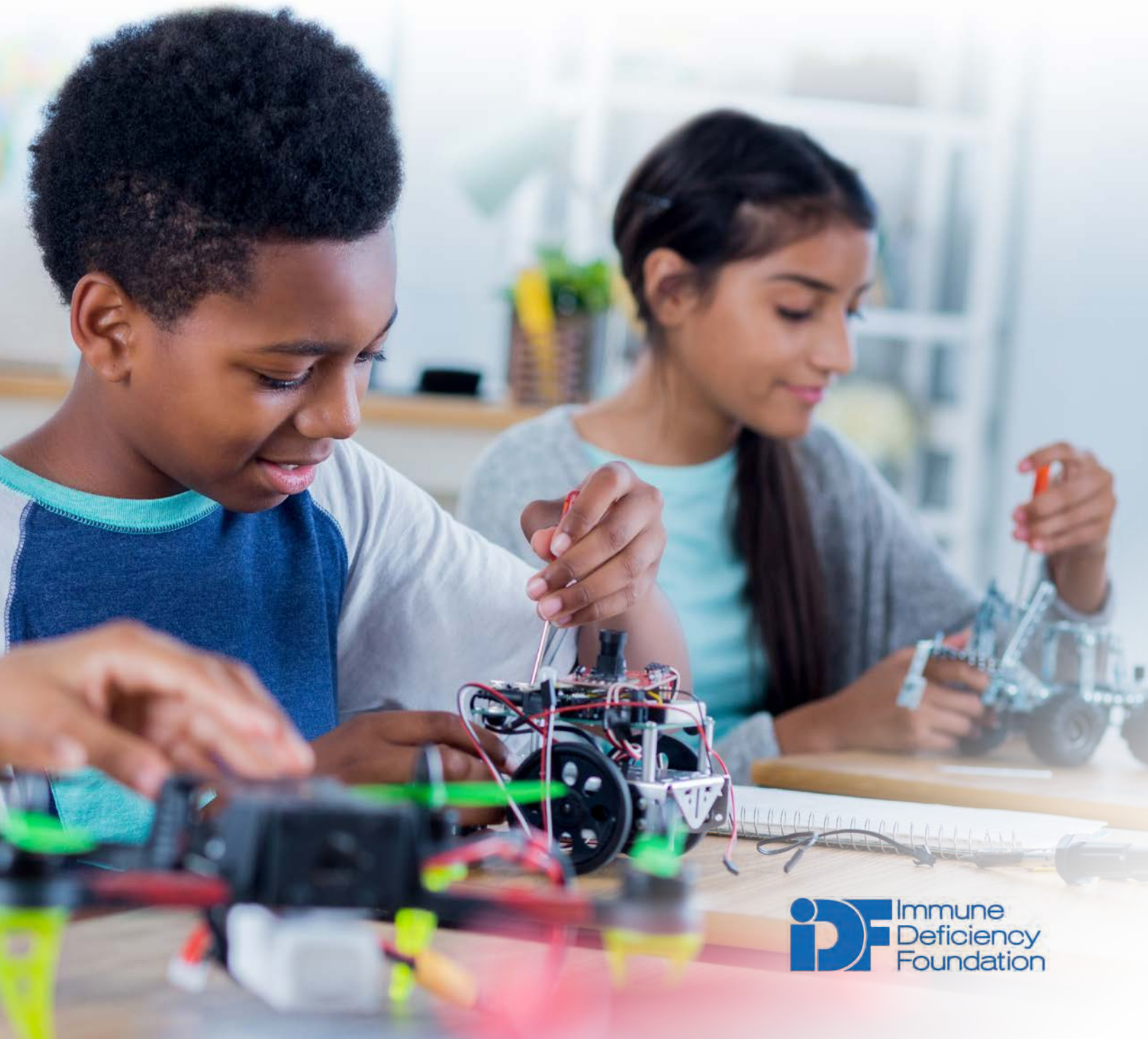
Immune Deficiency Foundation

School Guide for Students with Primary Immunodeficiency

FOURTH EDITION



About the Immune Deficiency Foundation

The Immune Deficiency Foundation (IDF) improves the diagnosis, treatment, and quality of life of people affected by primary immunodeficiency through fostering a community empowered by advocacy, education, and research.

Primary immunodeficiencies (PI) are a group of more than 450 rare, chronic disorders in which part of the body's immune system is missing or functions improperly. PI is caused by genetic defects in immune response pathways and can affect anyone, regardless of age or gender.

PI results in high susceptibility to infections. Illnesses such as repeated bouts of pneumonia, persistent skin abscesses, and sepsis, or blood infections, are common and can lead to permanent organ damage. Antibiotics often have little effect on the infections longterm. The infections can become chronic and develop into life-threatening conditions requiring hospitalization. PI is also linked to autoimmune disorders and increased risk of certain forms of cancer.

According to the National Institutes of Health, there are approximately 500,000 individuals in the U.S. with a primary immunodeficiency. Every year, thousands go undiagnosed. Individuals affected by PI often find it difficult to receive proper diagnosis, treatment, and specialized healthcare. They experience difficulties financing healthcare, finding educational materials, and locating others who share their experiences.

As a nonprofit organization headquartered in Maryland, IDF provides accurate and timely information for individuals and families living with PI and offers valuable resources and support. IDF operations are carried out by staff, medical professionals, and volunteers. Through this network, IDF conducts research on various PIs, provides education seminars and support groups, coordinates nationwide fundraising activities, influences healthcare policy, develops PI specific programs, assists with navigating health insurance, provides general information about managing care, and offers annual conferences for the PI community.

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IMMUNE DEFICIENCY FOUNDATION SCHOOL GUIDE FOR STUDENTS WITH PRIMARY IMMUNODEFICIENCY

FOURTH EDITION

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Chapter 1
To Members of the Educational Team

Parents & Guardians

You are your child's first teacher. You know your child better than anyone does and when they enter school, you become partners with the school and are part of your child's educational team. In time, your child should be invited to join the team.

Since primary immunodeficiencies (PIs) are a group of rare, chronic disorders, most people are not familiar with them. The teachers and staff at your child's school will likely need information about your child's condition and what they can do to ensure that your child has the best educational experience possible. Below are some ways to ensure your child receives the best opportunities to learn and participate.

