

M.D. NEWS

A BUSINESS AND LIFESTYLE MAGAZINE FOR PHYSICIANS



Northwest Medical Center

Changing the Traditional
Approaches to Surgical Care

**Ventilation-Assisted Children's Center
at Miami Children's Hospital**

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Twenty Years of Laughter ... Twenty Years of a New Lease on Life

By Julien Sharp

The Ventilation-Assisted Children's Center (VACC), a division of Miami Children's Pulmonology Department, applies a multidisciplinary approach to the management of its tracheostomy-, oxygen- and ventilator-dependent patients. These children rely completely on the continuing developments of biomedical technology to sustain their lives. All patients of the VACC have tracheostomies; some require oxygen and still others must be fed by gastrostomy tube.

One of the advances in recent years has been the wonderful development of more portable life-support equipment. That, combined with research showing that ventilation-assisted children thrive best in a supportive home environment, has led to a greater number of patients being discharged from the hospital into the care of their families.

While this is a welcome change for a patient formerly faced with spending literally an entire childhood in a hospital or extended-care facility, the stress that comes with home care can be extreme for the family. In need of 24-hour care, the patient usually requires professional home care, in addition to the sophisticated equipment. The parents become, in effect, the nurses and respiratory therapists for their child — most do this without a “day off.”



Recognizing the stress and the sometimes debilitating effects on even the strongest families, the division established its VACC Camp in 1985. At this camp, the patients get to experience — most for the first time — true “camp life.” The camp is unique in that the entire family — parents (or primary caretakers and siblings) — is welcome. VACC Camp's mission is to expand both the child's

and family's perception of the possibilities for social, educational and physical growth within a technology-dependent lifestyle. Campers are given the chance to socialize with others with similar medical needs, thus enhancing their self-esteem and social skills.

In April 2006, this amazing program, one that has saved the lives of so many, celebrates its 20th year in existence (the camp was postponed following Hurricane Andrew in 1992). For 20 years, for a fun-filled, action- and laughter-packed week, children who might normally never experience the camping experience have converged upon the welcoming group at VACC Camp.



The camp, held at A.D. Barnes Park (a 65-acre Miami-Dade Parks & Recreation facility at 3401 SW 72 Avenue), is offered for patients and their families completely free of charge. It was created to give the children on ventilator-assisted equipment a week of just being a kid — to see the world outside of their hospital rooms, outside their homes, to be the guests of honor at a party every single night. Children from all over the country, ages 5 and up, have participated in the VACC Camp experience over the past two decades. Out-of-town campers and their families stay overnight at the camp site, while South Florida families and youngsters from local residential care facilities join in as day campers.

The families are responsible for bringing all required equipment for the care of their children, as well as transportation to Miami. Once in Miami, VACC Camp takes care of the rest: transfers to and from the airport (courtesy of a special van donated to the camp each year), all food, lodging, and, of course, the activities are

at no charge to the campers or their families.

For most, a visit to the beach is a “first-time” experience. They go sailing, regardless of the amount of equipment that must accompany them. Some are able for the very first time to be free of the constant gravitational pull on their limbs and float in a pool, literally the only time in the year they get to feel the water all around them. Some can, with the assistance of doctors, nurses and countless volunteers, even experience going “all the way” under water.

Both the heart and brains behind this amazing venture is Moises Simpser, M.D., FAAP, FCCP, Director of the Divisions of Pulmonology and Pulmonary Care at Miami Children's Hospital. Born and raised in México City, Simpser completed medical school at Universidad Nacional Autónoma de México in México City, where he graduated with honors. He completed a three-year residency at Hospital Infantil de México, moving then to Boston for a fellowship in pediatric pulmonology at the Harvard Medical School.



After an additional two years of training in pediatrics at Boston City Hospital (Boston University), Simpser moved to the Children's Hospital of New Jersey, where he was the director of the pediatric ICU and pediatric pulmonology.

