

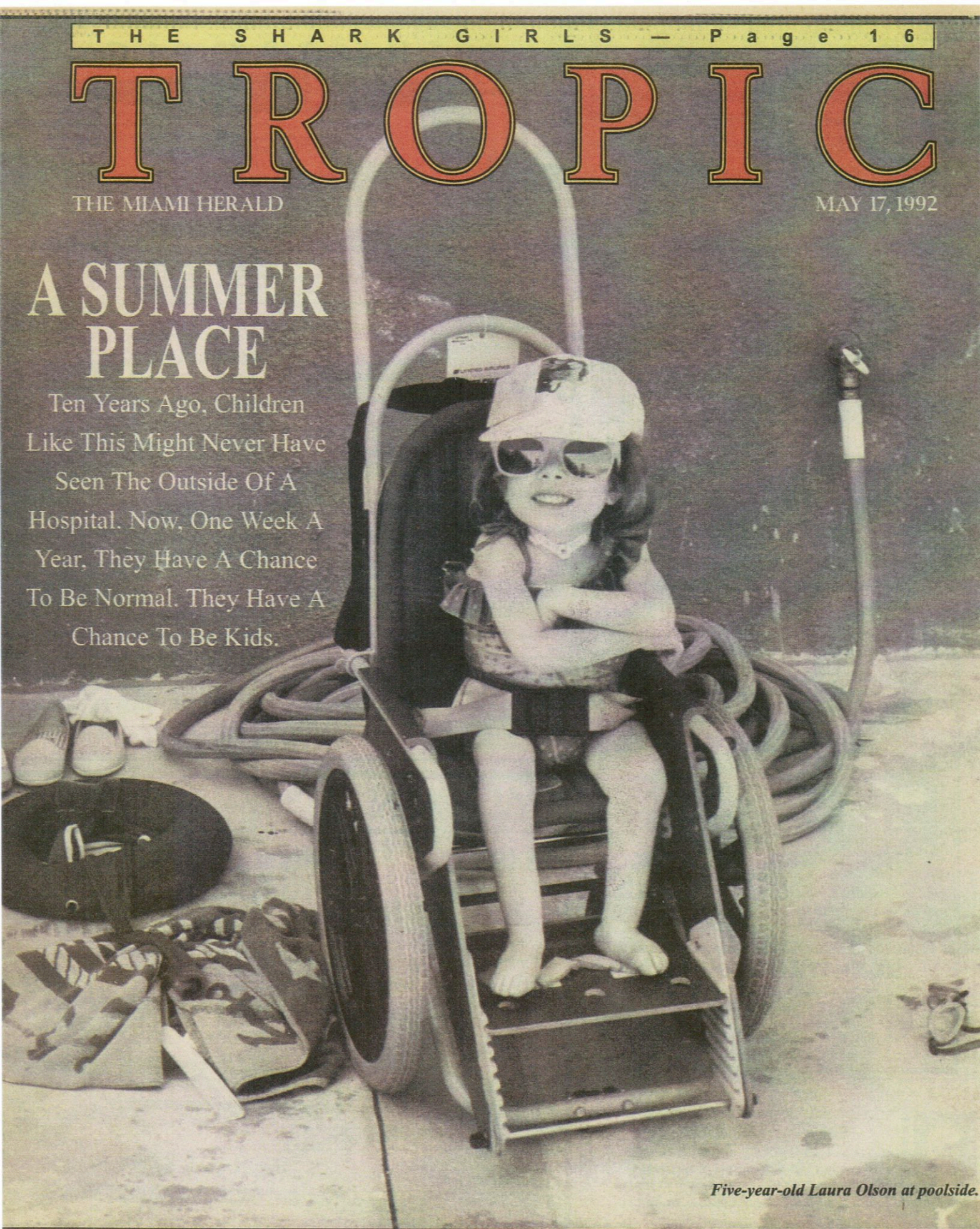
# TROPIC

THE MIAMI HERALD

MAY 17, 1992

## A SUMMER PLACE

Ten Years Ago, Children Like This Might Never Have Seen The Outside Of A Hospital. Now, One Week A Year, They Have A Chance To Be Normal. They Have A Chance To Be Kids.



*Five-year-old Laura Olson at poolside.*

# A BREATH of FRESH AIR

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 buckling 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 blurting 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 oximeter 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 Hiialeah — 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 lucked out and been selected for sleep-over camp, unlike the other Miami families who will come for day camp only.

