

VENTILATION'S Great Outdoors

More than 10 years ago, Moises Simpson, MD, director of the pulmonology division at Miami Children's Hospital, imagined a camp for his young patients. A camp where children dependent on ventilators and other cumbersome equipment could experience, often for the first time, swimming, sailing, and other activities. If these children had a place to experience the world, Simpson thought, they would grow both physically and emotionally. The Ventilation Assisted Children's Center (VACC) Camp (named after the ventilation-assisted children's center at Miami Children's Hospital, a program dedicated to returning ventilator, tracheostomy, and oxygen-dependent children to their home environment), has been evolving ever since.

The annual weeklong camp—the world's first, according to Simpson—is held in a 65-acre urban park in Dade County, Fla. "At camp, we see a child's potential, not [his/her] handicap," Simpson says, "and the children leave camp more outgoing and self-confident."

The children arrive from all over the country, from different ethnic and economic backgrounds, and with disorders ranging from paralysis to genetic disease. "What these children have in common," says Cathy Klein, program coordinator, "is the technology that they all use and live with every day."

In fact, many of the children who attend VACC Camp have never lived outside a hospital setting. Others have spent much of their life inside the hospital but have been able to successfully move home. In either case, few have ventured beyond a very limited setting. "Despite the parents' dedication and willingness to try," Simpson says, "it's almost impossible to get some of these children out and about."

But because Simpson understands that everyone in the family feels trapped by the child's equipment and special needs, he envisioned a camp that would be a vacation

Miami Children's Hospital's decade-old program gives children a "place to experience the world."

By

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bring everything that they might need during the week. An average camper may have to pack as much as a tractor-like wheelchair, angled and padded for full body support from the head down, a portable ventilator, a suction machine to clean the trachea, an oximeter, 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.

At camp, the children and their families are pushed in a safe and nurturing setting to experience new things. The participants feel like one of the group as they interact with people who have similar disabilities and play, uninhibited, with volunteers their age who welcome and accept them as friends. Parents, with the help of night nurses, are able to sleep without interruption. They learn that, when they return home, they can sleep better at night, checking on their child a few times rather than staying up the entire night watching their every breath. Parents leave camp more inclined to encourage their child to participate in community activities and they learn how to be concerned about their child, but not be overprotective. Camp is also an opportunity for parents and children to swap stories about how their handicaps have affected their lives and share successful solutions to common problems.

***SWIMMING**

One of the greatest experiences for the children is the opportunity to go swimming. The swimming pool, equipped with a hydraulic lift that allows even wheelchair-dependent children access to the water, makes the children feel good because physicians and medical literature have repeatedly told them that they could not swim.

Simpson discovered that this information was flawed when a patient's mother showed

for the entire family. The camp is structured so that, together, families can relax and enjoy themselves.

However, the camp is not set up like a hospital. Although volunteers are available if a problem were to arise, there is no formal care for the children. The family must take full responsibility for their child and