Simpser then moved to South Florida and Miami Children's Hospital in 1984, and within months after that, VACC Camp was born. “It was a very simple camp at first,” remembers Simpser. “We started with only three volunteers — two nurses and me — and plenty of good will. We had eight families that first year; it was a bit disorganized, but we had a great time.” After enlisting the help of teenage volunteers,

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the growth of the camp literally exploded. Now full-time Camp Coordinator Bela Florentin, VACC, works year-round ensuring the organization runs smoothly.

Dr. Simpson's camping background includes 10 years of personal experience in scouting, plus experience in camp development, organization and personnel training for the Mexican Red Cross. In 1980, he founded the first YMCA asthma camp in Frost Valley, NY, to mainstream severe asthmatics from poor inner city neighborhoods with healthy youngsters. After relocating to Miami, he served in 1984 and 1985 as the medical director of the asthma summer camps sponsored by the American Lung Association of Dade and Monroe counties.

M.D. News recently spoke with Dr. Moises Simpson about the camp: the inspiration for its creation, the operation and how he has amassed a dedicated team of volunteers who come back, year after year, working tirelessly to ensure a truly magical week for the campers. The following narrative is in Dr. Simpson's own words:

"We started this camp because we wanted to transition the children from the hospital, to the house ... to basically just a normal life for these kids. The challenge for this camp is that the children don't just have one disease. There are multiple reasons that they require a ventilator.

"For some, their muscles don't work, so they can't breathe; others have had fractures in the cervical (neck) bones and are paralyzed, so they can't breathe on their own; some of our campers were born prematurely, and now have chronic lung diseases. Others have malformations of the chest. Some have basic problems with swallowing and must have tracheostomies so they won't aspirate everything they eat.

"Still others have sleep apnea or can't breathe because of obstructed airways. There are a variety of reasons, but what they all have in common is a tracheostomy, a ventilator, or require help breathing in some way. There is such a variety of possibilities of the type of patient who attends that it can be difficult for people who haven't experienced the camp firsthand to visualize it.

"Our camp is run almost entirely by teenage volunteers. We have found that the best way to ensure continuity to the program is to bring the community to the children, and the children to the community. Having the team of teenagers enhances the experience for the children, so they have not just doctors and nurses taking care of them, as is their normal experience (although



there is an experienced team of professionals at the camp at all times).

"Bringing the teens and other volunteers into the camp brings in more of a feeling of: 'Let's not dwell on what the campers cannot do, but let's look at what they can do, to see what they can develop into.' For example, the mother of one of the kids had the idea of using the red plug from her child's oxygen tanks — she simply plugged the tracheostomy of the child when he is in the pool and there you go — he could swim!

"Now, thanks to that idea, we have developed a cap that the (nonventilator-dependent) children can put in and swim. In medical literature it says they cannot shower, and certainly not swim, but they can!"

Partners from all over the community help make VACC Camp the incredible experience it is. With the exception of two night care respiratory-trained nurses, the entire camp is run by volunteers and donations. Adults use vacation time from work, and as the camp is scheduled during Miami-Dade County public schools' spring break week, teen volunteers are free from school obligations for the duration of the camp.

Set-up and break-down volunteers ready the camp for occupancy, with tasks such as cleaning, making beds, stocking the refrigerator, storing other supplies and decorating with welcome signs and balloons. When the camp is over, all materials must be packed up and returned to storage.

Volunteers are also needed from 7:30 a.m.-10:00 p.m. during the camp session to assist with meal preparation, serving and cleaning, keeping the campsite tidy, picking up supplies and donations, and generally being on standby to help wherever an extra hand is needed.

Volunteers are also needed to act as "campers' companions" and accompany their special "buddy" on all camp activities — both onsite and on field trips. Other volunteers facilitate

special activities, including swim sessions, the beach field trip, carnival night, and "Parents' Dinner Out" night. The volunteers often work in "shifts" from 7:30 a.m.-4:30 p.m. and from 4:30 p.m.-10:00 p.m.

While there are plenty of new faces amongst the volunteers each year, many others come back year after year, including one who has spent the last 16 years as a volunteer.