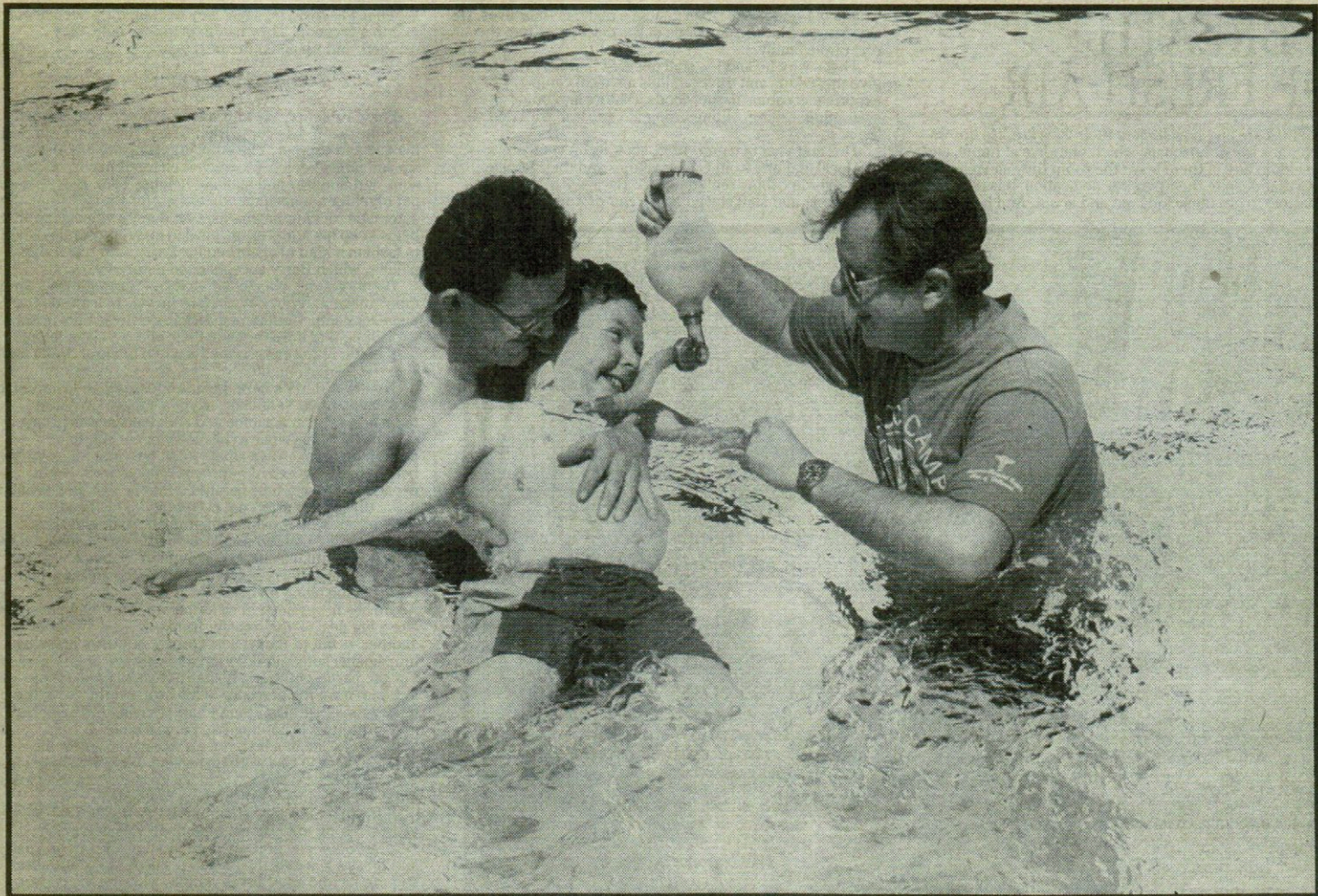
Oscar, who has trouble talking and rarely talks to anyone but his mom, nods and smiles. The two boys sit side-by-side looking up through the vines, bromeliads and oak branches at the sleeping raccoon. Racing down the path in their wheelchairs, they discover a swarm of bees making a hive in a hollow tree. Farther down, they stop at a fish pond, where a camp counselor finds 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 be so deliciously defiant.

Oscar and Derrick and all of the other kids at VACC Camp have been prodded, poked, turned and cut, over and over. They have accordion 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-away camp (along with the 17 day campers and their families). But it is something that Moises Simpson, who came to Miami Children's Hospital as a pulmonary pediatrician in 1984, decided these kids needed. He knows how severe their

B Y M E G L A U G H L I N



*Above: Barry Kelleher, 11, from Grand Junction, Colo., with father, Tom, and camp founder Dr. Moises Simpson (right). Breathing with the aid of a hand-pumped air bag, Barry experiences the simple (for other kids) joy of swimming.*



*Left: Barry takes a walk with camp counselor Roman Perez. His motorized chair is really a portable intensive care unit, including a portable ventilator, a suction machine, an oxygen meter, a liquid oxygen tank, an air compressor, and other equipment. This camp outing is the first time he has been out of his hospital room in months.*

# A BREATH OF FRESH AIR

disabilities are and how limited their lives are. He knows which ones live at hospitals, which ones live at home, and how seldom any of them leave the room they sleep in. He knows that despite their parents' dedication, it is next to impossible to get these kids out and about. And he knows

what a big difference small changes make in their lives. He also knows how the demands of the disabilities trap the rest of the family.

That's why he and his staff decided that they had to give these kids and their families a typical camp experience: cabins in the woods, critters and bugs, swimming, sailing, outings, sing-alongs, trail trips and all the rest.

The first year of camp, 1985, six kids on ventilators — five local and one from Gainesville — and their families slept over in cabins rented in A.D. Barnes Park.

Simpser and staff stayed at the camp 24 hours a day.

When it was over, he says, they felt like they needed a month's vacation. They had to get more help, they decided, and try again the next year.

