

Yale-New Haven wall gives hope for ICU babies

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Every time Rachel Anderson of Fairfield looks down at her 2 1/2-year-old son as he runs through the house and teases his older brother, she can't help but think about the days she spent wondering if he'd even make it to toddlerhood.

Patrick was born seven weeks early, and because he had a very rare vascular tumor, he was put on a ventilator before his umbilical cord was even cut. He spent 120 days in the neonatal intensive care unit at the Children's Hospital at Yale-New Haven, with total system failure.

"No one believed he would live," said Anderson.

But on Thursday night, the Anderson family was on hand at the hospital for quite a different reason: to celebrate the lives of Patrick and the other many children who have survived the traumas of their earliest, most helpless days — days they spent in the NNICU, being watched over by staff members and their parents.

That's when the hospital dedicated a Wall of Hope, a collection of photographs and stories of 23 of the "graduates" of the unit, providing examples of inspiration and hope to all who come to see the photos. The 23 kids, which includes two sets of triplets and one set of twins, are all now between 7 months and 11 years old, and they spent anywhere from 7 days to nearly a year on the unit after birth.

The Wall of Hope is the project of members of the Family Advisory Council, which was formed in 2010, to come up with ways of helping families and patients. Staff members, administrators and parents all work together on the council to improve parents' experience.

Anderson, who is a parent on the committee, said that one of the very hardest things about being a parent coming to the unit was facing the uncertainty of her child's future.

"When I was there, I would have loved to see the stories and faces of kids who had come out of the NNICU and who are now kids running around with soccer balls," said Anderson. "I wanted to talk to another mother who had been through this, who'd had a child who was sick for so long, and who could let me know that things could one day be okay."

The photographs were taken by Jacklyn Greenberg, of New Haven, a professional photographer who volunteered her time and expertise. She met with the children in a playground this past summer, one at a time, over a four-day period and snapped hundreds of photos.

"The challenge was finding each kid's light and energy," she said. "I want the people who come through here and look at these photographs to get lost in the eyes of these children — to see the hope and courage and strength there, that allowed them to recover when they were so young."

Over 100 former patients, parents, aunts, uncles, grandparents, and staff members jammed the hallway at the ribbon-cutting event. The children, including Patrick, zoomed around the hallway, dancing and playing. Many of the adults had tears in their eyes.

Kathy Blankenbaker, of Guilford, a registered nurse has worked for 11 years in the NNICU.

"The hard part is that it doesn't always have a happy ending," she said. "It's so good to see when it does."

And that's the point of this Wall of Hope, said Cynthia Sparer, the executive director of the Children's Hospital and vice president of women and children's services.

"We understand. When you're here, you can feel so alone. You watch the healthy babies go home, and you wonder what's ahead for your own child. This wall tells people, 'You are not alone. There are people who have stood in your shoes and walked out the other side.'"

The children's photographs are accompanied by a plaque that gives the child's first name, birth weight, a description of the health challenge at birth, and then a statement about what the child is like today.

Fabrizio Fiondella, 6, of North Haven, was the longest resident of the NNICU, staying for 363 days, or until he was nearly one year old. Currently he's a healthy kid with big brown eyes and a ready smile, who remembers nothing of his stay there. Today, laughing and talking about Indiana Jones and Spiderman, his favorites, he has no idea that he was born 16 weeks premature and that he weighed 1 1/2 ounces, and was small enough to curl up in the palm of his mother's hand.

His parents, Federico and Dayana, will never get over it, of course. Dayana Fiondella lived at the hospital for that whole first year, she said, while Federico Fiondella, a teacher at North Haven High School, came every day after work to stay with her and the baby.

Anne Marie Merrill, of Woodbridge, gave birth to triplets there, nearly two years ago. Anastasia, Andre, and Addison weighed between 2 pounds 13 ounces and 4 pounds and 3 ounces, and spent varying times on the unit, before being allowed to come home, one by one.

"You feel so bad leaving your babies at the hospital," said Merrill. "It's the very hardest thing. And even though I had so much support, I still felt so alone."

Molnar said the Wall of Hope was a priority for the council. "We wanted to give some comfort and hope to the families who are here," she said. "When you're here and going through such a scary time, you need a glimmer of hope — and looking at the faces of these children who are the graduates can provide that."