Most of the activities are donated as well; only a few charge a nominal fee to the camp. (Any fees are taken care of through private donations and the proceeds of an endowment started several years ago.) The children participate in activities all day long, most of which they never would have dreamed of doing prior to coming to camp, such as field trips that include, but are not limited to, a boat ride around Biscayne Bay on a boat donated by Bayside Marketplace; a day at the beach; lunch at Hard Rock Café at Bayside; not to mention frequent trips to the pool.

They even get to go sailing, courtesy of Shake-a-Leg Miami, an organization providing sailing experiences to those with disabilities and their families. A special partnership between VACC Camp and Shake-a-Leg resulted in the design of a special boat with gears that the kids can operate with their chins. "They can sail the boat!" exults Simpson. "This special sailboat was developed with our kids in mind; now they use it for other people with disabilities."

At the campsite itself, the children participate in art events, a "carnival" night (complete with clowns and games), a D.J.-hosted dance evening, a Western night, a "Pirates of the Caribbean" evening and a wild animal show. There are activities for the siblings as well, and the parents get a well-deserved break on "Parents' Dinner Out."

Continues Dr. Simpson:

"It is really a 'sleep over' camp. We have spaces for 27 at the park facilities. This year, though, we have so many that we have had to look for area hotels to accommodate the overflow. We needed 20 extra rooms this time.

"We use a tremendous amount of teenagers. Some of them are rough around the edges when they join us for the first time, and after a week at camp, they have changed as well. We started utilizing teenage volunteers some years before the county's required community service hours, and today they just love to come, so the community service hours are irrelevant.

"The dedication and passion of most people

who come to the camp is incredible. It's like fire going on there. It's just incredible, everybody helping everybody. It is a truly professional 'system,' but they are primarily teenagers!

"We teach the teen volunteers how to ambu-bag the patients, like a balloon that you squeeze to breathe for the children, so they can go in the pool. They must be disconnected from the respirator to go into the pool, and we have to help them breathe.

"What is fascinating is the relationship between the kids and teenagers. For example, on the Parents' Dinner Out day, we were afraid at first that the parents wouldn't leave the side of their kids, but the kids, excited to be with the teens, tell their parents: 'Go away, go away!'

"The kids feel independent, and the parents become invigorated to have a night to themselves — comfortable with our excellent system of safety and security. We have nurses and respiratory therapists there at all times. In fact, medical professionals wear a different color t-shirt than the volunteers, so they are always visible in case of an emergency. In 20 years, though, we've never had any problems — no accidents, hospitalizations of a child, or anything else."

Many of the campers literally live for this one week. For example, Cory is 10 years old and lives in tropical South Florida. Elliot is 14 years old and lives in the "Windy City" of Chicago. One might think that these two boys, who live hundreds of miles apart, may not have much in common, but they do. Both Cory and Elliot are quadriplegic and look forward to attending VACC Camp.

"I wanted Elliot to see that he's not alone, that there are other children like him," said Judy Santiago, Elliot's mom. "He used to love to go swimming. It had been three years since Elliot's been in a pool — that was before a virus left him quadriplegic," explained Judy. "I just couldn't wait to have him back in the water."

VACC Camp means a whole week to talk with other patients and families with similar life challenges. According to Simpser, the participants leave at the conclusion of the camp feeling, "I am not the only one; there are other people just like me!" And the camp participants become literally members of an extended family. "The whole family looks forward to VACC Camp every year," explains Cory's father, Maurice Harrison. "Everyone at the camp is extended family and this is our annual family reunion."

This year, on Monday, April 10, VACC

Camp celebrated its 20th anniversary, and Bela was very busy hunting down "alumni" of the camp. Former campers, many of whom have gone on to live fulfilling lives, visited the current campers and provided a wonderful

role model for them. Many former campers are now working and leading full lives. "One is starting college now; another even works for IBM," states Simpser, proudly.

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CHILDREN'S SPECIAL NEEDS

Other issues common to the child dying at home include immobility, feeding difficulty, speech problems, incontinence or constipation, seizures, decubiti, difficulty with respiratory secretions, infections, anxiety, depression and fatigue.

