

Primary Immunodeficiency Diseases Information Sheet

Primary immunodeficiency diseases (PID) — also called primary immune disorders or primary immunodeficiency — weaken the immune system, allowing repeated infections and other health issues to occur more easily. PIDs are classified into six groups based on the part of the immune system that is affected: B cell (antibody) deficiencies, T cell deficiencies, combination B and T cell deficiencies, defective phagocytes, complement deficiencies and unknown (idiopathic). PID can be specific to one cell type or generalized to several components of the immune systems.

Signs and Symptoms

- Increased susceptibility to infections (more frequent, longer lasting or harder to treat)
- Frequent and recurrent pneumonia, bronchitis, sinus infections, ear infections, meningitis or skin infections
- Blood infections
- Inflammation and infection of internal organs
- Blood disorders, such as low platelet counts or anemia
- Digestive problems, such as cramping, loss of appetite, nausea and diarrhea
- Delayed growth and development
- Autoimmune disorders, such as lupus, rheumatoid arthritis or type 1 diabetes

Treatment

Treatments for primary immunodeficiency involve preventing and treating infections, boosting the immune system and treating the underlying cause of the immune problem. In some cases, primary immune disorders are linked to a serious illness, such as an autoimmune disorder or cancer, which also needs to be treated.

Educational Implications

Frequent infections are a possibility in children with primary immunodeficiency diseases. To stay healthy, minimize exposure to germs. Good hand hygiene, including washing hands with soap and water before meals and after using the restroom is important. When soap and water are unavailable, alcohol-based hand gels and individually wrapped and disposable hand wipes are effective alternatives. Periodic washing of manipulatives may be beneficial.

Notify the school nurse of signs of illness immediately. Contact the parents to ensure appropriate follow-up care. Report outbreaks of communicable disease to the student's parents as soon as possible. Primary concerns are chickenpox, influenza, meningitis, methicillin-

resistant Staphylococcus aureus (MRSA), hepatitis and measles. Cuts or other wounds should receive immediate first aid treatment by the nurse and parents alerted so they can continue proper care at home.

Students may miss more school than their peers. These absences are typically a result of illness, side effects from medication, regularly scheduled treatments and doctor's appointments.

The challenge of living with a chronic illness can cause significant stress and have a great impact on the psychological well-being of the student.

Educational Options

Those students whose primary immunodeficiency disorder adversely affects their educational performance may benefit from special education under the Individuals with Disabilities Education Act (IDEA). To qualify under IDEA, a student must meet eligibility criteria in one of thirteen specific disability categories. Under IDEA, a student with a disability is entitled to a free appropriate public education (FAPE) and an individualized education program, including individual goals, objectives, related services, accommodations and modifications.

Students that do not qualify for services under IDEA may qualify under Section 504 of the Rehabilitation Act. To qualify under Section 504, a student must have a physical or mental impairment that substantially limits one or more major life activities (for example learning, breathing, thinking, concentrating, walking, bodily functions). Under Section 504, a student is entitled to equal opportunity, and may qualify for a Section 504 plan that provides regular or special education and related aids and services.

A student with a health condition who does not require special instruction and related services can receive, as appropriate, a wide range of supports in the general education classroom, including accommodations, individualized health plans (IHP), emergency care plans (ECP) and local education agency supports.

Resource

[Immune Deficiency Foundation](http://www.primaryimmune.org) (www.primaryimmune.org), 800-296-4433 (toll free). The Immune Deficiency Foundation (IDF) has a peer support program, as well as information on day-to-day living with primary immunodeficiency, including a downloadable guide for school personnel.