

Camp Shifts Focus

For these children, Camp Wonder means a week with others who live like them: Camp shifts focus from skin ailments

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By Sandy Kleffman of the Contra Costa Times

LIVERMORE - Natasha Starkey and Lizie Fernandez, best buddies at camp, prepare to launch into a song they composed. "One, two, three, let's hit it," they chant, breaking into "Olivia, the Black-Nosed Bunny." It's a scene that could be repeated at camps throughout the United States: two girls, 9 and 10, sharing the joyous creation of a close friendship. Except that behind a curtain next to the girls, a young boy with a serious skin disease screams in agony as adults change his bandages.

Natasha and Lizie undergo their own dressing changes while they sing. With sores and blisters covering much of their bodies, they have become pros at the painful procedure, accepting it with grace and good cheer. Such are the incongruities of Camp Wonder, the only camp in the western United States for children with chronic and often disfiguring skin diseases.

Seventy-four boys and girls gathered at the Livermore camp last week. Away from the stares of strangers, they swam, rode horses, climbed a rock wall, slept in bunk beds and devised crazy skits. As much as possible, for five days, they left their diseases behind. "The main thing I wanted to do is give the kids a sense of self-respect and let them know there are people who will accept them," said camp founder Francesca Tenconi. "Many of these kids are very ill, and there's always a question about who will come back next year."

Tenconi, a 21-year-old Walnut Creek resident, can empathize with the campers. A decade ago, she became one of the youngest people in the United States diagnosed with pemphigus foliaceus, a rare autoimmune disease that blistered her body, causing her skin to peel like tissue paper. She shows few signs of the disease today, after discovering the best medications to use. But Tenconi has continued her dedication to the camp she founded after her 16th birthday. Now in its fifth year, Camp Wonder is one of several weeklong events for children with a variety of life-threatening illnesses and disabilities held each summer at Camp Arroyo in Livermore.

Tucked in the tree-studded foothills south of Wente Vineyards, the camp is supported by the Taylor Family Foundation. Eleven-year-old Alex Coil spent a sunny afternoon last week in the pool, sporting swimming trunks over his bandages. "This is my favorite place in the world here at camp," the freckled boy said with a smile. The Grass Valley resident arrived at the camp with his 10-year-old sister, Brandi. The siblings have a genetic condition known as epidermolysis bullosa, or EB. Lizie and Natasha also have the disease.

Structural weaknesses in the children's skin cause deep sores and scarring. The skin is so fragile that slight friction will make it blister or slough off. The scarring is often so severe that fingers fuse to the palm, permanently shaping the hand into a fist. The webbing can also affect the feet, causing toes to curl into the skin. Although 16 children with epidermolysis bullosa attended Camp Wonder last week, the condition is rare. Depending on the type of EB involved, it strikes one in 20,000 children, or one in 50,000. Walking can be painful for EB sufferers, so many use wheelchairs.

Swimming is therapeutic. The chlorine keeps the sores clean and the soaking makes it easier to pull bandages off for a dressing change. Yet, many EB patients find it difficult to use public pools at home. Some have been grilled about their condition or asked to leave by people worried that the disease is contagious. It is not. There are no such concerns at Camp Wonder, where everyone is accepted and welcomed. "I'm heavier than anything," Alex says as he steps out of the pool, his sopping bandages and a life vest weighing him down. He begins a slow, halting shuffle to his wheelchair, displaying his wry humor. "I'm a penguin," he says of his stiff movements. "Where's my limo?" The camp has a "Club Med" where the children go for bandaging. Most EB patients have their dressings changed every other day, a two- to three-hour task.

The host of medical professionals who volunteer at the camp make Club Med their headquarters. This year, the medical staff included 10 doctors from UCLA, in addition to doctors rotated in from UC San Francisco, Stanford and elsewhere. Six full-time nurses, additional part-time nurses and numerous medical students rounded out the staff. Older children with skin diseases frequently return to the camp to serve as counselors and role models. Beyond the feel-good experience, the camp provides a learning opportunity for the medical staff.