## "I Did It!"

Barry Kelleher, 11, who was in a motorcycle accident when he was 3, has come from Grand Junction, Colo., with his dad and brother. The shipping company has lost his sip-and-puff wheelchair, which it charged his dad \$2,300 to ship, and Simpson and staff are helping Tom, Barry's dad, put together a makeshift wheelchair for Barry. Minus the automatic rocking mechanism on Barry's wheelchair that helps keep his lungs clear, his dad and Simpson have had to fashion a kind of chair-bed for Barry with ropes and pillows, which Barry accepts good-naturedly.

But forget the wheelchair snafu — Barry himself almost didn't make it. A few days before he was to leave on the plane for camp, Continental Airlines canceled his ticket, explaining that it was against their policy to take people who might require prescribed oxygen in flight. Delta took Barry at the last minute.

Now that Barry's here, he has one thing on his mind: to be a camper. His ventilator, oxygen supply, pressure monitors, suction machine and cath bags are all propped on the rear of his chair as his dad wheels him to swimming. It takes five adults to lift him into the pool. Not because he is so heavy — he's only 80 pounds — but because he is so totally paralyzed that he can do nothing to make the lifting easier, not even hold up his head.

Simpser, who is overseeing the effort, holds Barry's shoulders and squeezes a plastic bottle called an ambu bag to force air into his lungs. Surrounded by people, tubes, coils and bags, Barry is carried across the aquamarine pool, gliding along on his back.

He has never been in water before. This may not seem like a big deal — the transfer from one kind of matter to another — but to Barry, it is. Gravity is always pressing him against some hard surface; it is always pressing back. For the past eight years, he has not had a moment of freedom from the pressure of his own weight. Now, the tender molecules lap around him, swaying his body back and forth. It feels nothing like life in a chair. It feels nothing like life in a bed. It feels like a whole new life, being so light in this wafting, teasing thickness. In his face you can see the change. He looks up at the sky. He closes his eyes. He whispers something to his dad.

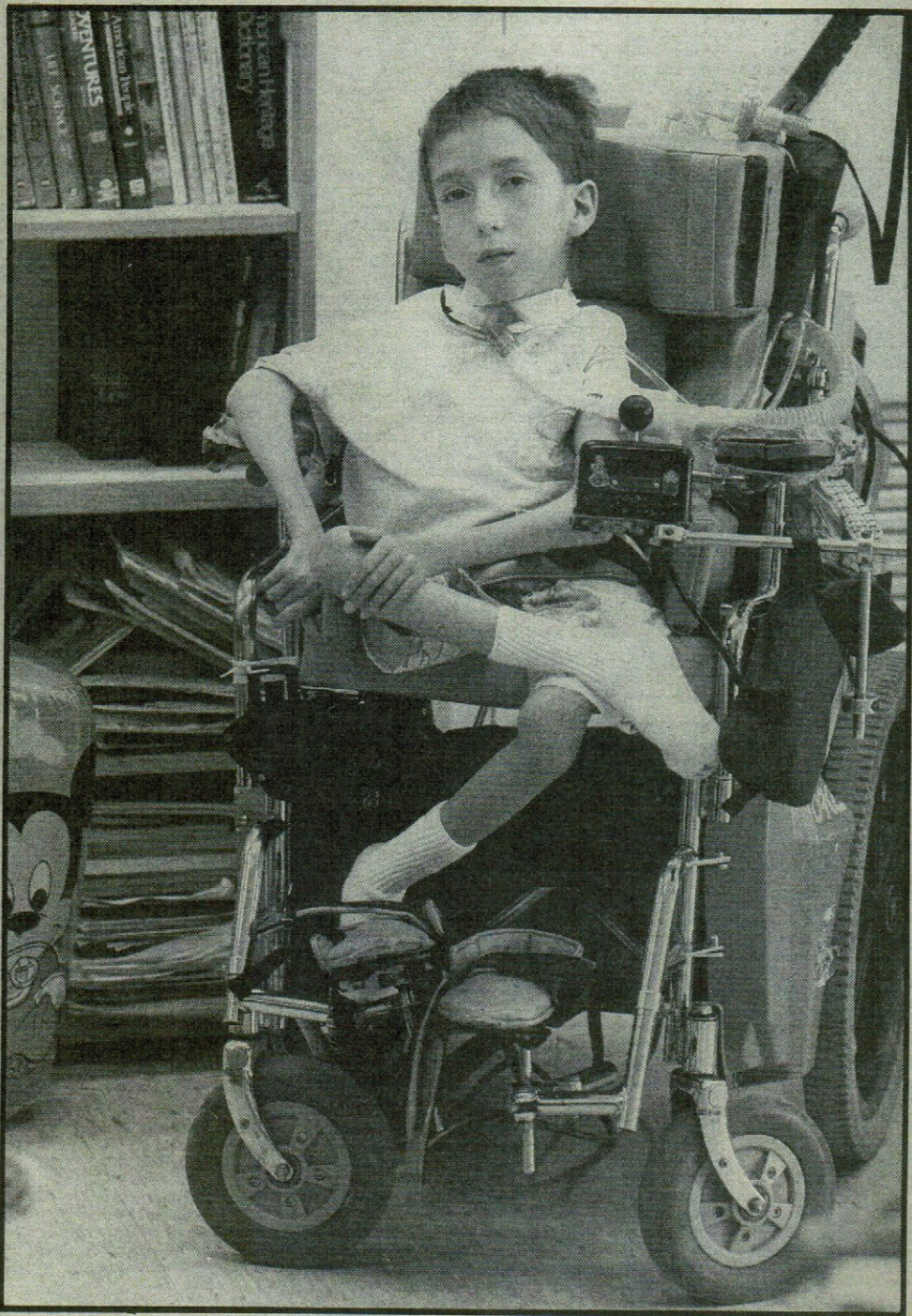
Suddenly his dad is shouting. Barry needs a spoon, he yells, pointing to a bag near the pool. Faces tense. A seizure? Someone grabs a large plastic ladle out of a bag and throws it across the pool to his dad, who pokes the spoon's handle into Barry's mouth, while he leans over Barry's face and whispers something to him. Everyone watches nervously as Barry loosens his jaw-lock on the ladle and it dips limply into the water. Then, Barry chomps down on the handle again, hard enough to force the full ladle of water flying into Simpson's face.

