

The

Spotlight*

Sammy



On the sixth floor of Vanderbilt Children's Hospital (VCH), families often escape the hospital environment on the balcony playground. This February day was unseasonably warm, but it's getting cold again, so no families are playing on the swing, or in the castle.

Just inside, Luz Jirasko and Rodrigo Martinez are speaking with DSAMT about their 18 month old miracle, Sammy, who is in for one of his last rounds of chemotherapy.

"When we came back to VCH, one of the families said, 'Thank God you are here. Sammy is like sunshine for us,'" says Luz.

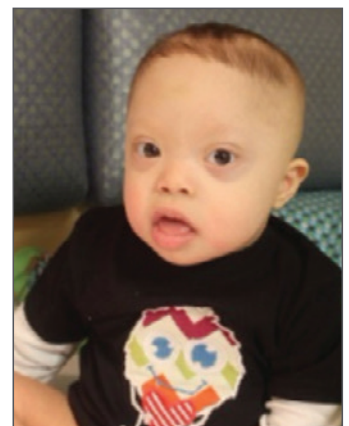
Rodrigo adds, "The nurses fight over him."

Luz and Rodrigo found out Sammy had Down syndrome two weeks before he was born. Sammy and his parents met DSAMT just after he was born, when parent mentors visited them in the hospital and gave them a Celebration Bag, as DSAMT does for

all new families. "Celebrating and supporting individuals with Down syndrome and their families is at the purpose of our First Call Program and at the heart of our organization," says Alecia Talbott, DSAMT's Executive Director. "We especially want to be there for our families when they receive the diagnosis and if they go through lengthy hospital stays, such as Sammy has done. All of us who have met Sammy and his parents have felt inspired by their strength, courage and outlook on life."

Even before his DS diagnosis, doctors told Sammy's parents that his esophagus wasn't connected to his stomach properly, which is a serious condition. Many, many people prayed for Sammy. When he was born on July 4th, the issues doctors had anticipated weren't present. Sammy did have heart problems, but after surgery months later, doctors cleared Sammy to travel to Colombia to visit family. After two days in Colombia and new symptoms, Sammy's parents learned he had leukemia. The family rushed back to Tennessee so quickly that they left their stroller behind.

Sammy needed seven rounds of chemotherapy, at a month each, with only a few days between each round. One night when moving Sammy, his IV line came loose, and some of the chemo liquid got on Luz's arm, severely irritating her skin. Luz thought about what that must feel like inside of Sammy. It showed how miraculous Sammy's demeanor is.



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Sammy tends to sleep all day and stay awake all night, but when he is awake, he loves to see people, smiling and waving at everyone. To break the monotony of longterm hospital life, Rodrigo started walking the halls of the 6th floor with Sammy in a wagon, playing country music from a phone. Sammy's good times began to rub off on his neighbors. One neighbor, Sierra, who was 17, had been morose for a

while, with good reason. She mostly stayed in bed and waited for the worst. When Sammy started his musical wagon and waving tours, Sierra noticed. She started sitting up and waving back to Sammy. Eventually she started making her way to her door when she knew Sammy was coming.

"I want to pray for Sammy. He makes me feel beautiful inside," Sierra said to Luz. She put her hand on Sammy's shoulder and said, "In the name of Jesus, I declare you cancerfree." Just before she left to enter hospice care, Sierra gave Sammy \$100, which his parents used to replace the stroller they had to leave in Colombia. Two weeks after she left the hospital, Sierra passed away, and Sammy's blood results came back showing 0% evidence of leukemia after only one round of chemotherapy.

"I believe in God," Luz says, thinking of this story, and many others. It's just evident: Sammy is special.

Sierra is far from the only stranger Sammy has had such a positive effect on. Luz says, "This lady came to our door and told me a story. Her son was really sick the other day, he was laying down, he didn't want to eat, or take a shower, or anything. At the moment we passed his room with the wagon, and Sammy waved, her son said, 'Mom, you know what? Order food for me. Help me take a shower, and turn the TV on. If this little guy is going through the same thing as me, and he is smiling and waving, so can I.'" Sammy's hospital neighbors, doctors, and nurses all have hard experiences, but when you talk to the people staying and working on the sixth floor of VCH, many of them will tell you that Sammy's presence has made life more fun, and the outlook more positive, even when the outcome is not.

Sammy, Luz, and Rodrigo are looking forward to the day when the outside world gets to enjoy Sammy, too. After the final round of chemotherapy, they plan to move from their home in Clarksville to somewhere much closer to Nashville.


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Down Syndrome Association
of Middle Tennessee

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DO YOU KNOW SOMEONE WHO SHOULD BE IN THE DSAMT SPOTLIGHT?

Sammy is receiving \$100 and a special gift for being our Spotlight focus! Do you know someone who wants to be our Spotlight of the Month?

Email a photo and a short explanation why to lisa@somethingextra.org.

Winning submissions will receive \$100 and a special gift!