UF | Department of Pediatrics
UNIVERSITY of FLORIDA

Cystic Fibrosis Center

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Date:

Dear Teacher/Principal/School Counselor:

_____is a student in your school this year. He/she is followed at the University of Florida Cystic Fibrosis Center and has some special considerations for participation in school. This letter provides information about Cystic Fibrosis and about _____'s needs in school. Should you ever have questions about this information or about this student's needs or abilities, please feel free to contact the staff at our center. Our team includes physicians, nurses, nutritionists, social workers and pharmacists who will be happy to help.

What is Cystic Fibrosis?
Cystic fibrosis is an inherited chronic disease that affects the lungs and digestive system of about 30,000 children and adults in the United States (70,000 worldwide). A defective gene and its protein product cause the body to produce unusually thick, sticky mucus that:

- clogs the lungs and leads to life-threatening lung infections; and
- obstructs the pancreas and stops natural enzymes from helping the body break down and absorb food.

What are the symptoms?

- Respiratory symptoms: Thick, sticky mucus builds up in the lungs, leading to recurrent lung infections and eventually, permanent damage to the lungs.
- Digestive Symptoms: Mucus blocks pancreatic enzymes from moving from the pancreas to the small intestines. The result is fat and protein malabsorption, leading to poor growth, stomach cramping, and frequent, loose, foul-smelling stools.

Issues that arise at school:
Coughing: Children with CF often have a chronic cough. Coughing helps the child to clear the lungs of the thick mucus and defend against chronic lung infections. Please help the child feel comfortable about their need to cough. Remember, this cough is not contagious.

Restroom privileges: Because of the digestive symptoms of CF, teachers can help by allowing children with CF to leave class at any time to use the restroom. Privately initiating a discussion of this issue with the child helps to avoid any embarrassment.

Medications: Most children with CF need to take medications at school. The most common medication is supplemental **pancreatic enzymes** which must be taken ***immediately before eating***. This means anytime food is served. Without the enzymes, these children have increased symptoms like gas, bloating and uncomfortably large stools. This student takes _____ enzymes. He/she needs ___ enzymes prior to all meals and ___ enzymes prior to all snacks. (Note: these enzymes simply promote breakdown and absorption of food and do not pose a risk to other students.) Other medicines that children might need to take periodically include antibiotics or breathing treatments.

Nutrition: People with CF need extra calories to maintain weight and lung function. This need is further increased during lung infections. Good nutritional status for people with CF is extremely important, as it closely correlates with good lung health. There are no food restrictions for people with CF. Often nutritionists recommend larger portions, high calorie nutrition supplements or suggest ways to increase calories in the child's meals. High-calorie snacks between meals should be a routine part of daily care for children with CF.

Physical Education and Sports: Exercise helps people with CF maintain stamina and keep their lungs clear. However, CF may decrease a student's tolerance for physical exertion. If this is a problem, teachers can help by working with students on an activity plan that meets their needs for exercise while not overdoing it. Remember, if a child coughs during exercise, it is beneficial. Allow the child sufficient time to finish coughing and then recommence exercising.

Absences: A severe lung infection can cause a child to miss up to 3 consecutive weeks of school. Children sometimes have to be in the hospital to receive intravenous (IV) antibiotics. Some children are able to receive this therapy as an outpatient and may be able to return to school while still receiving intermittent IV antibiotics. Teachers can help by sending assignments home, communicating and working with home or hospital based tutors and working with the child after hospitalization to catch up with missed schoolwork. Generally, within a week of beginning IV therapy, children feel well enough to resume some schoolwork.

Peer Relationships: Some children with CF may be smaller and thinner than their peers. They may differ from their peers in their physical abilities, need for school absences, chronic cough and need for medications. Teachers can help by being knowledgeable about CF and working with students, peers, and families to individually address peer relationship difficulties.

Academic Performance: Students with CF should be provided the same academic program as their peers unless their health deteriorates too much to allow this. They can perform at the same level as other students. Intellectual impairment or other academic problems are not a direct result of having CF. However, in some cases, the impact of a chronic illness (such as increased fatigue, more school absences, accumulated effects of decreased lung function over time) can affect a student's academic performance. Students with CF should be encouraged to make the most of going to school since we now expect individuals with CF to live into their 30's or 40's. We do not expect frequent CF related absences and when we are aware of such, will address need for changes in care with families to assure the child is well enough to attend school.

We appreciate your partnership in the care of the children and families we serve. It is our goal to help them live a normal life and you are a big part of bringing that goal to fruition!

Sincerely,

Pamela M Schuler MD
CF Center Director

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CF Center Coordinator