The campers have a variety of diseases, some common and some very rare, including psoriasis, eczema, ichthyosis, vitiligo, nevoid basal cell carcinoma syndrome and pemphigus. "You don't see the whole picture of what skin disease is like when you just see kids in your office," said Stanford dermatologist Dr. Anna Bruckner. She treats Alex, Brandi and their older brother, Corey, who also has EB. "It's wonderful to be able to help out in some way and see another side of their life." Doctors rarely get to view the scope of an EB patient's sores because it takes too long to remove and reapply bandages during a typical visit. "These doctors don't get to see how these moms and parents are wrapping these kids," said Lauren Clark, a home health nurse for the Coil children. "Everybody does it a little bit different."

Bruckner took advantage of her time at the camp to help with Alex's dressing change. He first soaked in a tub while enjoying a vanilla milkshake and a movie. "It was just nice to be able to spend some time with Alex," she said. "He's really good at air hockey. It's fun to see the kids being kids." The volunteers try to minimize the focus on disease and make Camp Wonder about singing, dancing, arts and crafts and just having fun.

The camp has one paid staff member: director Barry Vigon, a big man with a booming voice who has worked as a comedy writer for such shows as "The Facts of Life," "Roseanne" and "Who's the Boss." "I bring my comedy to camp," he said. "I get silly with them, and they love it. They give me so much more than I give them. They are so appreciative." "For many of these kids who may

not live long or have been suffering, this becomes the highlight of their year. Something happens as soon as they step on the property -- the bonding, the smiles, the experience of independence."

The camp turned away 17 children this year after reaching capacity. Tenconi admits those with the severest conditions first, the ones she figures may not have many summers left. "Honestly, most camps just would not accept them because of their medical regimens," she said. For some children with rare conditions, the camp provides the first time they meet others who have their disease. "Some kids don't get to socialize like normal children do," said Pat McClelland, a UCSF nurse who has volunteered at Camp Wonder from the beginning. "They don't have many friends except their families."

Some have such visible signs of their maladies that they frequently draw stares in public. One girl told Vigon she cannot go through a day without getting teased or made to feel uncomfortable. "When she comes to this camp, she can let her defenses down," he said. "Here they are in a completely relaxed environment. They share their stories and support each other." During the day, the camp talk centers on typical kid stuff -- music, movies, the activities at hand. But at night, when tucked safely in their beds, the kids often share information about medications and how they cope with their diseases.

Tenconi calls skin disease an "orphan field." Most of the conditions are so rare that pharmaceutical companies refrain from funding research on treatments, figuring they can make more money elsewhere. Tenconi spends much of the year raising money to support the camp. She formed the Children's Skin Disease Foundation, a nonprofit organization to fund Camp Wonder and other programs. The camp is free for the children. "A lot of these families are burdened with huge medical expenses," she said. "I just did not want finances to be a factor in choosing who comes."

Few children seemed to form a closer bond last week than Lizie and Natasha, who first met at an EB conference several years ago. Lizie lives in Texas and Natasha in Ohio, so they rarely see each other. At Camp Wonder, they chased each other in their motorized wheelchairs, giggling like any children playing tag. They formed a band with Brandi and were eager to perform. Stepping out of their wheelchairs, holding a fake microphone and plastic guitar, they sang to recorded music, stepping in synch with each other. Natasha kneeled forward in a sizzling guitar solo.

Lizie's mom stayed at the camp and handled her dressing changes. Natasha's mom sent along a box of dressings with detailed instructions for the volunteer nurses. When it came time to have their dressings changed, the two girls asked to be side-by-side to keep each other company. They sang songs and shared stories, ignoring the screams from behind the curtain. A group of four nurses gathered around Natasha, following her mother's instructions. They removed the outer bandages, but when it came to the ones closest to her skin, Natasha slowly peeled them off herself, revealing the raw skin. "Ouch, ouch," she said several times before asking for pain medication.

Both girls can eat regular food but have tubes in their stomachs to take the bulk of their sustenance. Every three months, Lizie has her esophagus stretched because scarring has narrowed it. She had surgery on her right hand to open up the fingers after they closed into a fist and may have a similar operation on her left hand. As her mother changed her dressings, Lizie showed a visitor how she can wiggle her nostrils and ears and lock both feet behind her head. She always maintains an upbeat attitude, her mother said. "She accepts herself. She gets past the staring; she gets past the questions and just moves on from there. She gets a whole lot out of life. She enjoys things and appreciates things, more so, probably, than you and me. "I hope she never looks in the mirror and says anything other than 'I like what I see.'"

Reach staff writer Sandy Kleffman at 925-943-8249 or skleffman@cctimes.com

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