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Photo project helps teens describe life with painful disease

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When Ryan Buck thinks about life with sickle cell anemia, he imagines himself a character in a storybook.

But his story is told without words. The 14-year-old instead uses photographs to help explain to others what his life has been like with the debilitating disease.

Thursday, Buck and six other Seattle-area teenagers afflicted with sickle cell anemia shared the photos about their lives and what the disease means to them at a gallery-style show at Odessa Brown Children's Clinic. The teens are part of the Central District clinic's adolescent group for sickle cell patients.

The clinic has served mostly poor and uninsured children since 1970, now offering dental, mental health and medical services and special programs for children with sickle cell disease, asthma, school underachievement and obesity.

Through the photo project, called Photovoice, group leaders at the clinic gave the teens disposable cameras and sent them to visually describe a life with the disease.

"Sometimes we give cameras to people who don't feel like they have power and it helps them create change," said Seema Mhatre, Photovoice's coordinator. "When these kids have pain crises, they have to be admitted to the hospital many times and they sometimes don't feel like they're understood."

The idea was to give them a voice to share with others.

"I never really thought about sickle cell all the time, but this really helped me think about what it really means to me," Buck said.

Like everyone afflicted with the disease, Buck was born with sickle cell, which causes the body to make abnormally shaped red blood cells. The resulting hard and curved cells pass painfully through the system, and can block blood flow to organs, causing organ failure. Frequent hospital visits for blood transfusions and pain medication are common.

Buck's family stopped counting at visit number 50.

His project, displayed on large poster board, includes a picture of a cat, which he said represents nine lives and having strength. A car accident represents the unpredictability of life. A stop sign reminds people to stop and think about what life means. A picture of his dirt bike shows people what the pain and sickness of sickle cell takes away from him.

Buck, who also suffers from severe lung disease, can't hike or take long walks with his Boy Scout troop, and has passed out on the side of a mountain when he was snowboarding.

"This was one of the few times for him to stop and see how sickle cell impacts his life and the things he can and

can't do," said his mother, Lesley Buck. "I was so impressed that he actually took time and had meaning behind each photo."

Crystal Lyons, community programs supervisor at Odessa Brown's Children's Clinic, said the project provided a good outlet for the teens, and the results were surprisingly profound.

"One boy took pictures only of himself, and at first we didn't think he really took the time to think about the project," she said. "But then we realized sickle cell is really all about him and that's all he knows."

The gallery night, planned to look like professional photographers showcasing their work, was designed to give people a chance to experience sickle cell through the eyes of children.

"Each display is very telling of each of these kids," Mhatre said. "It really shows who they are and the different ways they feel about their disease."

SICKLE CELL ANEMIA

Sickle cell anemia is a serious disease in which the body makes abnormally shaped red blood cells, causing pain, organ damage and a low blood count.

It's a genetic disorder affecting about 72,000 Americans. There is no cure. Pain medication and blood transfusions are common treatments. One in 600 African Americans and one in every 1,000-1,400 Hispanic Americans are born with the disease.

While the disease in the U.S. most commonly affects people of African descent, people with ancestors from South America, Cuba, Central America, Saudi Arabia, India and Mediterranean countries such as Turkey, Greece and Italy also can be affected.

Source: National Heart, Lung and Blood Institute

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