

A R E A T I I of R E C H A I N

Kids Who Are Hooked To Ventilators Need A Lot Of Help To Stay Alive. Suction Machines, Liquid Oxygen, Bladder Catheters, Mucus Vibrators, Feeding Tubes, Machines To Measure Oxygen In The Blood. It's No Fun. Except When They Go To The One Summer Camp In The Country Built Especially For Them.

At the age when most toddlers are pulling themselves up and attempting a few steps, Oscar Gonzalez couldn't stand at all; his legs kept bucking under him. At 13 months, he was diagnosed with Werdnig-Hoffman disease, a rare genetic illness related to muscular dystrophy that causes spinal and muscular atrophy and gets increasingly worse. As a result, Oscar never took his first step; he went straight from a stroller to a wheelchair. It was the same story with talking. Just as he was beginning to say a few words, coordinating talking with breathing got too difficult. He went from blurring out "mommy" and "daddy" to being dependent on a ventilator — a portable machine that did the breathing for him — and relying on a computerized voice to talk for him.

But, at age 7, he reached the lowest point of all when he got double pneumonia. He went into a coma in ICU at Jackson. His mother doesn't remember exactly how he started improving, months after he seemed too far gone to ever get better, but she does remember when he improved enough to mouth a few silent words to her. She leaned over his face to read his lips, nodding encouragement over his closed eyes.

"How many . . ." Oscar began but couldn't finish. "How many what?" his mother, Delores, shouted frantically, trying to keep him conscious. "How many what?"

"How many more days to camp?" whispered Oscar. "I want to go."

And he did.

It has been three years since Oscar's miraculous recovery in time for VACC (Ventilation Assisted Children's Center) Camp — the only camp in the country specifically for ventilator-dependent kids — and he has made it back every year since. And every year since, he has gone with the same amount of machinery and equipment that accompanied him three years ago — "enough for a portable intensive care unit," says his respiratory therapist, Noelia Beno. Instead of a duffel bag full of labeled shorts and shirts, Oscar goes to camp in his tractor-like wheelchair, angled and padded for full body support from the head down. He carts the portable ventilator that breathes for him, a suction machine that cleans out his

trachea, an oscimeter to measure the amount of oxygen in his blood, a liquid oxygen tank, an air compressor, a nebulizer to give measured doses of medicine, a bladder catheter, a mucus vibrator, a feeding tube and an assortment of pills, straps, tubes, pads, batteries and spare parts. And he goes with 22 other kids — who for a variety of reasons ranging from paralysis to genetic disease — need as much equipment as he does.

It is Saturday, April 4, the first day of VACC Camp, which will run for a week in A.D. Barnes Park on Bird Road at 72nd Avenue. The six sleep-over campers and their families — mostly from out-of-town — are arriving and settling into their cabins. On Monday, they will be joined by 17 day campers and their families from Miami.

Paulette Kempinger has brought her son William, 13, down from North Carolina. Mother and son are sharing a cabin with Delores and Oscar, who though they're local, got to come to sleep-over camp this year. Normally, Miami families come to day camp from 9 a.m. to 9 p.m. and go home to sleep, leaving the cabins for the out-of-town campers. But when a family of six from California canceled at the last minute, Oscar and Delores — who live in Hialeah — got two of the 24 sleep-over spaces. Oscar was ecstatic over this.

The year that he came straight from intensive care to camp — when there were only local kids there — Oscar got to sleep over. He would lie in bed and stare at the cabin ceiling for hours. It is a high, vaulted, wood-beamed ceiling, so different from the low ceilings in the hospital and at home — the only ceilings he had ever seen. And because he spends so much time lying on his back, he pays a lot of attention to what's over his head.

"I love this ceiling," he whispered to his mother one morning that first year at camp, when she asked him why he was smiling.

Let The Good Times Roll

But on this first day of VACC Camp 1992, Oscar, 10, is not staring at the ceiling. The mobile intensive care unit that is Oscar is zigzagging through the woods. The wheels crunch over pine needles, oak leaves and palm fronds, as the child, strapped in a seated position, gently presses,

with the little strength still in his hand, the control stick that sends him and his 400 pounds of equipment in the direction he chooses.

It is a mild, cool afternoon, and the sun flecks across his face through sprawling oaks. A Jay calls. Oscar stops to watch a huge golden orb spider link its web between a tall pine and a sabal palm. A monarch butterfly circles his head and when he tilts back to look up at it, he spots a huge raccoon sleeping on an oak branch.

Another camper, Derrick Green, 11, wheels up to Oscar. "Hey, Oscar," yells Derrick, "remember me?"

Derrick Green, from Homestead, has also locked out and been selected for sleep-over camp, unlike the other Miami families who will come for day camp only.

Oscar, who has trouble talking and rarely talks to anyone but his mom, nods and smiles. The two boys sit side-by-side looking up through the vines, bromeliads and oak branches at the sleeping raccoon. Racing down the path in their wheelchairs, they discover a swarm of bees making a hive in a hollow tree. Farther down, they stop at a fish pond, where a camp counselor feeds them and tells them it is time to get back to the mess hall for games. But after she leaves, they purposely linger. It is not often that they get to go so deliciously defiant.

Oscar and Derrick and all of the other kids at VACC Camp have been prodded, poked, turned out over and over. They have acrodon coils coming out of their throats. They have surgery scars all over their bodies.

Very few of them have any strength in their arms or their legs. Most of them use feeding tubes and diapers. All of them get around in wheelchairs, most by sucking or blowing at a straw.

Ten years ago, they would have never gotten out of the hospital. But now with portable equipment, most of them live at home with the help of their parents, home-care nurses and respiratory and physical therapists.

It's hard enough getting one of these kids from the hospital to home, much less transporting six of them and their families across the continent to sleep-over camp (along with the 17 day campers and their families). But it is something that Moses Sampson, who came to Miami Children's Hospital as a pulmonary pediatrician in 1984, decided these kids needed. He knows how severe their