

PROVIDENCE Journal

Entertainment

R.I. child's courage leaves a comforting legacy for families struggling with cancer

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Tina Robison and Kyle Wohlrab will show you.

The couple are the founders and driving forces behind the Providence-based Izzy Foundation, a nonprofit group dedicated to supporting children with cancer and their families.

Robison and Wohlrab's 1-year-old daughter, Isabelle, was diagnosed in 2009 with rhabdomyosarcoma, a cancer that affects muscles. She went through two years of treatment -- surgeries, chemotherapy and radiation -- but right before her third birthday, Izzy had a recurrence. The family began the foundation to help defray the cost of a stem-cell transplant in Germany. They held a fundraiser in a park by their East Side home in the fall of 2011 -- and raised \$25,000.

Her parents had created a blog that documented Izzy's fight, and their support network continued to grow.

On March 12, 2012, Izzy died. As the family sought to honor her memory, the

“We thought, how can we keep that inspiration going?” said Robison. As Robison and Wohlrab are both physicians at Women & Infants Hospital, “We had a different perspective,” she said. “We really wanted to create something that’s unique, that filled in a lot of the gaps that we saw.”

Their first project was to carve out a space for families at Hasbro Children’s Hospital, both to honor Izzy and to help parents stay connected to other families who were enduring similar struggles. The hospital already had a room set aside, but “it was tiny and dark and not inviting at all,” Robison said.

They got to work in May 2012. “We delved into ‘What do we want it to feel like? What do we want it to look like?’” Robison said. A family friend, New York-based architect Tom Morbitzer, had followed Izzy’s ordeal and volunteered his time.

“He came up with this amazing design,” Robison said.

As with any project, costs went up, so the foundation kept fundraising. Annual golf tournaments and yearly “Lavender Lights” galas -- for Izzy’s favorite color -- helped finance the project. Hasbro helped find donors, and the Children’s Miracle Network also contributed.

In addition, there have been independent fundraisers by “all kinds of kids [who] have really been moved by this story,” Robison said. Some have held events at their schools and sold bracelets they’ve made; one girl donated the profits from soap that she made and sold at farmers’ markets.

The Izzy Family Room, complete with a painting of a napping Izzy snuggling her dolls, opened this spring.

“There are very few things in life that exceed your expectations, but this was one of them,” Robison said.

The cheerful purple room has computerized skylights that project seasonal scenes, a full kitchen to cook family meals, even a vase of fresh purple flowers donated each week by Cranston’s Woodlawn Gardens Florist. There are computers, a flat-screen TV and a stock of movies, and a picture window with a sweeping view of the city. Most important, visitors find a place to relax and have family time away from the more traditional, sterile hospital setting.

Erin Scott, the room's program director, helps keep everything in order, down to the Go-Gurt tubes -- a favorite of a young patient -- that she stocks in the freezer. It has also served as a space for yoga classes, back-to-school haircuts, massages, even an improv session inspired by a boy who said he just wanted to laugh.

"It's an incredible resource for children and families," said Michael J. Cerio, communications officer for Hasbro. "It gives them an opportunity to recharge."

"My family is here all the time," said Eliz LaVallee, of Hopkinton, mother to 2-year-old patient Brayden and his sister, Isabella, 4 1/2. Brayden likes to sit at the computer and watch "Barney" episodes on YouTube and have tea parties with his grandmother. "He drinks mint tea in the window seat."

With the warm reception the Izzy Family Room has received, the foundation is looking to expand the room's offerings and is planning other projects, including a holiday program in which it adopts bereaved families. The foundation also gives scholarships to children with cancer, as well as their siblings, this year awarding \$21,000.

Businesses are pitching in, too. Pawtucket's Loisselle Insurance held a dress-down Friday for their employees, then donated the money to pay for a pizza-and-movie night. Dunkin' Donuts keeps the room stocked with coffee, and Wal-Mart provides snacks.

"It's been unbelievable, the amount of support," Wohlrab said.

Next up for the foundation is its third annual Lavender Lights gala, billed as a "purple-tie" affair, set for Saturday at the Providence Biltmore. The hotel will be decorated with purple lights for the event, and the State House will glow purple during the gala.

In the future, Robison would like to start a specialized daycare center near the hospital for children with cancer, as well as their siblings. "Especially with younger kids, you don't put them in school and daycare because you're worried about infections," she said.

The foundation's projects stretch to North Carolina, where it has a branch that helps children with disabilities. The group, started by Izzy's family members there, is working with Rhode Island architect Mark Saccoccio to build an all-abilities playground.

"She was always so positive, and we've kept that philosophy in our mission," Robison said. She is, her family says, an "izspiration."

Find more information about the Izzy Foundation and the Lavender Lights gala at theizzyfoundation.org and on Facebook at facebook.com/TheIzzyFoundation.

