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Camp Wonder: For kids, a week away from the stares

By Jason Millman, USA TODAY

When Francesca Tenconi turned 16, she didn't ask for a Sweet 16 party and she didn't ask for any presents, although no one deserved a good time as much as she did.

Tenconi, 24, was diagnosed at 11 with pemphigus foliaceus, a skin disease that threatened her life and eventually claimed most of her skin. During the four years it took to recover, Tenconi learned the loneliness of having a severe skin disease.

"It's hard to deal with because it's so visual," she says. "Kids at a toy store would look at me and question. It's something that's very, very difficult to deal with."

After the four years of treatment, Tenconi's skin grew back and the disease went into remission.

For her 16th birthday, she didn't want any lavish celebrations or gifts. Instead, she asked friends and family to make a donation to a summer camp she was about to start to give children suffering from severe skin diseases what they needed most: a feeling of normalcy.

At Camp Wonder, which is about to enter its eighth summer, Tenconi gives 80 children each year a week to feel just like any other kid, to be able to go swimming or to wear short sleeves without having to constantly hear the whispers from strangers.

For many first-time campers, the week at the camp in Livermore, Calif., at the end of June is their first time they feel comfortable in their own skin.

"It's not just a week at camp," Tenconi says. "It's the beginning of friendships. It's the beginning of this new lease on life."

When Tenconi came down with pemphigus foliaceus, the following months became the loneliest of her life. She spent three months in isolation, during which she lost 85% of her skin before doctors diagnosed the rare, potentially fatal autoimmune disease.

"We sort of lived in a cocoon like a caterpillar," says her mother, Christine. "She couldn't do anything with her friends."

Now, her Children's Skin Disease Foundation provides full funding of almost \$1,500 a child to attend the camp. With support from individual donors and medical companies, she has sent hundreds of kids to camp.

Campers can interact with other children who are experiencing the same pains and the same troubles fitting in with others who do not understand that their skin diseases are not contagious. For one week, their diseases stop defining them.

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"I think they talk about it so much during this year, this is the one time they get to have fun and be themselves," says Stephanie Pham, 18, who was a camper two years ago before becoming a counselor last summer.

Almost 50 medical professionals volunteer to make sure campers are safe and healthy enough to participate. Some campers require bandage changes every day, which can be a painful process that takes up to five hours.

"It's exhausting. It's like running the marathon, and I've done that, so I know what it feels like," says Jenny Kim, one of the camp's co-founders and a dermatologist. "We just want to make sure we're there for the children."

Those children have become "Francesca's kids," as her mother describes it. Tenconi has become attached to the campers who return year after year.

"I have a camper who calls me twice a week, and he tells me every week, 'I can't wait to come to camp,' " says Jennifer Pham, 24, Stephanie's sister and a counselor the past two summers. "Something happens up there during that one week that's magic."


Tenconi, who hopes to open a second camp on the East Coast, wants to become a pediatrician. She earned her undergraduate degree in 2006 from Duke University, where she studied the biological and psychological effects of chronic illness in children. As she works for her foundation full time, she plans to attend medical school soon.

"Even before I was sick, I always wanted to be a pediatrician," she says. "I've always really liked kids and have been comfortable around them and wanted to help them. Having an illness so young even reinforced that."

For more information, visit the foundation's website at www.csdf.org.

Find this article at:

http://www.usatoday.com/news/health/2008-04-06-camp-skin-disease-tenconi_N.htm?csp=34

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