The doctor sputters and shouts, which sends Barry into gales of laughter. Then, together, Barry and his dad plot against their next victim. Around the pool, Barry and his entourage go, with Barry flicking water in everyone's faces, with Barry, so disabled a major airline wouldn't carry him, laughing so hard the tears are streaming down his face.

Oscar, who has decided to go swimming, is floating in a corner of the pool while his mother, Delores, holds his shoulders and head and someone on the camp staff uses an ambu bag to pump air into the tube connected to a surgically created opening in his trachea. Near Oscar, William from North Carolina has ventured into a deeper part of the pool with a group of counselors and camper Whitney Foster, 8, who lives in Miami Beach at The Baby House with other disabled children. Both Whitney and William are temporarily off their ventilators and are being swished in circles through the water by the counselors.

William announced earlier, as the campers got off the bus from a visit to Parrot Jungle, that, on this day, he would try to go under water — something that would normally be out of the question for a child on a ventilator. But, said William, he would be sure to cap the hole in his neck and try really hard to blow out of his nose and mouth to keep the water out. William's mother is very nervous about the whole project because she knows the danger of infection and pneumonia if water gets in his trachea, but the camp staff has persuaded her to let him try it.

This is a first for both Whitney and William. Neither has ever been under water before. A simple thing, but for these kids anything beyond the routine of computer games and cable TV is an indescribably big deal. Everything that gives them a choice, a different view, a new environment is something they talk about, dream



Buddy Bryan, 11, from Broward Children's Center, where he lives. His stay at camp was short. All campers need to be accompanied by someone to operate their equipment, and the children's center could only spare staff for one day.

about and think about long after it's over.

The moment builds as they swirl through the water. They are singing with their counselors. *Ring around the rosie, pocket full of posie* . . . When they get to the "all fall down" part, they duck beneath the surface.

Whitney and William emerge, drenched and startled. Immediately, the counselors start cheering and applauding, and the campers join in. All over the pool people are yelling and clapping for William and Whitney.

"Oscar, I did it!" whoops William to his friend, who is floating nearby.

"Great," yells back the normally silent Oscar, who has forgotten he can't talk.

### 24 Hours A Day

At night, the parents gather outside the cabins on the patio to talk about life with their children. They talk about failed attempts at getting them schooled. Practically all of them have had to fight battles to get the public school system to take their kids. Practically all of them say their kids are miserably behind grade level, not because of mental deficiencies, but because the kids spend so much time in critical care, and the school systems all over the country seem unable to accommodate them when they are well enough to learn. Some go to public school, but most are like Oscar: The only schooling they get is a couple of hours of homebound tutoring a week.

The parents sit under the pines while camp counselors serve them *cappuccino* and brownies. Delores, Oscar's mother, comments on how nice it is to be waited upon and pampered since it is she who is always doing the waiting and the pampering.

"I went back to work this year," says Charlene, the mother of Garret Frey, 9, who was totally paralyzed in a motorcycle accident when he was 5. "I had to have a life of my own."

Delores listens intently. Last year, she and Oscar's dad got divorced. Delores has started back to college and needs encouragement to stick with it. She is trying to have some goals for herself, without feeling guilty. One of the members of the camp staff says something about how difficult it is to find the right balance between being

supportive and being overprotective.

Then the parents' conversation turns to the lack of privacy in their homes with nurses constantly coming and going. William's mother says she asks the nurse to step outside so she and her husband can argue. Garret's parents say they yell at each other in front of whoever happens to be there.

"We're not perfect; we're human," says Jerry, Garret's father. "We figure if Garret can accept his disability, the least we can do is accept who we really are."

There is talk about the kids approaching puberty and how to deal with it. A sadness comes over the parents when they talk about their kids' futures. Some of the children are not expected to get better. Most have degenerative diseases. Derrick's mother, Francine, reminds the other parents that her son was diagnosed with muscular dystrophy years before, and she was told he would get worse and worse until he died. Two years ago he came to camp, and he had so little muscular control, he couldn't even open his eyes. But now he has enough strength to propel his unmechanized wheelchair by hand. He can even take a few steps. Simpson thinks he'll be totally off the ventilator by the end of the year.

