

Camp Wonder: Where nobody looks at you twice

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LIVERMORE - The only wondering going on at Camp Wonder is, "When do I get to come back?"

Camp Wonder, an annual weeklong camp put on by the Children's Skin Disease Foundation (CSDF), is a place where kids and teenagers with various skin diseases can participate in normal camp activities without the stares and second looks that accompany their daily lives.

Every year, dozens of kids from all across the country flock to Camp Wonder — located at Camp Arroyo near Livermore — seeking the one week in the year where they can enjoy swimming, horseback riding, arts and crafts, performances and trips to the reservoir with friends.

Austin Milam, 10, makes the annual trip from Colorado Springs because he enjoys Camp Wonder's accepting atmosphere, something he can't get at other, closer camps. Even though Austin suffers from a skin disease that severely dries his skin, he finds time to participate in arts and crafts, his favorite camp activity.

Ten-year-old Nicky Zahorcak of Lancaster suffers from a skin disease called epidermolysis bullosa (EB), a rare condition that causes blistering and a breakdown of layers of the skin. Nicky has to remain heavily bandaged, otherwise the slightest touch or friction on his skin can cause it to blister uncontrollably.

At Camp Wonder, Nicky enjoys playing air hockey, and he said if he could, he would stay at the camp all summer.

"I love it here," he said. "It gets a little boring at home."

The organization's founder, Francesca Tenconi, recovered from her own skin ailments — she was diagnosed with pemphigus foliaceus (PF), a condition that causes blisters and sores, at age 11 — and established CSDF as a nonprofit organization on her 16th birthday. Not long after, the Walnut Creek native launched Camp Wonder after discovering a large

number of kids with skin diseases were unable to attend summer camps due to their sensitive conditions.

With the help of the Taylor Family Foundation, which owns Camp Arroyo and "rents" it to Camp Wonder free of charge, Tenconi, 23, was able to create a week specially reserved for kids like her. Tenconi works with a devoted core of volunteers, including parents Don and Christine Tenconi, to run the camp's many activities and events.

Adopting the motto, "Here, nobody looks at you twice," Camp Wonder is geared toward bridging the emotional disconnect that so many of the kids endure from the outside world, Francesca Tenconi said. The camp is about establishing an environment that fosters confidence and builds self-esteem.

Parent Lorraine Spaulding of Newman brings her 10-year-old son Garrett to Camp Wonder because she appreciates the family atmosphere. She said the camp's "top-notch" medical staff also relieves her of some of the responsibilities when it comes to caring for Garrett's condition, which like Nicky's, causes the skin to separate and blister.

For Spaulding, the challenge comes in explaining the condition to those who don't understand.

"It's not cognitive," she said. "Most of these kids are very smart, but people don't think that and it gets to the kids emotionally."

Neither the Tenconis nor the camp's staff get paid for their services. Instead, the camp is supported solely through sponsorships and donations.

Stiefel Laboratories Inc., the world's largest privately held pharmaceutical company specializing in dermatology, is the primary sponsor for Camp Wonder, donating money, medical supplies and volunteers annually.

"Our sponsors approached us. It wasn't the other way around," Francesca Tenconi said. "It's very refreshing to see pharmaceutical companies doing this out of the goodness of their hearts."

Lyra Myers, global chemical category manager for Stiefel, said the company has a genuine interest in Camp Wonder and will continue to support the camp financially and otherwise for as long as possible.

"As responsible companies, we have to support them, especially with us being in our field and them being right in our backyard," said Myers, who works out of the company's Palo Alto office.

She said the company dedicates two walls of their office space to photos of kids from the camp.

"We want to keep it very personal," Myers said, referring to the employees' relationships with the kids. "We want to remind our employees why we come to work everyday."

The counselors and volunteers are a big reason why campers come back year after year, Francesca Tenconi said.

Soroush Aboutalebi, 13, of Walnut Creek is a seasoned veteran of four straight years at Camp Wonder. Diagnosed with ichthyosis since birth, Soroush is one of the most confident campers at Camp Wonder and doesn't let his "permanent sunburn," as he calls it, stop him from participating in everything the camp has to offer.

Soroush's experiences growing up with the disease and his time at the camp have also nurtured his maturity.

"I consider myself lucky and unlucky at the same time," Soroush said. "Coming here, I realize that I could be a lot worse. I think a lot of people take their health for granted."

For more information or to make a donation to the Children's Skin Disease Foundation and Camp Wonder, visit <http://www.csdf.org>.