[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 primary ciliary dyskinesia (PCD).

**WHAT IS PCD?**

PCD is a rare genetic disorder that can cause health problems throughout the body. But the main symptoms are:

* chronic infections of the upper (sinuses) and lower respiratory tract (lungs)
* recurrent ear infections
* hearing loss

**What causes PCD?**

People inherit the genes for the PCD from their parents. Mutations or abnormalities in the genes cause defects in specialized structures called cilia.

**What parts of the body are affected by PCD?**

Cilia are microscopic projections from the tissue lining certain areas of the body. Because of the way they look, many people think of cilia as just tiny hairs. Actually, cilia are very complex structures that perform important roles throughout 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 some of which include:

* respiratory (lungs and sinuses)
* auditory (ears on the “inside)

**What symptoms does PCD cause?**

When the cilia don’t move properly certain areas like the lungs, ears and sinuses, are subject to repeated infections because of a build-up of fluid and mucus. Sometimes these recurrent infections and fluid in the ears can lead to hearing loss. **While we monitor** [child’s name] **hearing regularly, it would be helpful if you notice things like lip-reading, talking loudly, failing to respond when called, etc., please let us know. As hearing can fluctuate without a child noticing, a seating assignment close to where the teacher presents information is essential.**

Like most people with PCD, [child’s name] has a daily “junky” cough which at times might sound concerning. This “junky” or “juicy” sounding cough is caused because without normal movement of the cilia, mucus collects in the in the nose, sinuses and breathing tubes. We encourage [child’s name] to cough and will provide tissues for him/her to use as well as a water bottle to help with the cough. It is very important for [child’s name] to feel comfortable coughing everywhere as a healthy productive cough is essential for moving mucus out of the breathing tubes where it can get stuck and infected. **We would love you to partner with us in encouraging [child’s name] to get the cough out, even with just a simple quiet smile to show you understand without embarrassing them.**

PCD can also cause chronic runny nose and severe sinus disease with pain and infection. [Child’s name] may need to blow his/her nose frequently. Because there can be **A LOT** of strangely colored mucus, nose blowing can be embarrassing for children with PCD. **Again, we would like you to partner with us by allowing [child’s name] be excused from the classroom when it is necessary for him/her to blow his/her nose.**

While the cough and runny nose might look/sound like [child’s name] has an infection; in general people with PCD are generally more at risk to catch something from others than to pass something on. **Please partner with us in encouraging use of hand sanitizer with [child’s name] and discourage him/her from close contact with sick individuals.** For a child with PCD, another child’s “little cold” can easily become pneumonia. **So please join us in taking reasonable precautions to prevent the spread of contagious illnesses and let us know if you hear/see a change in [child’s name]’s cough.**

**How does PCD affect children in school?**

People with PCD have normal cognitive ability. However, because of the repeated infections and breathing treatments, children 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.**

**Any specific precautions?**

If you are aware of there being more than one person with PCD or cystic fibrosis (another genetic disease that causes mucus problems) at your school, it is essential that they keep 6 – feet distance from each other.

We look forward to you getting to [child’s name] and having a successful school year together. There are so many more things that make [child’s name] special but we wanted to share his/her PCD diagnosis with you as you will be a key person in our family’s life over the next year. If you have more questions about PCD in general, feel free to contact us or look at the PCD Foundation website, pcdfoundation.org.

Sincerely,