Learn about your child's educational rights. **Chapter 3** of this guide includes information about laws that protect your child in an educational setting. As parents/guardians, it is essential for you to ask questions of school personnel whenever you need more information. If necessary, bring an advocate to meetings. Review education or healthcare plans carefully before signing them. Again, ask questions if you need more information.

Communicate with school personnel. Develop a communication plan with school personnel and regularly discuss your child's progress. Inform school staff of any changes in your child's health status or medications as soon as possible. A phone call, during the teacher's free time or at a pre-established time, or an email is all that is typically necessary to keep in contact. However, an effective means of communication is something that needs to be clearly established and agreed upon by all parties.

Understand and help develop your child's education or healthcare plan. Information about education and healthcare plans is included in **Chapters 4-7** of this guide. As your child gets older, encourage them to provide input on the plan and advocate for themselves during the school day. However, until your child is 18, you are responsible for developing a plan and advocating for your child.

Keep good records. Keep copies of all written communications for your records in one place where they can be accessed easily. After in-person or phone conversations, best practice is to follow up with a short email outlining what was discussed and any agreed-upon actions. In addition to keeping good records regarding your child's education, it is vitally important to keep good records about your child's health.

Know your resources. Education and PI-specific resources are listed at the end of this publication. In addition, IDF has staff available to help you navigate issues in your school system. Contact IDF at https://primaryimmune.org/ask-idf/ or 410-321-6647.

Disclosing Your Child's Diagnosis

One of the decisions you face is whether to disclose your child's diagnosis of primary immunodeficiency to their school. Disclosing a diagnosis of PI, or any chronic illness, is a very personal decision. There are some things to consider.

If the condition does not affect the student's education, it is up to you and/or the student whether to tell the school about the diagnosis. However, in order to receive an education equal to other students, it is important to tell the school in the following situations:

- If the student needs to take medication at school.
- If the student expects to be absent more than other students.
- If the student needs accommodations or modifications that are not available to other students.
- If there are specific emergency procedures that need to be followed if the student becomes ill at school.

Notifying the school about a diagnosis of PI before the school year begins or as soon as a diagnosis is received will enable everyone to work together to support the student at school. If you decide to disclose your child's diagnosis, consider sharing the following resources and information with school personnel:

- A letter from your child's healthcare provider, listing the medical condition, treatment/medication, and, if necessary, recommendations for accommodations/modifications. A sample letter is included in **Chapter 10**.
- Copies of IDF publications:
  - » This publication (*Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency*©).
  - » The chapter from the *Immune Deficiency Foundation Patient & Family Handbook for Primary Immunodeficiency Diseases - 6th Edition*© that describes your child's specific type of PI.
  - » *Our Immune System*©, a children's storybook that provides an easy-to-understand explanation of immune system function.
  - » *Is It Just an Infection?*© poster to be displayed in the school nurse's office to promote awareness of PI.

Tips for Communicating in Writing

- Clearly and respectfully state your request or concern.
- Include your child's name, grade, and teacher, as well as your contact information.
- Always date the communication; if you are communicating by email, the email system will automatically record a "sent" date.
- Add a "thank you" at the end.
- Review your letter/note for clarity and accuracy.
- Ask someone else to review the letter/note if you aren't sure you are getting your message across and make changes if necessary.

Tips for Meeting with School Personnel

Before the Meeting

- » Prepare and know what you hope to accomplish during the meeting.
- » Complete the Meeting/Conference Planner, included in **Chapter 10** of this guide.

During the Meeting

- Take notes.
- Ask questions when you need more information.
- Remain calm and stick to the facts.
- Review and discuss the next steps and who is responsible for them.
- Review any paperwork school personnel need you to complete to make sure you understand it.
- Request a follow-up meeting or communication date.

After the Meeting

- Complete any paperwork requested by school personnel. Legally, you have the right to review any paperwork before completing and signing it, and it is okay to take paperwork home and return it when you have had time to check it over.
- Follow up in writing to reiterate what was discussed and the plan moving forward; thank school personnel for their help.
- Keep in touch with key school personnel.

Students

School is a major part of your life until you graduate. When you turn 18, you are responsible for making decisions that affect your education and health. It will be valuable for you to begin working with your parents/guardians and school personnel before you turn 18 to learn how to advocate for yourself at school. Below are questions to keep in mind:

- Do I have an education or health plan at school?
- Do I know which accommodations or modifications are included in the plan?
- Did I provide input to create the accommodations or modifications?
- Are the accommodations or modifications working for me?
- Do I know who my "go-to" person is at school when I have questions or concerns about the plan or a health issue?

If you answered "yes" to all of the questions above, you are well on your way to being your own advocate. Keep it up!

Don't worry if you didn't answer "yes" to all the questions. It's never too late to start being your own advocate. Your parents/guardians, school personnel, and IDF are here to help.

As an individual with PI, it is important to keep the "I Am Immunocompromised" card included at the end of this chapter with you at all times. Your parents/guardians or healthcare provider can help you fill out the information.

This card gives emergency responders important information they need to treat you in situations where you are not able to provide that information yourself (for example, if you lose consciousness). The card can be laminated and kept in your wallet, backpack, or ID holder while you are at school. You can also upload a digital version of the card to a smartphone or use built-in features that make this information available from your lock screen (called "Emergency Information" on Android and "Medical ID" on iPhone).

School Personnel

This guide will provide you with general information about PI, examples of issues a student might encounter in the educational setting, and how you can help.

What is primary immunodeficiency?

Primary immunodeficiency (PI) describes a group of more than 450 rare, chronic disorders in which part of the body's immune system is missing or does not function properly. Because one of the most important functions of the immune system is to protect against infection, people with PI are generally more susceptible to infections than the wider population. People with PI often have frequent, severe, or difficult to treat infections and/or infections with unusual germs. People with PI may also experience autoimmune and inflammatory conditions; an increased risk of some kinds of cancers; and/or an increased risk of allergies—all stemming from an immune system that does not function properly.

According to the National Institutes of Health, there are an estimated 500,000 people with PI in the U.S. Years ago, a diagnosis of PI meant a significant impact on both the patient and their family. Today, with early diagnosis and appropriate therapies, many people diagnosed with a PI live healthy, productive lives. However, people with PI may still face frequent health problems and can develop serious and debilitating complications.

What causes primary immunodeficiency?

