

Boom in Camps for Chronically Ill Kids

By LAURAN NEERGAARD

The Associated Press

Tuesday, April 15, 2008; 6:05 PM

WASHINGTON -- Summer camps just for kids with chronic diseases are booming _ places to learn about epilepsy or finally meet someone else with Tourette's tics or slice open a cow's heart to see what's wrong with their own.

Now fledgling research suggests such special camps may offer more than a rite of passage these children otherwise would miss: They just might have a lasting therapeutic value.



It's work that helps explain why children's hospitals increasingly are sponsoring disease-specific summer camps. One in the nation's capital actually integrated the camps into the neurology department. "How do you live well with a chronic condition? I believe in part, the power of being amongst your peers normalizes the experience," explains Sandra Cushner-Weinstein, a social worker at Children's National Medical Center who founded the hospital's weeklong camps for five illnesses, and is studying the impact on campers.

Special-needs camps got their start in the 1970s, for children with cerebral palsy and cancer. Today, the variety is tremendous: There are more than 130 asthma camps around the country, and dozens for muscular dystrophy, diabetes, hemophilia and sickle cell anemia. Even rare diseases are getting camps, like ones Weinstein organized for Tourette's syndrome and neurofibromatosis, a genetic disorder where multiple tumors form on or just under children's skin.

In many ways, chronic-disease camps are like any summer camp, with some extra safety steps and accommodations. "They have this zip-line there," 12-year-old Andrew Frascella of Rockville, Md., says excitedly about epilepsy camp. "It's really high above the trees. You get strapped on and go flying." But some of these camps go beyond recreation to also teach children about their illness in ways they may never have experienced _ with doctors and nurses clowning around in shorts instead of scrubs to gain youngsters' trust, and counselors with the same illness acting as mentors.

Cardiology nurse Betsy Adler says children born with heart defects often don't know exactly what's wrong with their hearts, just that they're sick or need an operation. So every summer, she brings about 20 cow hearts _ the same anatomy as a human's, just much bigger _ to Cincinnati Children's Hospital's Camp Joyful Hearts. The campers help slice them open while cardiologists point out valves, chambers and arteries, and explain to each child who asks how their own heart is different. Adler recalls a teen who never understood why he had to take the blood-thinner Coumadin every day, and got a hands-on explanation about artificial heart valves.

Or consider epilepsy. You can't see your own seizures, but kids do see parents worry and classmates withdraw _ a fellow second-grader once asked Andrew if his seizures meant he was "crazy." Weinstein contends how patients imagine their seizures appear can be far worse than reality. At her Camp Great Rock outside Washington, D.C., doctors and nurses use campers' seizures as teachable moments: See, not all seizures are convulsions; let's role-play how to explain this kind or that kind to a classmate. A counselor's seizure in the pool provided a lesson on water safety. Andrew Frascella's father recalls the pain of watching his happy-go-lucky son rapidly become shy and isolated when seizures began at age 8, and worsened dramatically over the next two years. Joe Frascella, himself a government neuroscientist, was skeptical when Weinstein and her husband, Andrew's neurologist, pushed the camp stay. "To say that after a week of these kids being in camp where it wasn't clear what magic they were spinning we would see a change?" he says.

But Andrew remembers that his first trip to Camp Great Rock at 8 as the time he was no longer left out. "You get to learn about each other, how you're not different from everyone," he says. Plus, "It was kind of special because not just anybody can go there." Joe Frascella remembers being amazed that Andrew returned able to volunteer to acquaintances that he had epilepsy. "It wasn't something he had to hide. ... That was tremendous," says Frascella, who saw Andrew gradually become happier both as he finally found medication that worked _ his seizures today are well-controlled _ and increased his base of camp friends.

Despite patient advocacy groups and children's hospitals increasingly sponsoring camps, there has been little research showing they can provide more than a fun experience. A few studies show short-term behavior improvements; others found none. But Weinstein kept hearing parents talk about kids learning to cope at camp. So with government funding, she paired with a team of neuroscientists to track children who attended epilepsy camp for three consecutive years. Standard psychology measures showed the children grew steadily better in social interaction, with some improvements in how they communicate and handle responsibility, too, Weinstein reported in the journal *Epilepsy & Behavior* last year.

The findings aren't a surprise to Connor Chilton, 16, of Alexandria, Va. He eventually outgrew his epilepsy, but still volunteers as a camp counselor because he remembers vividly being about 6 and witnessing a fellow camper's seizure. The adults acted "like it was normal," he says. "I know personally that made me feel more normal about having seizures."