

YOUR STORIES

MIAMI-DADE

A REAL FANTASY CAMP

VENTILATOR DEPENDENT CHILDREN GOT TO SWIM — SOME FOR THE FIRST TIME — AT MIAMI CHILDREN'S HOSPITAL'S CAMP

When he was 11, the walls of Elliot Ortegán's bedroom were lined with sports memorabilia and diving medals.

The Chicago boy practically lived in the pool, his mother, Judy Santiago said, until the day he woke up to go to school and was paralyzed from the tongue down.



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IDY FERNÁNDEZ

An unknown virus attacked his body as he slept, Santiago said, and doctors remain baffled as to its cause or how to treat it.

Now 13, Elliot, who is unable to speak or move, is hooked to a ventilator. Gone are the diving medals hanging on his bedroom walls. In their place are oxygen tanks, sterilized tubes in air-tight packages and the ventilator with its backup, his mother said.

As for the pool, Elliot hasn't gone outside in two years.

But two weeks ago, Elliot had the sun's rays on his face again while in the pool water at A.D. Barnes Park in West Miami-Dade. He and some 92

other children dependent on ventilators were able to go into a pool — some for the first time — thanks to Miami Children's Hospital's Ventilator Assisted Children's Spring Camp.

"For a parent, this camp is the greatest thing that can happen to a kid like Elliot," Santiago said. "He became such a loner after the virus. I haven't seen him like this in a while."

The weeklong sleep-away camp is the idea of Dr. Moises Simpson, chief of pulmonology at the children's hospital, who created the camp nearly 20 years ago as a way to give children a world beyond syringes and oxygen tanks, he said.

Over the years, it has attracted ventilator-assisted children from all over the nation who meet other children with similar ailments, Simpson said. The campers, who range from age 2 to 21, also interact with teenage volunteers who are recruited from local high schools, Simpson said.

"The incredible thing about our camp is that when you look into the crowd, you can't pick out the sick children from the healthy children," Simpson



TIM CHAPMAN/HERALD STAFF

TIME FOR A DIP: Elliot Ortegán, 13, who survives with a ventilator, takes a dip with the help of volunteers at the Ventilator Assisted Children's Spring Camp at A.D. Barnes Park.

said. "All the children blend in, and they get to behave like children are supposed to."

At this year's camp, which is all inclusive and paid for by the hospital through grants, fundraisers and donations, the kids and their families were treated to field trips to Parrot Jungle, Bayside and Don Carter's Bowling Lanes, said the camp's coordinator, Bela Florentin.

The kids were also able to go sailing and kayaking through Shake-A-Leg Miami, a watersports center for disabled and able-bodied kids and adults, Florentin said. But swimming is always the kids' favorite activity.

The whole process of getting them into the water takes about 20 minutes for each child, she said, and can be a five- to six-person job.

First, the kids are wheeled to the side of the pool. Then they quickly disconnect from their battery-packed ventilator and connect to a manual ventilator, which is essentially a long tube with one end connected to the child and the

or volunteer, Florentin said.

The nurses and volunteers are trained to time the air bag to their own breathing as they pump air into the kids' lungs, she said. While one person is handling the air bag, two or three others are carrying the child from their wheelchair and into the water, where they are received by Simpson and another volunteer or nurse.

Once in the water, the kids are held by nurses and volunteers, Florentin said, while the person in charge of the air bag continues to pump air into the child's lungs.

The usual pool games then start, like relays and water fights, she said.

"This is my second time at the camp, but my first time in the deep end," said Brittany Dupont, a 13-year-old from Plantation whose tracheotomy was sealed with a special plug provided by the camp while she was in the pool. Brittany became quiet and introverted after chronic respiratory problems left her needing a ventilator to breathe, her nurse, Melissa Roman, said.

cheerful and chatty.

"When you see those kids smile and you know you're changing someone's life," camp coordinator Florentin said, "you think you're going to teach them something, but they actually teach you how to really appreciate life."

Idy Fernandez is a Herald staff writer. She can be reached at imfernandez@herald.com.

SMART BOX

IDEA SUBMITTED BY

- **Who:** Cynthia Gutierrez-White, 31, of Coral Gables.
- **How she came across the idea:** Gutierrez-White helped coordinate Miami Children's Hospital's Ventilator Assisted Children's Spring Camp.
- **Why she submitted the idea:** 'I wanted to share the beauty of this camp, which helps families of ventilator-dependent children see new possibilities in life,' Gutierrez-White said.



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SMART BOX

HOW TO HELP

- **What:** Miami Children's Hospital's Ventilator Assisted Spring Camp for children who are dependent on ventilators to breathe.
- **Information:** To become a volunteer, participate or make a donation, call Bela Florentin at 305-662-8222 or visit