

Los Angeles Times

Camp Caters to Kids With Broken Hearts

Therapy: Founded by a doctor and a nurse and staffed by volunteers, Camp del Corazon gives children with cardiovascular disease a place where they can forget about being sick for a while.

September 17, 2000 | MATTHEW FORDAHL | ASSOCIATED PRESS

Four months after her transplanted heart briefly stopped beating, 14-year-old Carina Gonzales pulls herself up a 20-foot wall at summer camp.

John Klymshyn, whose heart condition keeps him out of P.E. class, snorkels and kayaks in the ocean off Santa Catalina Island. And Adam Loyd, after eight surgeries and counting, burns up the dance floor.

For five days each summer, children with broken hearts can forget about their cardiac problems and become regular kids at a Catalina Island camp organized by volunteer doctors and nurses.

"I'm just having so much fun I don't think about being sad," said Carina, an Arizona girl who may soon be listed for another heart transplant because of the rejection of her first.

Camp del Corazon--"of the heart" in Spanish--was founded in 1995 by a pediatric cardiologist and nurse who realized that more than surgery and pills were needed for children who have lived most of their lives in the shadow of death.

This year the program comprised two five-day sessions separated by Labor Day. More than 200 children ranging in age from 7 to 17 paid nothing to camp with three doctors, more than 20 nurses and dozens of volunteer counselors.

Though some campers have overcome their heart problems, others like Carina face more transplants, surgeries and other health hurdles. A few must be fed through tubes; one a few years ago had to be carried in a wagon.

Because of their medical conditions, most have never been to camp before, said Dr. Kevin Shannon, one of the co-founders and a pediatric cardiologist at UCLA.

"It's not different from a regular summer camp other than the nurses, the medication and the medical backup," he said. "We consciously try to avoid trying to make this have anything to do with the fact that they have heart disease."

Nearly any child with a heart condition is welcome. Most enjoy a full range of activities including volleyball, music, hiking, kayaking, crafts and swimming.

Shannon and cardiology nurse Lisa Knight started the camp after a young patient said he was embarrassed by scars from three operations. After Knight made a few phone calls, they were organizing the first session for 49 campers.

"I thought it would be good if he could meet other kids with heart disease," Shannon said. Only a handful of other camps around the nation cater to children with heart disease, and few are free.

Companies, individuals and organizations fund the program, with a budget of more than \$150,000. Doctors and nurses from UCLA and nearby hospitals donate their time--as do the counselors.

Shannon says the challenges are significant: Parents have to be convinced the camp is safe, money must be raised and arrangements made for medical equipment or helicopters to airlift sick children if the need arises.

Then there's seasickness while ferrying the children to the sheltered island cove 22 miles off the coast of Southern California.

"The first year, everybody got sick. I was terrified," Shannon recalled. "All these children with heart disease getting dehydrated, their electrolytes abnormal. I was thinking, someone's going down on this. But everybody did fine."

So far, no children have died or even become seriously ill at the camp.

The camp infirmary, which rivals a hospital emergency room, is loaded with boxes packed with pills and thick binders of medical histories. It also has three beds, a defibrillator and other equipment to keep hearts pumping.

"They're a lot closer to medical care than they would be if they were . . . playing in their backyard," Shannon said.

Though the medical staff and counselors do not focus on heart problems, the topic arises among the campers. At night, Shannon said he hears campers talking about having chest tubes removed and other procedures.

But the children seem more excited to talk about the climbing wall or "eagle's perch," where they are harnessed before leaping off a pole suspended high off the ground. In keeping with the true camp experience, there are no soy burgers or fruit cups here. "We roast marshmallows. We eat bacon. We salt our eggs," Shannon said.

The camp attracts volunteers like Linda deBeaumont, a 42-year-old mother who heard about the program while awaiting her own heart transplant. "I think of what I've paid to send my kids to camp," she said, "and I know they don't get half of what these kids get out of this--a chance to just be kids, to get away and to not even think about being sick."