PI disorders are also known as inborn errors of immunity (IEI) because they are caused by inherited variants in the genes that are important for the function of our immune defenses. These conditions are often discovered early in life (in most, but not all, cases) and are not contagious.

Importantly, PI is not the same as acquired immunodeficiency syndrome (AIDS). AIDS is caused by the human immunodeficiency virus (HIV) and is a secondary immunodeficiency (when immune system damage is caused by an outside source, not a genetic variant). Secondary immunodeficiencies can also be caused by other factors including some medications.

Although some types of PI are detected at birth or in early childhood, PI can affect and be diagnosed in anyone, regardless of age or gender. Some types of PI affect a single part of the immune system, while others may affect multiple components of the system. While the disorders differ, they all share one common feature: each results in atypical functioning of one or more parts of the body's immune system.

What are some types of primary immunodeficiency?

Innate Immune Disorders

The innate immune system is our first line of defense against infection. This system is always "on the lookout for danger" and is activated early in the course of an infection. Innate immunity includes chemical signals that stimulate the production of proteins that coat invading germs (disease-causing bacteria, viruses, fungi, or parasites) and recruit white blood cells to the site of infection. The role of the white blood cells is to engulf and kill those germs.

The innate immune system is also responsible for activating the adaptive immune system, which includes the production of specific antibodies and cellular responses to help clear infections. People with the disorders listed below do not have properly functioning innate immune systems.

- Chronic Granulomatous Disease (CGD)
- Hyper IgE Syndrome
- Complement Deficiencies

Antibody Disorders

Antibodies are proteins that recognize specific germs and are produced by the B cells of the adaptive immune system. Of note, vaccinations induce these B cells to make germ-specific antibodies that protect us from future infection without causing the disease. Antibodies are also known as immunoglobulins (Ig) and different types of Ig have different functions. People with the disorders listed below have issues with one or more types of Ig.

- X-Linked Agammaglobulinemia (XLA) and Autosomal Recessive Agammaglobulinemia
- Common Variable Immune Deficiency (CVID)
- Selective IgA Deficiency
- Specific Antibody Deficiency

Cellular Disorders

B cells and T cells form the adaptive immune system, which responds to specific pathogens. People with the disorders listed below are either missing these cells or have forms of them that are not properly "trained" to respond to pathogens.

- Severe Combined Immune Deficiency (SCID) and Combined Immunodeficiency
- Wiskott-Aldrich Syndrome (WAS)
- Hyper IgM Syndromes
- Ataxia-Telangiectasia (A-T)
- DiGeorge Syndrome

What are the symptoms of primary immunodeficiency?

Nearly everyone has suffered from a cold, the flu, or a sinus or ear infection. Even in the case of severe infections, we expect symptoms to 'run their course,' aided by medications and our body's own immune response. When this expected process does not take place and recovery from an illness is delayed or the illness persists, that is a possible indication of a PI.

People with PI are more susceptible to infections and often endure recurrent serious and debilitating health problems. These health problems may include other conditions associated with PI, such as autoimmune and autoinflammatory diseases. The frequency of these conditions varies with the type of PI. Examples of conditions that may occur in students with PI include inflammatory bowel disease, rheumatoid arthritis, impaired thyroid function, lack of platelets leading to excessive bruising or bleeding, anemia, and allergies.

However, many persons diagnosed with PI look healthy. PI disorders are often described as hidden conditions, similar to other chronic conditions like asthma or diabetes. Schools are accustomed to making accommodations for students with asthma and diabetes, and schools may also need to make accommodations for students with PI.

How is PI treated?

There are a number of specific medical therapies available to individuals with PI. The type of therapy depends on the type and severity of the specific disorder.

Immunoglobulin (Ig) Replacement Therapy

Many individuals with antibody deficiencies receive immunoglobulin (Ig) replacement therapy, either intravenously (IVIG) or subcutaneously (under the skin; SCIG). Immunoglobulin refers to the fraction of blood plasma that contains immunoglobulins or antibodies. The Ig replaces antibodies that the body should be making but does not help the patient's own immune system make antibodies. This is sometimes called "passive immunity" since the Ig only provides temporary protection and repeat doses are required at regular intervals in order to keep antibodies at protective levels.

The immunoglobulin used for replacement therapy is made from human plasma, the liquid, cell-free component of blood, which is donated by healthy volunteers who are screened for viral infections such as HIV and hepatitis. For more on donating plasma, including plasma donation centers near you, visit https://www.plasmahero.org/.

Antibiotic and Antifungal Therapy

While people with types of PI that require immunoglobulin replacement therapy are well protected, some individuals still experience recurrent bouts of infection, especially during the winter months of the year. For this reason, some people with PI take preventative antibiotics or antifungal medications on an ongoing basis (i.e., as prophylaxis). People with other types of PI may also take preventative antibiotics or other antimicrobial medications for specific reasons relevant to their immune deficiency.

Enzyme Replacement Therapy

Enzyme replacement therapy is used by individuals with one particular type of severe combined immunodeficiency (SCID) who do not make the enzyme adenosine deaminase (ADA). Intramuscular injection of replacement enzyme (PEG-ADA) two or three times a week maintains enough ADA activity in the bloodstream of these patients to remove toxins that cause the immune deficiency.

Interferon Gamma

Individuals with Chronic Granulomatous Disease (CGD) often receive interferon gamma three times weekly subcutaneously. Interferon gamma is found naturally in the body and improves killing of bacteria by phagocytes, the white blood cells which engulf and kill disease-causing microorganisms.

Bone Marrow or Hematopoietic Stem Cell Transplantation (HSCT)

Stem cell transplantation is a form of treatment for individuals with T cell, granulocyte, or combined immunodeficiencies. Stem cells from the bone marrow, cord blood, or peripheral blood of a compatible donor are transplanted intravenously into an immune-deficient recipient. It is a highly specialized treatment that can involve lengthy hospital stays.

Granulocyte-Colony Stimulating Factor (G-CSF)

G-CSF is used in patients with PI that have had bone marrow transplants in order to get the new marrow to produce white blood cells faster. G-CSF is also used in patients who do not make enough granulocytes because of defects in their own bone marrow or secondary to autoimmune disease.

