

[Date]

Dear [insert teacher's name],

My child, [insert child's name], will be a student in your classroom this year. [Child's name] has a rare genetic disorder called primary ciliary dyskinesia (PCD). PCD is a multi-system disorder, but chronic infections of the upper and lower respiratory tract, including the lungs, the ears and the sinuses, are the primary problems [child's name] will encounter.

Cilia are microscopic projections from the tissue lining certain areas of the body, including the lungs, sinuses, ears, ventricles of the brain and the reproductive organs. While cilia may look like tiny hairs, they are actually very complex structures that perform important roles in the body. In some areas of the body, the sweeping movement of the cilia is crucial to the proper cleaning and functioning of organ systems.

In PCD the sweeping motion of the cilia is impaired because of an inherited defect. When this happens, areas that rely on ciliary activity for proper function, like the lungs, ears and sinuses, are subject to repeated infections.

You may notice that [child's name] coughs a lot. Sometimes his/her cough can sound alarming, however it is rarely contagious. Without functioning cilia, mucus that would normally be "swept" up the respiratory tract to be swallowed collects in the airways. Trapped mucus is a source for repeated infections. For people with PCD, a healthy productive cough is essential for moving mucus out of the airways. We encourage [child's name] to cough and will provide tissues for him/her to use.

People with PCD are susceptible to opportunistic infection and may get sick from bugs that don't usually infect healthy people. This means that they are generally more at risk to catch something from others than to pass something on. We stress the importance of hand washing with [child's name] and discourage him/her from close contact with sick individuals. A cold for a healthy child can easily become pneumonia for a child with PCD, so reasonable precautions to prevent the spread of contagious illnesses is very much appreciated.

Hearing loss is a common consequence of chronic ear infections in PCD. We monitor [child's name] hearing closely, but at times fluid can collect behind the ear drum and cause subtle hearing changes that he/she may not be aware of. If you notice changes consistent with hearing problems like lip-reading, talking loudly, failing to respond when called, etc., please let us know. If possible, a seating assignment close to where the teacher presents information would be helpful.

PCD frequently causes severe sinus disease. Sinus pain and infection are common consequences of the disorder. When [child's name] has active sinus disease, he/she will need to blow his/her nose frequently. Because of the nature and volume of the mucus

PCD people produce, this is often an embarrassing procedure for PCD kids. We request that [child's name] be excused from the classroom when it is necessary for him/her to blow his/her nose.

Because of repeated infections, kids with PCD may have multiple absences from school. We will work with you to try to minimize the number of absences and to help with any make up work that may be required due to absences.

Roughly 50% of people with PCD have issues with organ placement (*situs*). Most have a condition called *situs inversus totalis* where all of the abdominal and chest organs are reversed. When this happens the disorder is sometimes called "Kartagener syndrome." Less frequently, people with PCD may have random issues with specific organs. [Child's name] has [fill in specifics if needed]. Usually, there are no significant problems with organ function in PCD, but we would be happy to discuss [child's name] specific concerns with you.