"That child of mine," says Francine, "is a miracle boy." "All the kids seem to get better at camp," says Barry's father.

For meals, the campers and their families line up at long tables in the mess hall. Some of the kids hoe into ziti, Italian sausage and salad. All of the parents and brothers and sisters do. But most of the kids sit at the camp table, amid all of the eating, while a nurse or parent fills their feeding tubes with canned formula. One boy, 3-year-old Jeremy Martinez, insists upon an empty plate and a spoon. He scoops the spoon along the plate and puts imaginary food in his mouth while his mother pours a chalky liquid into his feeding tube.

Late nights in the cabins are like nights in intensive care. Nurses and parents are up, off and on, all night. Alarms scream. There is the constant clicking of dials and the sound of people gurgling. Gauges are periodically checked. Most of the children must be turned and suctioned every few hours. Nurses go from bed to bed catheterizing bladders, inserting suppositories and

changing soiled pads.

Just to get one child ready for bed takes hours. The sponge baths. The bronchial dilators. The vibrating, pounding on backs and suctioning to free plugs of mucus. The catheterizing, the hydrating, the careful cleaning around incisions, the administering of medications, and more medications.

When you see the kids dressed and hot-rodging around in their wheelchairs, despite the ventilators and equipment, despite the obvious disabilities, you have no idea what goes into their care. But when you see their frail atrophied bodies being handled, rubbed and manipulated, as they lie in bed exposed and helpless, you get a sense of just how difficult it is for them to keep going. You also get a sense of what truly great sports they are. And how little the physical self has to do with who anyone is.

### Easy Sailing

It is the fifth day of camp and the kids are sailing, clipping along with their hair blowing and their faces full tilt in the salt air. Past Vizcaya and the colorful Brickell condos, and under the Key Biscayne bridge. Oscar is fascinated by the massive concrete columns and the underside of the bridge — the highest and most massive ceiling yet. Gulls and cormorants circle the catamaran's massive sail as the boat glides through bright sun and jade-green water.

The kids on ventilators from Broward's Children Center — Jason, Tish, Buddy and Felicia — have joined the camp for a day. Jason Shomer, 22, in rainbow-mirrored sunglasses, is the coolest thing going. He does not say it to the younger kids, but his presence does: Look at me. You can have a life. He whips his motorized wheelchair around with impressive flair, tells true stories of driving it around town as if it were a car.

Jason is so disabled he has to live in a hospital, but he is so able, he's dead set on coming up with the money to go away to college by himself — to Edinboro State College in Pennsylvania. They have a dorm there, he says, that is staffed by nurses. He plans to become a high-school teacher.

The huge catamaran motors down the channel, into

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# A BREATH OF FRESH AIR

Bayside. Of the three outings the campers go on each year at camp — to the Parrot Jungle, the Seaquarium, and on this catamaran — this sail on the Pau Hana, owned by Bayside Cruises, is the only trip that is always free of charge. While the campers and their families never pay a cent, the camp does pay for the other outings — mostly with donations from Miami Children's Hospital, the American Lung Association and private donations. Of the 40 people who work at the camp — Simpser, his office staff, van drivers, high school- and college-age counselors, nurses, respiratory therapists, cooks, maintenance crew — all but two (the all-night nurses) do it for free.

It is time to lift the kids off the boat: Crew, camp staff and parents gather around to heave each child strapped in an equipment-laden wheelchair into the air. Barry's chair, which finally made its way to Miami, is especially heavy, and the lifters sweat, grunt and tremble under the weight. Barry is thrown from side to side as they hoist him skyward. He, too, breaks into a sweat as the chair slams into the side of the boat and tilts him backward. When they finally get the chair down on the deck, there is much face-wiping, groaning and gasping.

"Thank-you," says Barry. So quietly but earnestly do the words echo out of his ventilated throat, that everyone is quiet. For a brief moment, there is a profound realization of what is tied up in that thank-you — what Barry has been through, and what he knows about how much the people around him want to make things better for him.

The campers leave the boat and head for lunch on the water. The wind blows through the outdoor restaurant and music plays. The kids, their brothers and sisters and their parents talk excitedly. Oscar is so into the camaraderie of it all, even though he can't eat, he gets his mom to order a burger plate, and sucks the salt off the fries.

## A "Great Deal"

For this outing to Bayside, Delores has brought Oscar in her van, instead of riding on the camp bus. Oscar has trouble with the heat on the bus, explains Delores, as they head back to her air-conditioned car. But as she drives down Biscayne Boulevard, stopping at a red light, the car stalls, and she can't get it started. Over and over she tries, the battery growing weaker with each attempt. The motor won't turn over. It is a hot afternoon and the interior of the van heats up quickly. Cars honk at them. People scream at them. For anyone, this would be a miserable situation. But for Delores Gonzalez, it is a grave emergency. Oscar's oxygen supply is limited. He is stuck in the hot van.

Delores jumps out of the car and goes from car to car behind her.

"My son is on a respirator in the van," she says, enunciating each word carefully because she is deaf. "I've got to get it started. Do you have cable jumpers? Can you help me?"

But she is in downtown Miami, where people are often approached in their cars and are tired of being hounded. She is in a place where people are suspicious and distrusting of stories of misfortune. They know the scams. They've heard the sick child story before.