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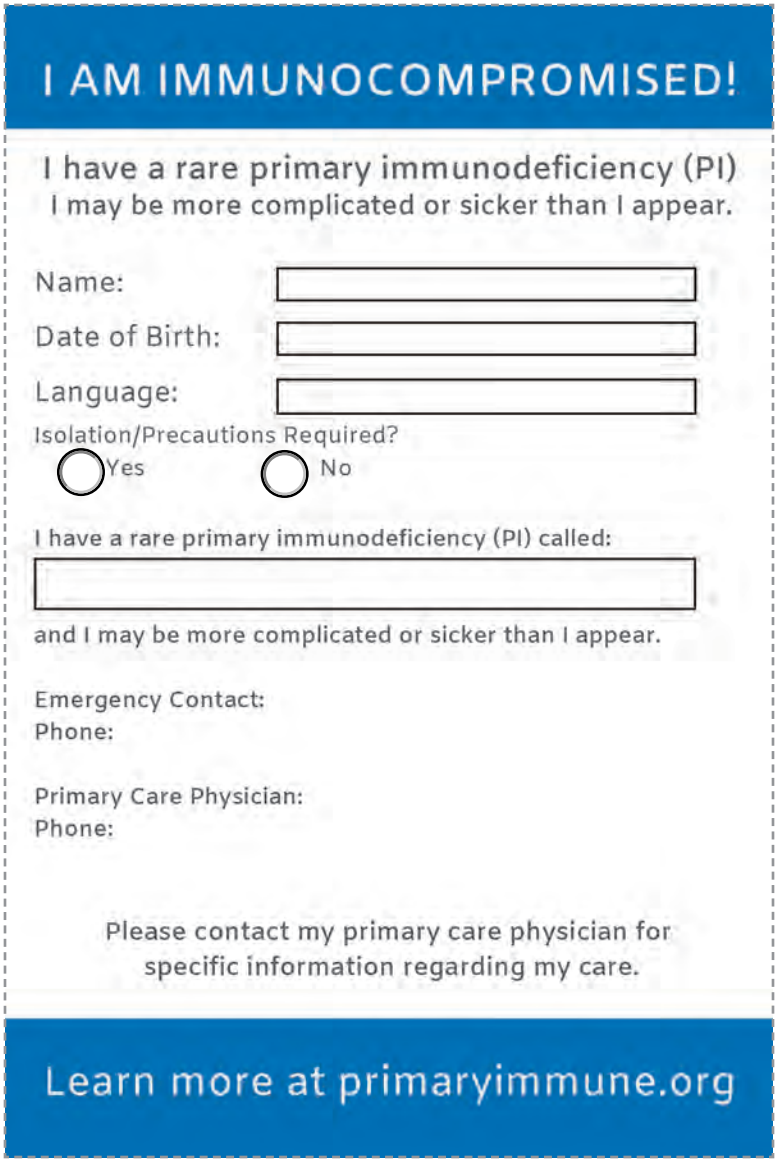

I AM IMMUNOCOMPROMISED!

I have a rare primary immunodeficiency (PI)
I may be more complicated or sicker than I appear.

Name:

Date of Birth:

Language:

Isolation/Precautions Required?

Yes No

I have a rare primary immunodeficiency (PI) called:

and I may be more complicated or sicker than I appear.

Emergency Contact:
Phone:

Primary Care Physician:
Phone:

Please contact my primary care physician for specific information regarding my care.

Learn more at primaryimmune.org

Critical Points:

- All fevers should be taken very seriously and treated empirically.
- Lack of a fever may not be an indication of the severity of my illness.
- I may be neutropenic, lymphopenic, and/or thrombocytopenic.
- NO oral steroids should be prescribed without consultation with my PCP.
- In some patients with PI, antigen/antibody tests for infection detection may not be accurate, and PCR is advised.
- Infections may be caused by atypical organisms.
- I may be more at risk for more severe infections with COVID-19 (SARS-CoV2) and need access to medications or monoclonal antibodies that are known to modify COVID disease.
- Blood products should be irradiated for infants with SCID.

Additional Considerations: allergies, additional medical conditions, other specialist phone numbers, etc.

Immune Deficiency Foundation

Learn more at primaryimmune.org

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Gene Therapy

Gene therapy is being researched as a treatment for some types of PI where the gene variant that causes the disorder has been identified. With this treatment, a functional copy of the gene is inserted into the cells of the patient to correct the inherited gene variant. Gene therapy has shown success in the treatment of ADA-deficient SCID, Artemis-SCID, X-linked SCID, and Wiskott-Aldrich syndrome.

No gene therapies for PI have been approved by the U.S. Food and Drug Administration (FDA) yet, but ongoing research is very promising for people with ADA-SCID, and a curative therapy may be approved in the near future. As with bone marrow transplantation, gene therapy involves a hospital stay.

This information is adapted from the *Immune Deficiency Foundation Patient & Family Handbook for Primary Immunodeficiency Diseases - 6th Edition*©. Find additional information about types of PI and their treatment on the IDF website:

- https://primaryimmune.org/specific-pi-diagnoses
- https://primaryimmune.org/treatments

Chapter 2

Special Considerations for Students with PI

Primary immunodeficiencies (PI) vary in severity and the paths in life for students may be very different depending on the specific disorder. Some students face bone marrow transplantation and need significant support in school, while others with a milder immunodeficiency may do very well with treatment and have a more "normal" school experience. Below is a range of possible situations relevant to students with PI.

Susceptibility to Infection

Even with regular medical treatment, frequent infections are a possibility in students with most types of primary immunodeficiency (PI). These students may be more susceptible to developing an infection and tend to become sicker than their classmates when an infection develops.

One of the most significant things a student with a PI can do to stay healthy is to minimize exposure to germs. Good hygiene, including washing hands with soap for a full 20 seconds before meals, after being outdoors, and after using the restroom, should be routine. When soap and water are not available, alcohol-based hand sanitizers or disposable hand wipes are an effective alternative. For younger students, periodic washing of toys may also be beneficial. Students with PI should distance themselves if a classmate is sick and may need home or virtual schooling during a disease outbreak or pandemic. Finally, students with PI should not use water fountains or share cups, utensils, food, or drinks with other students.

The COVID-19 pandemic introduced masks to classrooms. Well-fitting masks can reduce the transmission of viruses, bacteria, and other germs and may be an added layer of protection that students with PI, or their parents/guardians, choose to wear. Cloth masks offer the least amount of protection (though more than no mask at all), surgical masks offer more protection, and N95, KN95, or KF94 masks offer the best protection, as long as they have been properly fitted. To be effective, masks must fit well so that air passes through the mask material and not around the edges of the mask. Masks must also be worn over the nose and mouth to be effective. See the Centers for Disease Control and Prevention (CDC)'s guidance on masks for more details: https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/types-of-masks.html.