Malnutrition and dehydration are issues of particular importance to parents, many of whom are unable to withdraw this basic support from their children. Children should be fed only to alleviate hunger or thirst, which are rare toward the end of life, or to preserve social activities. Supplemental fluids and nutrition can cause discomfort at the end of life, exacerbating pulmonary edema or respiratory compromise, worsening bowel obstruction or leading to placement of uncomfortable intravenous lines or feeding tubes.

The cause of fatigue should be identified — anemia? malnutrition? sleep disturbance? medication side effects? disease progression? — and treated, when possible, to improve the child's quality of life.

Depression and anxiety are neither appropriate nor inevitable. Of the 103 parents from the Boston Children's Hospital/Dana Farber Cancer Institute study who lost a child to cancer, 53 percent said that in the last month of life their child had little or no fun, 29 percent said their child had significant anxiety, 61 percent reported their child had significant sadness, 63 percent said their child was often not calm or peaceful, and 21 percent said their child often was afraid (Wolfe et al NEJM 2000).

A pediatric palliative home care team can change all this. The physical and psychological aspects of dying must be explored with the family, as well as with the child. Keep in mind children's varying concepts of death at different ages:

- Infants and toddlers have separation

issues and stranger anxiety, but no concept of death. They require maximum physical comfort.

- Children 3-6 fear separation, think death is reversible and believe death is punishment. They need assurance that they have done nothing wrong.
- Children 6-11 understand that death is permanent. They fear abandonment, have feelings of guilt and should participate in decision making.
- Adolescents recognize death as final and irrevocable. They suffer issues of independence vs. dependence, sexuality, isolation, anger, withdrawal and altered body image. Decision making with teens requires honesty, trust and respect.

Many children fear being forgotten. They should be given the opportunity to leave a legacy by making a scrapbook, journal or video. Many try to protect their parents by not expressing their fears, experiencing loneliness and anxiety as a result. Children should be encouraged to ask questions and express strong feelings. They deserve honest answers and unconditional love and support.

In Sweden, 449 parents who lost a child to cancer were asked if they had talked with their child about death. Of the 147 parents who had done so, none regretted it. Of the 258 parents who had not, 69 (27 percent) regretted not having done so (Kreicbergs et al NEJM 2004).

Unlike in hospice care, pediatric patients can enter a palliative care program early in the end stages of their illness, and there is no limit to the duration of time they can be cared for by the palliative team.

Similarly, there is no limit to the duration of bereavement counseling for the family. How can there be a time limit on grief after the loss of a child? ■

Many people have asked Dr. Simpser what it feels like to see the kids he once held helpless in his arms return as confident, successful adults. "When my staff told me of all the people they have found from over the last 20 years who will be visiting us, I feel 20 years younger," he beams. "Seeing these people become productive, young adults is an incredible feeling."

The following poem, written by teen volunteer and "Camper Pal" Luis Prieto, is a testimony to the life-changing experience that VACC Camp offers all involved — campers, their families and the volunteers who make it possible.

*I love to run, jump and play,
but I want to be like them for a day.
You don't live life till you meet kids like this;
If I was a genie I would grant their one wish.
I hope I've made a difference in their life;
It will be one great story to tell my wife.
I can't wait till next time comes around;
It is then that my heart will be found.
I smile all week and at the end I cry.
I hate the end — I hate good-bye
I try to stay positive and say there is always next
year,
But you guys give me comfort, so I am far from
fear.
I realized you kids are so cool,
From the very first time Stephonne jumped in the
pool.
You guys love life just as I do,
I just didn't realize what I had till I met you.
This I will tell you is straight from the heart;
So you guys have something to remember when we
are far apart ...
Cherish life and don't ever think
that someone is better than you.*

For additional information on VACC Camp, please contact Bela Florentine at (305) 666-6511, ext. 8222.

Founded in 1950, Miami Children's Hospital is the only licensed specialty hospital for children in South Florida. Ranked Miami-Dade County's "Best Pediatric Hospital" by South Florida Parenting magazine, Miami Children's Hospital offers medical care and services for children from birth to age 21. The 268-bed medical facility has expertise in all aspects of pediatric medicine. ■