As Delores goes from car to car, windows go up, doors lock, people turn away.

"Please," she begs. "We're desperate." A few people answer her. They haven't got cables, they say. They haven't got time. Delores goes back to the van for her portable phone with the hearing attachment. Last year, when Delores was with Oscar downtown, the electric wheelchair ramp in the van broke. She called 911 and got connected with the fire department. Station six sent a truck to help her.

Sorry, the 911 operator tells her this time. Broken down cars are out of police jurisdiction. Even if the child is on a respirator, the police don't furnish jumper cables.

Then, says Delores, connect me with station six at the fire department.

Sorry, the voice repeats. He can't transfer a call to station six.

Delores tells Jackie, Oscar's nurse, to run to the Bayside information booth and ask them for help. Maybe they can send security people over. But at the Bayside booth, they say sorry they don't have anything to do with security on Biscayne Boulevard. Maybe she should try 911.

Back at the van, Jackie takes a turn on the phone with 911 and gets a little further than Delores. The dispatcher says since it's an emergency they'll send help. But, first, he needs to know: "Is this the kind of emergency that requires a siren?"

"No," says Jackie. "You don't have to use the siren. Just get here soon and bring jumper cables."

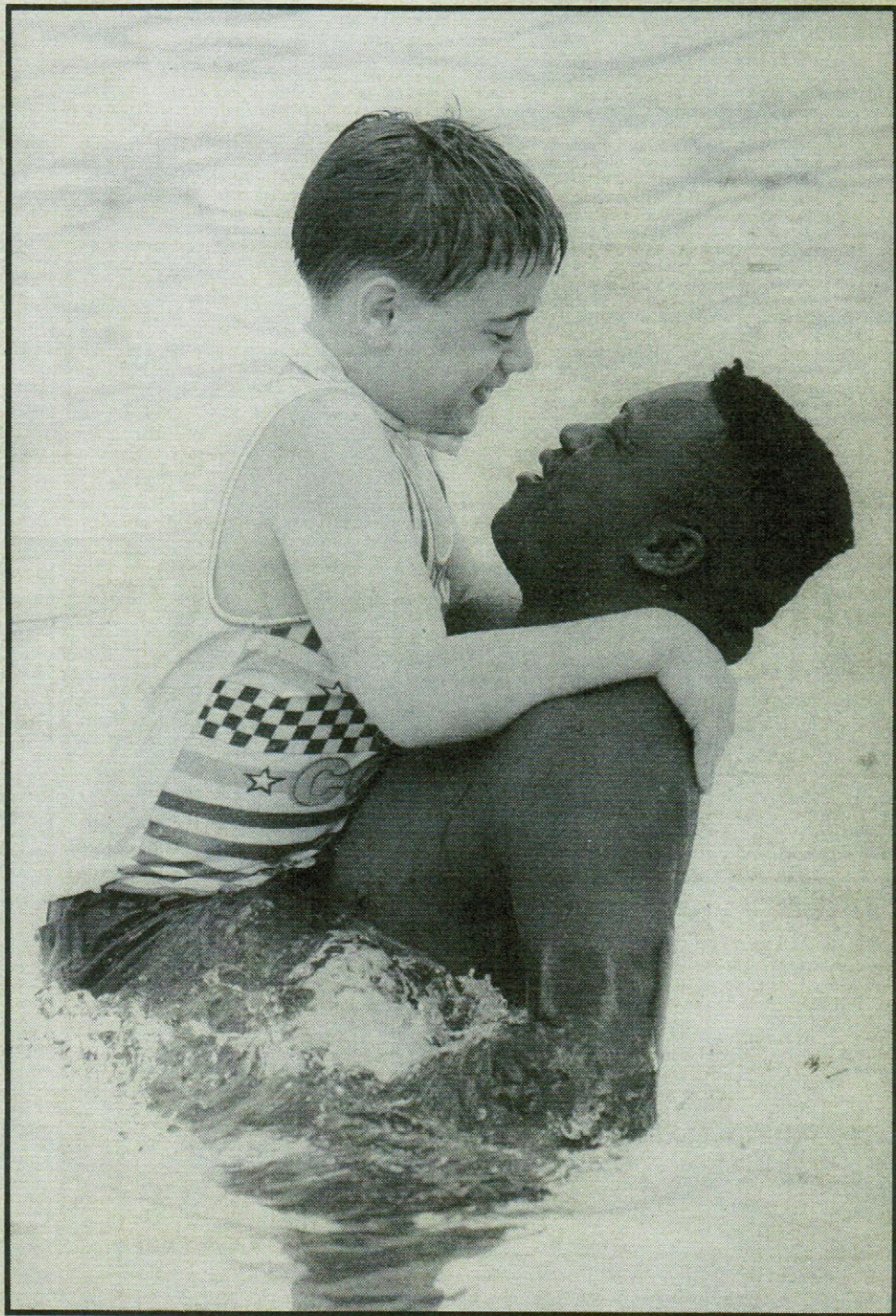
"If it's not an emergency," says the dispatcher before hanging up, "you've called the wrong number."