The school community also has a role to play in minimizing a student with PI's exposure to germs. School personnel and classroom teachers should encourage all sick students to stay home while contagious and to use good hand hygiene and tissues or elbows when sneezing or coughing. In cases where a school uses private well water, parents/guardians should be informed of how the water is treated and how often it is tested for disease-causing germs.

Good ventilation in school buildings can also reduce exposure to germs. Improving the air quality and circulation can be as simple as opening a window. However, other techniques, such as changes to the operation of the air handling system or

HEPA filtration, may require consulting a professional. The CDC has released recommendations for ventilation in schools and childcare settings in response to the COVID-19 pandemic: https://www.cdc.gov/coronavirus/2019-ncov/community/schools-childcare/ventilation.html.

When a classroom or school is experiencing an outbreak of an airborne disease, such as COVID-19 or measles, students with PI may need additional protections in order to stay in class. For example, the student may need to eat lunch away from others so that they are not exposed while they are eating, be excused from music classes where there is singing, or be excused from physical education. Any activity where the student cannot wear a mask or where others are expelling more respiratory droplets than normal or breathing heavily is high risk in this situation.

Given a student with PI's increased susceptibility to infection, the following situations must be handled with care:

- **Signs or complaints of illness** expressed by the student or noticed by a teacher or other faculty member should be brought to the school nurse's attention immediately. Parents/guardians need to be contacted as soon as possible to ensure that appropriate care is provided.
- **Outbreaks of infectious diseases** should be reported to the student's parents/guardians as soon as possible, without directly or indirectly identifying the health status of individual students (see the Family Educational Rights and Privacy Act, FERPA, in **Chapter 3**). Primary concerns are contagious illnesses including chickenpox, COVID-19, influenza, hepatitis, measles, meningitis, and methicillin-resistant *Staphylococcus aureus* (MRSA).
- **Cuts or other wounds** should receive immediate first aid treatment by the school nurse. Parents/guardians need to be alerted about these incidents so they can continue proper care at home.

Medical Treatments

Students with PI may undergo medical treatments that affect or disrupt their schooling. Parents/guardians should share information regarding a student's specific medical therapy with the school in the following situations:

- **Side effects:** If the student is experiencing side effects from medical therapy, the school should be notified and a plan developed based on information from the healthcare provider to help the student manage the side effects at school, if possible.
- **Increased absenteeism:** There is no replacement for direct instruction. If a student is absent due to side effects or while receiving medical treatment, a plan to help the student keep up with classmates should be created and put into place.
- **Administration of medication at school:** Notify the school, work with the student's healthcare provider, and complete the school's procedures to ensure that medication is administered appropriately.

Absenteeism

As noted above, students with PI may miss more school than their classmates. These absences are typically a result of illness, side effects from medication, regularly scheduled treatments, school or classroom-level outbreaks, and appointments with healthcare providers. Parents/guardians need to communicate frequently with their child's teacher(s) and school if there are changes to the student's condition, medical appointments, or illness. This communication serves as a reminder of any needed accommodations and the parents'/guardians' willingness to work with the school as an educational partner.

It is the responsibility of the parents/guardians and the student to become familiar with the school's attendance policy and work with the school to develop a plan if increased absenteeism is an issue. Permission for absences without penalty due to illness, doctor's appointments, and/or regularly scheduled treatments can be included as part of the student's special needs in a 504 plan or Individualized Education Program (IEP). Homebound or virtual instruction may also be an option. Additional information about these plans and possible accommodations and modifications are included in **Chapters 4-6** of this guide.

Frequent absences are not just a concern with regard to missed instruction and assignments but can be a source of major distress to students when they miss socializing with their peers. Some students worry that their friends have forgotten about them or do not like them anymore. It is important for parents/guardians and school personnel to recognize that these are serious concerns for students. Creative problem solving is key to ensuring that students' psychosocial needs are met during extended absences and when returning to school.

Vaccinations

Live vaccines, such as the rotavirus, chickenpox, MMR, and intranasal influenza vaccines, can potentially harm some individuals with PI who have severely impaired immune systems. Administering a live vaccine to persons with severe types of PI, including Wiskott-Aldrich syndrome, Combined Immune Deficiency, and complete DiGeorge syndrome, could result in an infection with the organism in the vaccine and a serious form of the illness. For this reason, under no circumstances should a student be administered a vaccination without written parental/guardian permission.

Untreated individuals with severe types of PI (such as an infant with untreated SCID) are also at some theoretical risk of contracting infection from another person who has recently received a live vaccine. With the exception of the oral polio vaccine, which is no longer in use in the U.S. or Canada, there are no reported instances of patients with PI acquiring an infection from a recently immunized contact. Regardless, parents/guardians and students should be notified of any vaccination program within the school system using live vaccines, even if the student with PI will not be involved. If a student has one of the more severe types of PI, parents/guardians and the student should also be notified if any individuals in the school have recently received smallpox vaccine, oral polio vaccine, or developed blisters after chickenpox vaccination (note that under FERPA, the school should not reveal information that can directly or indirectly identify such individuals).

Some students with PI may not be able to receive vaccinations required for school-aged students by state law. In that event, appropriate documentation from the student's healthcare provider must be submitted to the school. For informational purposes, recommendations for the immunization of children and adolescents with PI are included in the following table; however, parents/guardians should discuss all of their child's vaccinations with the student's healthcare provider.

