

Boy in school flap over cystic fibrosis

Jill Tucker

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By all accounts, Colman Chadam is a healthy, active 11-year-old boy who fit right in at Palo Alto's Jordan Middle School as a new kid in town.

Except now, school officials believe his genetic makeup means he is a health risk to some of its other students and ordered that he be moved to another district middle school 3 miles away.

Colman carries the genetic mutations for cystic fibrosis - but his doctor and parents say he does not have the disease. His parents, out of an abundance of caution, made the disclosure about his condition on a medical disclosure form when he began the school year.

The district - also out of an abundance of caution - decided that Colman would need to change schools seven weeks into the year because other students at Jordan have cystic fibrosis.

While the disease is not contagious, the bacteria those with cystic fibrosis carry can be dangerous to people with the same disease, and non-siblings are advised to stay at least 3 to 6 feet away from each other.

Colman's parents, Jaimy and Jennifer Chadam, tried to persuade administrators that Colman doesn't have classic cystic fibrosis and therefore isn't a risk.

On Wednesday afternoon, teachers pulled Colman aside to tell him to say goodbye to his friends.

"They made this decision without seeing one medical record on my son," Jennifer Chadam said. "We were shocked and dismayed."

Friday, the Chadams took the district to court to try and keep their son from being moved. The judge did not allow Colman to return immediately to Jordan, but did schedule a hearing to determine if he should be moved.

Dangerous infections

Cystic fibrosis comes in many forms, but is typically associated with mucous buildup in the lungs, causing dangerous infections that can be fatal.

While Colman carries the genetic mutations, he has never had the classic lung problems, has never required treatment and tested negative on a sweat test, the definitive diagnostic tool, his parents said Thursday.

A few weeks into the school year at Jordan Middle School, school officials took note of Colman's medical history, information that eventually was shared with another Jordan parent whose two children have classic cystic fibrosis and are predisposed to chronic lung infections.

"The school district freaked out," Colman's mother said.

It was unclear Friday whether Colman's medical privacy rights were violated during the process. Until the Oct. 25 hearing to determine whether he can stay or must go to Terman Middle School, Colman will stay at home doing an independent study, his parents said.

An 'unusual situation'

Palo Alto Unified administrators did what they thought best given the information they had and the significant risk to students, said the district's attorney, Lenore Silverman.

"This is a very unusual situation," she said. "The district is not willing to risk a potentially life-threatening illness among kids."

The administrators sought medical advice, Silverman said Thursday, which resulted in a recommendation from Dr. Carlos Milla, of Lucile Packard Children's Hospital, saying that, ideally, children with cystic fibrosis would attend separate schools.

The recommendation was not based on knowledge of Colman's specific medical history, his parents and their attorney said prior to Friday's court appearance.

Colman's only link to cystic fibrosis was a genetic test done 11 years ago, his mother said.

"Honestly, if I felt Colman was a risk to others, I would move him," she said. "I don't want anyone to get sick."

Genetic testing

In decades past, far less was known about cystic fibrosis. It was thought that a child either had the disease, typically determined by a sweat test, or didn't.

With the help of genetic testing, researchers have found that 1 in 25 people are carriers, and there are up to 2,000 genetic variations.

In the evolving field of cystic fibrosis diagnosis and treatment, there is debate about which variations mean someone has the disease versus being a carrier only.

Because of Colman's rare genetic combination, his parents and doctors have closely monitored him to make sure he doesn't have the disease.

His physician has documented that he doesn't, and he never had a clinical diagnosis of the disease, his parents said.

"For some reason, the school district wants to diagnose my son before the doctors know how," Jennifer Chadam said.



If a child has a normal sweat test and doesn't have classic cystic fibrosis pulmonary issues, "that child is at absolutely no risk to the children that have classic cystic fibrosis," said Dr. Dennis Nielson, UCSF chief of pediatric pulmonary medicine and head of the UCSF Cystic Fibrosis Clinic. Nielson has no specific knowledge of Colman's case.

Other possible protocols

Still, school districts have wide latitude in identifying health and safety concerns and in taking action.

Yet even if more than one child at a school has classic cystic fibrosis, it's unclear whether a midyear transfer is necessary.

The Cystic Fibrosis Foundation outlines standard protocols - disinfecting, wiping desks, washing hands, different classrooms, for example - to put in place in case multiple children with classic cystic fibrosis attend the same school.

The Chadams hope their son will be able to stay at Jordan, which his brother also attends.

He was the new kid in school back in August and was just starting to feel settled, his parents said.

His Jordan teachers told his parents he was "optimistic and enthusiastic and overall, awesome," Jennifer Chadam said. "Now he's been told he's unsafe."

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