Later, Juan Del Castillo, a public information officer for Metro-Dade Police, will say: "I've seen officers sent out for

far less. If a car's blocking traffic, if children are in it, if a motorist is stranded, someone will usually go out to help. But there are many individuals in the system and you're dealing with a complex communications network."

Oscar, stuck inside the van, has started gasping. His skin has grown very pale with splotchy red patches. Delores, afraid he'll soon pass out, leaves Jackie with him and starts frantically knocking on car windows again.

Yes, says a smiling man. He has cable jumpers, and he'll be glad to let her use them and his car. Delores is so relieved she practically hugs the man through the open



William Kempinger, 13, from North Carolina, temporarily off his ventilator, clowns around with counselor Clay Drewitt. His big moment would come later: a quick dunk under water.

car window.

"For \$15," he tells her.

Delores looks in her purse. She has exactly \$15, \$10 of which she is to turn in when she gets back to camp, for a plaque to the camp staff from the parents.

"Please," she tells him. "Take \$5 and I'll owe you the rest."

"No," he says. "It has to be at least \$10."

Delores is on the verge of tears. She is a person full of faith and goodwill. She is having trouble understanding this. Starting to feel disoriented and dizzy, she walks to her van to lean against it.

"OK," says the man, getting out of his car to follow her. "Five bucks. But you're getting a great deal."

### "I'm Like E.T."

Back at the camp, Delores and Oscar take a nap in the cool high-ceilinged cabin before dinner, while the camp staff sets up booths, drapes crepe paper everywhere, blows up helium balloons. For this last night of camp, carnival night, the kids will fish with poles in their mouths, catch Life Savers in their mouths (getting a brief hint of their flavor before having to spit them out) and do lots of calculating and guessing games. Those with a little bit of

strength in their shoulders will be able to do some of the tossing activities. There are also more athletic games for the siblings who aren't physically disabled.

In one corner of the mess hall are photos of five bright-eyed babies. They are pictures of camp children. Daddy's precious girl. Mommy's sweetest boy. The game is to guess who each one is. These photos were taken before anyone knew what would happen to these kids. Before any diagnosis or accident. Before the parents knew what their kids and they would go through. Before any of them knew that tragedy would force them to become the compassionate people they now are.

Dinner, on the patio under the pines, is pizza, a gourmet shrimp dish and barbecued chicken. It is festive and fun. Everyone has become like family and mixes easily. The Carcanos, from Miami Beach, who have participated in all of the activities as day campers, are with their son Jonathan, age 6. Jonathan's dad, Oscar, keeps a picture of Herald Assistant Sports Editor John Wolin taped on his bedroom wall as a reminder of how successful someone who is an achondroplastic dwarf, like Jonathan, can be. Jonathan has had repeated operations on the base of his skull and is on a ventilator most of the time because of malfunctioning lungs.

The last night of camp is Jonathan's favorite part. First,

a magic show with all sorts of little animals that he adores: a dove, a guinea pig, a rabbit and a parrot, which the magician will pull out of her hat. With each one, Jonathan will cup his hands as if it is he who is holding it.

"He identifies with them," says Esther, his mother. "He tells me he's different, somewhere between them and us."

"I'm like E.T.," whispers Jonathan.

And after the magic show, during game time, carnival night gets even better: the pie toss. Moises Simpser and his partner, pulmonary pediatrician Antonio Rodriguez, who has come for this event, take turns letting their young patients smash pies in their faces. Then the nurses take a turn at getting hit. The kids whoop and giggle as their parents help them lift the pans and aim. Jonathan gets in line five times.

As carnival night progresses, Oscar collects a huge pile of tickets from each activity. At the end, he goes to the prize booth to cash in. He can't decide between little plastic figures of New Kids on the Block, Miami Dolphin dolls, videotapes of movies, Miami Marlin baseball team T-shirts or Hurricane pennants. Laura Olson, 5, who sleeps in the cot next to Oscar, has decided on a golden-haired Barbie in a translucent glittery gown. William, who sleeps across from Oscar, has already decided on a T-shirt and a pennant.

The final day of camp is filled with activities intended to send the kids off in a wave of glory. There are farewell scrapbooks, photos and a *pinata*. Everyone exchanges addresses and phone numbers and mementos. The counselors sing special songs to each kid. But the kids are so tearful about having to leave and the counselors and staff are so weepy over having to say goodbye, that the grand finale turns into a huge sob session.

### Making Room

The one-week camp — which is run on \$80,000 in donated cash, goods and services — not including the cost of liability coverage, provided by Miami Children's Hospital, or the pay for counselors and staff, who aren't getting any — has grown as big as it can get.

It is unlikely that any of the kids sleeping over can be brought back next year, barring a last minute cancellation. The camp staff faces telling kids they know and love that they have to make room for those who have not yet had a turn.

As Simpser and nurses Cathy Klein and Tara Kelly meet to plan next year's camp, they'll try to figure out how to offer a second camp that can accommodate more out-of-towners. Simpser and his staff have also put together a camp blueprint in hopes that out-of-town camp parents can start similar camps back home.

"I'd like to start a camp like this where we live," says Garret's dad who has come from Cedar Rapids, Iowa with his family. "But you need doctors like Simpser, and I haven't seen too many like that around." Simpser works at the camp from 7 in the morning to midnight every day. He does everything from serving coffee to sweeping the floor to suctioning kids. With some of the campers from out of town, he sees medical things he would change. Maybe try to wean one or two completely off ventilators. Or cut back their medication. Or get them to do more exercises for the muscles they still have. But he says nothing.