TABLE OF VACCINE RECOMMENDATIONS FOR PEOPLE WITH PRIMARY IMMUNODEFICIENCY (PI)

Example Conditions	Notes	Should Not Receive
ANTIBODY DISORDERS		
• Common Variable Immune Deficiency (CVID) • X-Linked Agammaglobulinemia (XLA) • Other severe antibody deficiencies	• Effectiveness of any vaccine is uncertain • Ig replacement therapy can interfere with vaccine response • Only seasonal inactivated influenza vaccine is routinely given	• Live viral vaccines: oral polio, live attenuated influenza, yellow fever, smallpox • All live bacterial vaccines (BCG for tuberculosis, Ty21a *Salmonella* Typhi, cholera)
• Selective IgA deficiency • IgG subclass deficiencies • Other less severe antibody deficiencies	• All routine vaccines are recommended and probably effective • Ig replacement therapy can interfere with vaccine response • Live viral vaccines other than those contraindicated are safe	• Live viral vaccines: oral polio, yellow fever • Live bacterial vaccines: BCG for tuberculosis
CELLULAR DISORDERS		
• Complete DiGeorge syndrome • Pre-transplant Severe Combined Immune Deficiency (SCID) and pre-transplant Combined Immune Deficiency (CID)	• Effectiveness of any vaccine is uncertain • Ig replacement therapy can interfere with vaccine response • Only seasonal inactivated influenza vaccine is routinely given	• All live bacterial vaccines (BCG for tuberculosis, Ty21a *Salmonella* Typhi, cholera) • All live viral vaccines (MMR, MMRV, chickenpox, oral polio, yellow fever, smallpox, and rotavirus)
• Post-transplant Severe Combined Immune Deficiency (SCID)	• All inactivated routine vaccines are safe, but effectiveness depends on degree of immune suppression and reconstitution	• All live bacterial vaccines (BCG for tuberculosis, Ty21a *Salmonella* Typhi, cholera) • All live viral vaccines (MMR, MMRV, chickenpox, oral polio, yellow fever, smallpox, and rotavirus)
• Partial DiGeorge syndrome • Hyper IgM syndrome • Wiskott-Aldrich syndrome (WAS) • Ataxia-telangiectasia (A-T)	• All inactivated routine vaccines are safe, but effectiveness depends on degree of immune competence	• All live bacterial vaccines (BCG for tuberculosis, Ty21a *Salmonella* Typhi, cholera) • All live viral vaccines (MMR, MMRV, chickenpox, oral polio, yellow fever, smallpox, and rotavirus)
• Interferon deficiencies • Interleukin 12 axis deficiencies • STAT1 deficiencies	• All inactivated routine vaccines are recommended and probably effective	• All live bacterial vaccines (BCG for tuberculosis, Ty21a *Salmonella* Typhi, cholera) • Live viral vaccines: yellow fever; others if very low white blood cell count
INNATE IMMUNE DISORDERS		
• C3, C4, C2 Deficiencies • Factor B Deficiency	• All routine vaccines are recommended and effective	• None
• Chronic Granulomatous Disease (CGD)	• All inactivated routine vaccines are recommended and probably effective • All routine live viral vaccines are probably safe and effective	• All live bacterial vaccines (BCG for tuberculosis, Ty21a *Salmonella* Typhi, cholera)
• Leukocyte Adhesion Defects • Myeloperoxidase Deficiency	• All inactivated routine vaccines are recommended and probably effective	• All live bacterial vaccines (BCG for tuberculosis, Ty21a *Salmonella* Typhi, cholera) • All live viral vaccines (MMR, MMRV, chickenpox, oral polio, yellow fever, smallpox, and rotavirus)

Adapted from 2021. "Immunization and Other Considerations in Immunocompromised Children", Red Book: 2021–2024 Report of the Committee on Infectious Diseases, Committee on Infectious Diseases, American Academy of Pediatrics, David W. Kimberlin, MD, FAAP, Elizabeth D. Barnett, MD, FAAP, Ruth Lynfield, MD, FAAP, Mark H. Sawyer, MD, FAAP; https://publications.aap.org/redbook/book/347/chapter-abstract/5749334/Immunization-and-Other-Considerations-in. For informational purposes only, please see original document for full recommendations and discuss all vaccinations with the student's healthcare provider.

Students receiving regular immunoglobulin (Ig) replacement therapy for their PI, either intravenously (IVIG) or subcutaneously (SCIG), are generally protected from infection by the antibodies contained in the Ig. The one exception is seasonal influenza because Ig products may not contain antibodies to the current year's viral strain(s). In families with someone who has PI, it is generally recommended that all members of the family group (including the person with PI in some cases) be immunized each year with the inactivated influenza vaccine.

Note that mRNA vaccines, such as COVID-19 vaccines, have proved safe for those with PI, although those with certain types of PI (namely severe antibody deficiencies like CVID and XLA) may not mount a protective antibody response to the vaccine.

For more on PI and vaccines, visit https://primaryimmune.org/immunizations.

Emotional and Social Issues

Students with PI have the same developmental and psychosocial needs as their peers. In general, they do not want to be defined by their illness and would like to be treated like their peers. It is vital to allow the student to decide who they want to tell about their condition and when they want to share this information.

If necessary, the school nurse, social worker, counselor, case manager, and teacher can meet with other school personnel, a class, or a group of peers to provide information about PI and the student's needs. It is imperative that permission is given by the parents/guardians and student before discussing a medical condition with others.

School personnel should be sensitive about bringing unwanted attention to a student who has a special need or has returned after a long absence. If unwanted attention or treatment occurs, the parents/guardians or student should mention it to school personnel immediately.

As students get older, they should play a key role on the educational team. Becoming part of the team provides students with self-confidence and the realization that they have support in the school setting. Encourage students to become involved in the following ways:

- Before the school year begins, older students might want to write a letter to their teachers that includes information about the student's PI and how it affects their school day. A sample student letter is included in **Chapter 10**.
- Parents/guardians should discuss their child's 504 Plan or Individualized Education Program (IEP) with the student at home. Additional information about these plans is included in **Chapters 5-6**.
- Parents/guardians should ask their child for input regarding accommodations or modifications included in the student's plan.
- Parents/guardians should invite their child to attend a planning meeting. If the student is not interested in attending, still encourage input.

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. Depression is more commonly seen in individuals affected by chronic illnesses, and it is important for all school staff to pay attention to signs of serious psychological concerns. This recognition and awareness can help the student and family seek appropriate interventions in a timely manner.

Alternatives to Traditional Schooling

In some instances, students with PI may be best served outside of a traditional school environment. Since the COVID-19 pandemic, hybrid or virtual learning are accessible to more students than ever. In addition, homeschooling is also an option.

Virtual or Hybrid Learning

Accredited, tuition-free online education is available through several different models, including virtual charter schools and state- or district-run virtual public schools. Although a few school districts offered online school options prior to 2020, many more began doing so during the COVID-19 pandemic. Some districts also offer individual online courses for older students that can be incorporated into a hybrid virtual and in-person learning model.

