

PIDD and school

A guide for students with primary immunodeficiency disease



Students who have a primary immunodeficiency disease (PIDD) can be sick often. They might need special plans to help them succeed in school. Staying in close contact with your child's school nurse and staff can help.

Kindergarten – grade 5

Parents should:

- Meet with the principal or superintendent of your child's school. See how you can work together to set up a health care team that will monitor your child during their time in school.
- Ask what modification or accommodation programs are available. Your child might benefit from an individualized healthcare plan (IHP), emergency care plan (ECP), 504 plan or individualized education program (IEP).
 - A 504 plan is a process, plan and legal document that lays out accommodations for students with special health needs. Any student who has a physical or mental limitation that affects at least one major life activity can have reasonable accommodations.
 - An IEP involves a team of people who help your child. These people include the parent, a school administrator, one or more of the child's teachers and a guidance counselor.
- Meet with the school nurse and help them understand your child's condition. Be sure to mention that PIDDs are genetic – other students can't catch them.
- Ask the school nurse to tell you right away if there are illnesses "going around" at school, such as strep throat, the flu or measles.
- Tell the nurse and your child's teachers that your child's cuts or wounds need first aid and disinfectant right away.



Kindergarten – grade 5 (cont.)

Your Child should:

- Get a healthy diet and exercise.
- Get enough sleep.
- Have their own set of school supplies and label them with their name.
- Wash their hands and use hand sanitizer often.
- Get an open pass to the bathroom. Some PIDD treatments can cause diarrhea.
- Get two sets of textbooks – one for home, one for school. This helps if your child has to be home sick.
- Get all the vaccinations they are eligible for, and get waivers for the rest.
- Be careful not to get a nasal flu vaccination.

Grades 6-8

Parents should:

- Make sure your child still has a health care team at their school. This team should include you and your child, the school nurse, the principal, a teacher, and a guidance counselor.
- Make sure any needed modification or accommodation programs are still in place.
- Give the school nurse a list of medications your child takes and why. In most states, you will need to give the nurse a copy of your child's prescriptions before the school can dispense your child's medications.

Your Child should:

- Keep hand sanitizer in their locker and use it regularly.
- Stay away from people who aren't feeling well.
- Exercise and eat a healthy diet.
- Have regular appointments with their immunologist. The school nurse should get copies of case notes.



Grades 9-12

Parents should:

- Stay in contact with your child's health care team at school. Tell them about any changes in your child's condition or concerns you have.

Your child should:

- Wash their hands and use hand sanitizer often.
- Tell teachers, coaches and mentors about their PIDD on an as-needed basis.
- Not kiss their girlfriend or boyfriend when they are sick.
- Learn to take their own medications on schedule.
- Learn about their rights as a person and student who has PIDD.
- Have a plan in place in case they miss school for several days in a row. How will they get their work? How long do they have to make it up?

Your child's rights

Many federal laws protect students who have PIDD when they're in school. The most applicable laws are:

- Section 504 of the Rehabilitation Act of 1973
- Americans with Disabilities Act (ADA) of 1990
- Individuals with Disabilities Education Act (IDEA)

For more information

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