments. Their bond is so close that oftentimes Hayes would not say good morning to Kelsey or his dad, David, until he saw Anniston.

"He loves her, and I think really having her, just the love, he just wanted her to love on him," Kelsey said.

During the welcome-home parade, Kelsey said Hayes was so excited and surprised, and the entire family was blown away by the amount of people who showed up. She said it was such a simple gesture, but it meant so much to their family.

"He's still talking about it," she said.

"My favorite part was when Thor rode up and gave me his hammer," Hayes said.

Kelsey said her family is grateful for the continued support, and is so appreciative of everything the community has done for them.

Kelsey said she has been inundated with calls, texts and messages of support and there hasn't been a week where Hayes has not at least gotten a card. Kelsey also said a thank you will never be enough.

"He's the true inspiration out of this, he's the one who taught me how to be patient and how to really see the light even through some of those dark days," Kelsey said.

Child images

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LANNWS-07-12-23 HAYES BONE MARROW MUG



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