Students with PI can benefit from access to quality online learning that meets the needs of their specific immunity challenges. Learning from home can enable better infection control measures, such as well-maintained ventilation and less interaction with potentially ill individuals. If the virtual schooling option includes asynchronous learning (i.e., periods of time where learning is not conducted via live lessons), another benefit is schedule flexibility. This flexibility can better accommodate frequent medical appointments, as well as periods of rest for a student experiencing fatigue or other PI symptoms.

However, as many parents/guardians learned during the pandemic, there are also challenges with virtual learning. Younger students need significant supervision, which can be a burden for working parents/guardians. Students in virtual schools can also feel isolated without in-person social interactions with their peers. It is always about balancing healthcare, education, and psychosocial needs.

Occupational and other therapies for some students can be done successfully virtually in certain situations. However, in situations where virtual delivery is not possible or successful, alternatives need to be specifically identified within the student's IEP. The instructor can do home visits instead of the student going to a center or school, which will reduce exposure to germs. In cases where instructors visit the home, ventilation and mask guidelines are important to help reduce exposure in the home. The PACER Center, Minnesota's Parent Training and Information Center, has several resources about distance learning for students with IEPs: https://www.pacer.org/parent/, search "distance learning."

Homeschooling

Homeschooling offers many of the same benefits and challenges as full-time virtual school. By definition, homeschooling is not supported by curricula or programs offered by school districts, so parents/guardians assume much more responsibility for their child's learning and progress. However, homeschooling is also the most flexible option for students who are not thriving in traditional schooling environments or for families that need to accommodate complex medical situations.

The requirements for homeschooling vary by state, so be sure to understand the state's specific requirements. If the student has an IEP, it is important to understand how homeschooling will affect their access to services. Some states provide special education services to homeschooled students through their local school districts, while others do not.

The Home School Legal Defense Association is a member-based advocacy organization that offers resources and support for families who choose to homeschool their children: https://hslda.org/.

Chapter 3

Educational Rights Under Federal Law

Federal laws include requirements and guidelines for how schools should respond if a student's learning is affected by a health condition, such as primary immunodeficiency (PI). Parents/guardians, students, and school personnel should be aware of the laws that ensure equal opportunities for individuals with disabilities for the following reasons:

- The laws help parents/guardians, students, and school personnel work together to assure academic success.
- The laws enable parents/guardians and students to effectively advocate for their educational rights and participate as members of the educational team.
- The laws assist school personnel in understanding all the services available to students, ensuring the protection of civil rights, and creating a partnership with families and other agencies.

This section provides an overview of some of the federal laws that protect students with disabilities in the educational setting. Most parents/guardians of students with PI do not view their child as having a disability. However, in order for a school to provide accommodations or modifications, the student must be "identified" as disabled. It is important to remember that each individual is different, and a diagnosis of PI does not necessarily mean a student will be identified as an individual with a disability, or meet the criteria for special education.

Please note—the student does not need to apply or qualify for disability benefits provided by the Social Security Administration. The Americans with Disabilities Act (ADA) and the Social Security Administration define disability differently.

FEDERAL LAW BY YEAR OF FIRST PASSAGE	ADMINISTERING OFFICE OF THE DEPT. OF EDUCATION	JURISDICTION	ELIGIBLE INDIVIDUALS
Section 504 of the Rehabilitation Act	Office of Civil Rights	All public and private schools that receive federal funds.	Students with disabilities.
	PURPOSE • Defines disability. • Prohibits discrimination on the basis of having a disability. • Specifies that school districts, K-12, must proactively identify students with disabilities. • Specifies that school districts must provide students with disabilities a free, appropriate public education (FAPE) and equal opportunity to participate in academic, non-academic, and extracurricular activities.		
Individuals with Disabilities Education Act, Part B (IDEA)	Office of Special Education and Rehabilitative Services	Public schools; private schools are not covered by IDEA, but if a public school system places a student in a private program as part of an Individualized Education Program (IEP), the public school is responsible for ensuring the private school implements the IEP.	Students, aged 3-21, with disabilities that affect their educational performance.
	PURPOSE • Provides special education funding to states. • Defines who qualifies for special education. • Sets out the process for developing an Individualized Education Program (IEP) for students who qualify for special education.		
Family Educational Rights and Privacy Act (FERPA)	Student Privacy Policy Office	All public and private schools that receive federal funds.	All students.
	PURPOSE • Says that schools cannot disclose student educational records without parental/guardian consent, except in specific situations. • Specifies that parents/guardians have a right to review educational records.		
Americans with Disabilities Act (ADA) & Americans with Disabilities Act Amendments Act (ADAAA)	Office of Civil Rights	All public and private schools, except private schools affiliated with religious organizations that do not receive federal funds.	Students with disabilities.
	PURPOSE • Defines disability in further detail. • Prohibits discrimination on the basis of having a disability.		

Section 504 of the Rehabilitation Act of 1973 (Section 504)

Section 504 is a civil rights law designed to protect the rights of individuals with disabilities in programs and activities that receive financial assistance from any federal department or agency. Because public schools receive funds from the U.S. Department of Education, Section 504 applies to public education. Private schools also must adhere to Section 504 if they receive federal funds from any source. The Office of Civil Rights within the U.S. Department of Education administers this law.

Like ADA and ADAAA (later section), Section 504 defines individuals with disabilities as persons with a physical or mental impairment that substantially limits one or more major life activities; with a record of such an impairment; or who are regarded as having such an impairment.

- Major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.

- A major life activity also includes the operation of a major bodily function, including but not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.

In addition, this law requires school districts, kindergarten through grade 12, to proactively identify students with disabilities. Section 504 describes a process for determining whether a student has a disability and helps teams decide upon the services needed by the student. The determination of whether a student has a disability must be made based on an individual inquiry since each student's needs are unique.

In the educational setting, Section 504 entitles students with disabilities to equal opportunity to participate in academic, nonacademic, and extracurricular activities through the furnishing of a free, appropriate public education (FAPE). To meet the FAPE requirement, educational programs for students with disabilities must be designed to meet each student's individual needs to the same extent that the needs of nondisabled students are met. FAPE may include regular or special education and/or related aids and services in order to accommodate the unique needs of the student.