"Camp is totally for fun," says Simpser, "not for unsolicited advice."

The last night of camp Oscar sleeps with his prize from the carnival. He finally decided on a Dolphin doll, because its legs and arms are floppy like his, and he can flick them with the little bit of strength he has in his fingers. He asks his mother to push the doll against his cheek so he can sleep touching it.

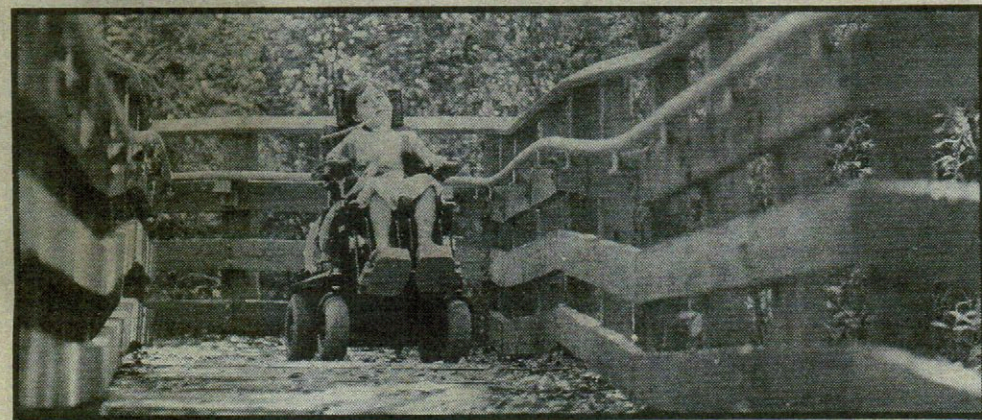
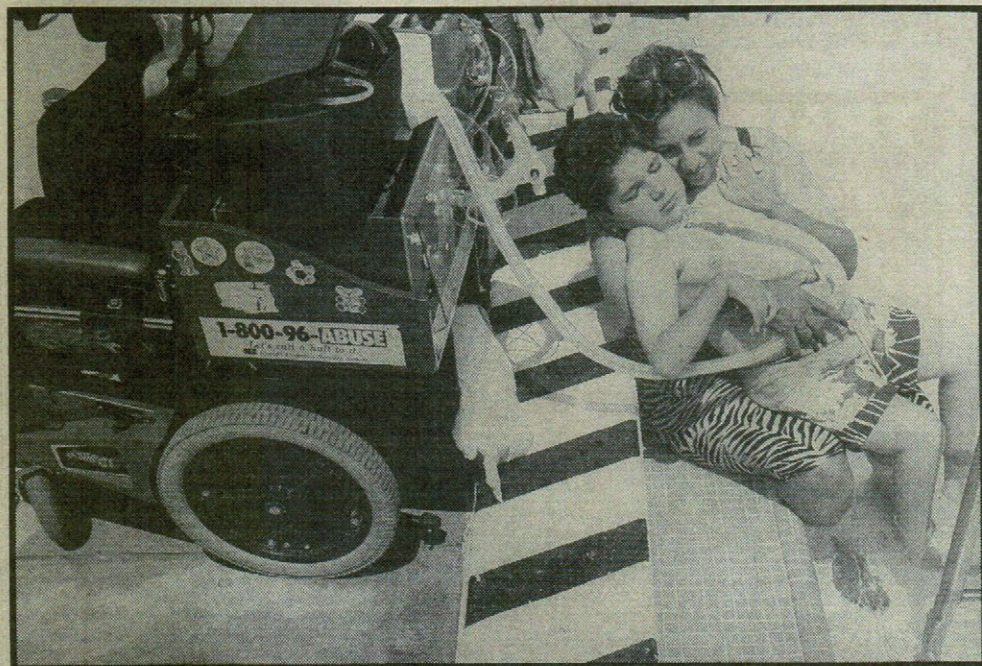
By now, Delores Gonzalez has put the van incident behind her and is dancing around her son's bed, having a great time. She picks up the stuffed animals and plastic dinosaurs he brought from home and talks as if she's them.

"You don't love us anymore, Oscar," she teases, in a scrunched-up voice. "You've thrown us over for a stupid Dolphin doll."

Oscar lies in bed with the covers up to his neck, looking like any healthy, happy child. He is watching his mother and laughing so hard his stomach is making the sheet billow up and down.

Then suddenly he stops and stares up at the far-away ceiling. "Mommy," he says aloud, instead of in his usual whisper, "I don't want camp to end."

MEG LAUGHLIN is a Tropic staff writer. Her most recent story was about an IRS audit.



Above, top: Oscar, age 10, with his mother, Delores Gonzalez. The tractor-like wheelchair is never left far behind. Above: Garret Frey, 9, from Cedar Rapids, Iowa, was totally paralyzed in a motorcycle accident when he was 5. Here, a rare moment of freedom. "I'd like to start a camp like this where we live," says Garret's dad, Jerry. "But you need doctors like Simpser, and I haven't seen too many like that around."