Primary immune deficiency diseases (PIDD) include more than 70 different forms of the disease. Some deficiencies are more severe than others, but every form puts the individual at risk for serious and sometimes life-threatening illness. One of the most important aspects of caring for children who have PIDD is in the early detection and treatment of illnesses.

One of the most common forms of PIDD involves antibody deficiencies. Antibodies, which are produced by B cells, are not produced properly due to inborn defects leading to increased risk for infections. Immune globulins are the part of our blood plasma that contains these antibodies or globulins. Most children with these defects receive temporary replacement of the antibodies they cannot make, in the form of intravenous immune globulin (IVIG), to help them fight infections. This therapy occurs every two to four weeks, and is often a lifelong therapeutic intervention. The infusions normally occur in an infusion center, outpatient clinic or student’s home, and typically last from four to six hours.

Side effects from IVIG vary, but the most common late side effects include headaches, joint pain, low grade fevers and occasionally aseptic meningitis. The side effects can occur two to seven days after the infusion. Any side effects a child reports to the school nurse need to be taken seriously and immediately reported to the child’s caregivers.

Children with PIDD will miss school for their infusions and for doctor appointments. Infusion centers are usually not open on the weekends, so the therapy must occur during the week. Be aware that, although children with PIDD may look healthy, the child and their caregivers will be well aware of specific symptoms of their illness exacerbations, and their opinions need to be respected and trusted. If a child comes to the nurse to complain of a specific problem, this needs to be given immediate attention.

Children with PIDD may need frequent visits to the nurse’s office for antibiotic administration, respiratory treatments or for other medical intervention. They may also need more frequent visits to the restroom, due to gastrointestinal complications of their illness. These children know their bodies very well, and they should be given every opportunity to use the restroom.

Children may also need to have frequent snack and meal breaks or breaks for nutritional supplements, due to weight loss and other dietary issues. Every attempt should be made to fit these breaks in with the other children to maintain a sense of normalcy for the child with PIDD.

Any disease outbreak in school—including varicella zoster, influenza, measles, meningitis or hepatitis—must be reported to the child’s caregiver immediately, even if the outbreak occurs in a different classroom.

Children with PIDD are more likely to suffer from chronic ear infections, sinus infections, fungal infections, pneumonia and any other communicable disease of childhood. Take any complaint seriously and report to caregivers immediately. If a child with an immune deficiency suffers a cut or abrasion while at school, clean the wound thoroughly and apply appropriate antibiotic ointment. Contact and update the child’s caregivers immediately, as the child has an increased risk of a serious infection from any opening in the skin.

A quick word regarding vaccines: Children with PIDD cannot receive any live vaccines. Their healthcare provider should prepare a note for the school explaining this fact and their condition. Children with PIDD are also at a very serious health risk if exposed to anyone who has received live vaccines recently, such as Varivax or Flumist. If you have any questions, contact the child’s caregivers.

If you have a child with PIDD in your care, contact the caregivers for more specific information regarding the child’s specific health concerns. You may need to ask the caregivers to complete a note for their school file. A PIDD caregiver note template can be downloaded at http://www.immunedisease.com/US/patients/living/school.html.


References
Primary Immune Deficiency. NIH Institute of Child Health and Human Development. 2005.