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**SOUTH JERSEY**

**Ill boy locked in battle with school**

Thursday, May 22, 2003

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 WOODLYNNE

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Steven Wark woke up last week on Monday morning and cried. He didn't want to go to school.

It wasn't the classwork - he normally gets A's and B's. It wasn't the students - he is generally popular and known as a class clown.

Steven, an 11-year-old fifth-grader who suffers from a rare skin disease that causes blisters throughout his body, didn't want to go to school because he knew he'd be wrapped in gauze.

"It hurts," he said.

Steven's family and doctors are locked in a dispute with Woodlynnne Public School over whether his wounds - particularly those on his elbows - should be covered up. The doctors say the cuts will worsen if they are covered; the district-appointed nurse insists on wrapping them.

Caught in the middle, Steven now has no choice but to stay home all day, mostly watching TV. He gets two hours of tutoring after 3 p.m., when he would normally ride bikes and catch snakes in the woods with friends.

"It's so aggravating because you can't do nothing," said his mother, Kelly Wark-Jankowski. "He should be in school. He shouldn't have to stay home for a skin disease."



CHRIS LaCHALL/Courier-Post  
 Steven Wark, 11, a fifth-grader at Woodlynnne Public School, suffers from a disease that causes blisters. A school nurse insists on wrapping them in gauze, which worsens them, doctors say.

Steven was born with epidermolysis bullosa, a rare genetic disease affecting one in 50,000 Americans. It is not contagious.

In Steven's case, the disease has caused long, thin cuts down his legs, and a cut the width of two quarters on each of his elbows. There are still small cuts on his face from three large lesions that have mostly been covered by skin grafting. But there is still a significant lesion on his neck, where a tube, called a tracheostomy, helps him breathe.

The instrument makes his voice high-pitched and garbled, and difficult to understand. But Steven has an innate wit and a contagious smile that makes his eyes squint devilishly, endearing him to adults and other children.

Asked about how other students react to his uncovered sores, Steven said: "They don't care."

Many of the students have known Steven since kindergarten, when he started attending Woodlynnne Public School. They are accustomed to the district-appointed nurse that stays in the classroom, monitoring his wounds and tracheostomy, he said.

But in September, Steven's relatively normal childhood began to unravel. And his family doesn't know why.

Steven started the school year with a new district-appointed nurse. She took him to the school nurse's office to get the wounds on his elbows wrapped in gauze, Wark-Jankowski said. This is not how she was told to care for her son, she said.

"You usually keep them open to air to let them heal up," said Dr. William Graessle, a pediatrician who has treated Steven at Children's Regional Hospital at Cooper University Hospital in Camden. "They are not infected. They don't cause a risk to anyone else."

Steven stopped going to school, and the family went to court. On Sept. 25, an administrative law judge in Mercerville ordered Steven be allowed to return to his class and mandated that only open lesions be dressed.

According to the state Department of Education, students are forbidden from school if the person has

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"uncovered weeping skin lesions." Wark-Jankowski said the school has a similar policy.

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But Steven's wounds do not regularly bleed or ooze, according to Deborah Holden, a nurse who works at home with Steven and his 17-year-old brother, who also has the condition. She said when Steven was wrapped at school, the bandages didn't even have bloodstains, proving that the wounds were not bleeding.

Still, the dispute fizzled for the winter. When Steven wore long sleeves, there was no perceived problem from the school or school-appointed nurse, his mother said.

But last Monday, on one of the first nice days of spring, Steven woke up and realized he'd be wearing his blue shirt and beige shorts to school. Then he got upset. He knew the nurse would wrap his elbows.

And she did.

"When she (the nurse) pulls it (the bandages) off, it sticks to his sores and bleeds," Wark-Jankowski said.

Steven hasn't been back to school since.

Last Friday, one of his doctors, Dr. William G. Sharrar, wrote a note to the school reading: "The child will need to be homeschooled for the rest of the year. He cannot have his arms wrapped and can't wear winter (long-sleeved) clothing."

The long sleeves, according to the doctors, aggravate the wounds in summer the same way that the bandages do.

"My kid shouldn't have to decide, 'Today it's not nice out, I can go to school, but tomorrow, it's nice so I can't,'" Wark-Jankowski said.

Faced with aggravating his medical condition or staying home, Steven began two-hour daily homeschooling this week.

For the family attorney, Jamie Epstein of Collingswood, discrimination is at play.

"He's being excluded from school due to his disability," he said, adding that he is pursuing further legal action.

The district-appointed nurse could not be reached for comment, and the district superintendent, attorney, school principal and school board members said they were bound by confidentiality laws and could not comment specifically on the case.

Dr. Bennett Schwartz, chief of the dermatology section at Virtua-West Jersey Hospital in Voorhees, does not know Steven. But he said EB, as it is known, causes fragility in collagen, the main fiber in the skin. This causes the blistering. He said the disease can worsen over time, but can only be contracted genetically.

Meanwhile, Steven is smiling. He got a new book on animals Tuesday from a neighbor. The family has birds, dogs, ferrets and a mouse, and Steven wants to work with animals when he's older.

"He has all the wants and needs of other children, he wants to be independent," said Holden, the nurse who cares for him at home. "He has the best personality. He's the class comedian."

As he waited for his tutor at 3:30 p.m. Tuesday, he read his new book with his 15-year-old sister Catherine. Later, he sat with his tutor, one hand in his brown hair and the other holding a big pencil, frowning at the thought of working out fractions.

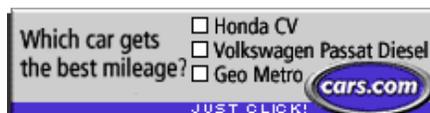
"I think somebody's afraid of his blood," Wark-Jankowski said.

"Or afraid of him," Holden added.

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