Importantly, a student does not need to qualify for special education services under the Individuals with Disabilities Education Act (IDEA; see next section) to receive accommodations or other educational services under Section 504. If a student does not qualify for special education, accommodations and modifications necessary for the student to receive FAPE are spelled out in a 504 plan instead. A 504 plan is a written document developed by the educational team (including parents/guardians and the student, if appropriate) to help a student with a disability succeed in school. Additional information and a template for a 504 plan are included in **Chapter 5** of this publication.

Additional information about Section 504 of the Rehabilitation Act of 1973 is available on the U.S. Department of Education, Office of Civil Rights website: https://www2.ed.gov/about/offices/list/ocr/504faq.html.

Individuals with Disabilities Education Act (IDEA)

IDEA is our nation's special education law. Congress originally enacted it in 1975 and it has been revised many times over the years. Congress passed the most recent amendments in December 2004, with final regulations published in August 2006.

IDEA is divided into the following four parts. This guide includes an overview of Part B.

- Part A – General Provisions
- Part B – Assistance for Education of All Children with Disabilities
- Part C – Infants and Toddlers with Disabilities
- Part D – National Activities to Improve Education of Children with Disabilities

Eligibility for Special Education and Related Services under IDEA

When does a student qualify for special education services? A diagnosis from a doctor or mental health professional alone is not enough. Eligibility for special education and related services under IDEA is a three-pronged process. A team of qualified professionals and parents/guardians must determine that the student meets these criteria:

- **Prong One: Does the student have a disability in one (or more) of the 13 disability areas listed in IDEA?**
  (see https://www.parentcenterhub.org/wp-content/uploads/repo_items/gr3.pdf for a complete description of these areas)
  After conducting a comprehensive evaluation, the eligibility team looks at the test results and determines under which of the disability categories the student qualifies. Most students with PI will be categorized under "other health impairment."

- **Prong Two: Does the disability impact the student's educational performance?**
  The eligibility team determines how skill areas are affected by the disability, which in turn impacts the student's educational performance. Functional assessment data is a source of information the team could use to assist in making this determination. A comparison between the student's current skill levels and the skill levels appropriate for their current age/grade level could be one indication of educational impact. State/district-wide assessment data and baseline data are also sources for determining educational impact.

- **Prong Three: Does the student require specially designed instruction to receive a free, appropriate public education (FAPE)?**
  Even if a student has a diagnosed disability and the skill areas affected by the disability adversely affect their educational performance, the student must also meet this final prong. The student must require specially designed instruction to benefit from education. For example, a student may meet the disability criteria for "other health impairment" based on having a PI. Data may indicate that the impairment impacts the student's educational performance. However, with the provision of class notes and extended time to complete assignments when absent, the student is able to successfully function in a general

curriculum with their peers; therefore, they are not eligible for special education since they do not require specially designed instruction.

Part B of IDEA: Services for School-Aged Children

Part B of IDEA requires school districts to identify all students (ages 3-21) with disabilities and to provide them with a free, appropriate public education (FAPE) that emphasizes special education and related services designed to meet their unique needs and prepares them for further education, employment, and independent living. The Office of Special Education and Rehabilitative Services (OSERS) in the U.S. Department of Education oversees IDEA.

Under IDEA, FAPE means the student is eligible to receive special education and related services that meet state standards and are provided in compliance with the student's Individualized Education Program (IEP). An IEP is a written document developed for a student who meets the educational qualifications of special education. The IEP is created to meet the educational needs of the individual student, provides an opportunity for teachers, parents/guardians, school personnel, and students (when appropriate) to work together to improve educational results for the student, and is reviewed at least once per year.

The IDEA regulations specify how school personnel and parents/guardians work together to develop and implement an IEP. Additional information about IEPs is included in **Chapter 6** of this guide.

Family Educational Rights and Privacy Act (FERPA)

The Family Educational Rights and Privacy Act (FERPA) is a federal law that protects the privacy of student education records. The law applies to all schools that receive funds under any program administered by the U.S. Secretary of Education. FERPA gives parents/guardians certain rights with respect to their child's education records. These rights transfer to the student when he or she reaches the age of 18 or attends a school beyond the high school level.

FERPA requires parental consent to disclose student educational records except in specific cases, such as when a student transfers to a different school or school officials have a legitimate educational interest in the student. FERPA also allows parents/guardians of students, or students 18 and older, to inspect and review the student's educational records. Under FERPA, schools may disclose 'directory' information, such as student name, telephone number, and address without specific consent, but must notify parents/guardians yearly to allow them to opt out.

Additional information about FERPA is available at the U.S. Department of Education website: https://studentprivacy.ed.gov/.

Americans with Disabilities Act (ADA) of 1990 & Americans with Disabilities Act Amendments Act of 2008 (ADAAA)

The Americans with Disabilities Act (ADA) is a civil rights law protecting individuals with disabilities. It applies to all public and most private schools, although private schools affiliated with religious organizations that do not receive federal funds are exempt. However, laws have been created in some states to address students with disabilities in religious schools. There is also an expectation that the public school district where a student resides and the student's private school collaborate in regard to the service needs of the student.

According to the legal definition from the ADA, including changes made by the ADA Amendments Act of 2008 (ADAAA), P.L. 110-325, a disability is:

- A physical or mental impairment that substantially limits one or more major life activity of an individual:
  - » **Major life activities include, but are not limited to**, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, **learning**, reading, concentrating, thinking, communicating, and working.
  - » **A major life activity also includes the operation of a major bodily function, including but not limited to, functions of the immune system**, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.
- A record of such an impairment.
- Being regarded as having such an impairment.

Additional information about the ADA and ADAAA is available on the U.S. Department of Education, Office of Civil Rights website: https://www2.ed.gov/about/offices/list/ocr/frontpage/pro-students/disability-pr.html.

Chapter 4

Selecting and Developing a Plan

Some students diagnosed with primary immunodeficiency (PI) may need a written education or healthcare plan to succeed in school. It is important to note that there is not a "one size fits all" plan for students with PI. The best plan will be based on the individual student's needs in the educational setting. The following types of plans may be appropriate:

- **504 Plan:** provides accommodations and/or modifications that allow a student with a disability to receive the same access to instruction, school activities, and facilities as students without disabilities; see **Chapter 5** for more details.
- **Individualized Education Program (IEP):** a written document developed for a student with a disability who meets the educational qualifications for special education under the Individuals with Disabilities Education Act (IDEA); see **Chapter 6** for more details.
- **Individualized Healthcare Plan (IHP):** a written healthcare plan that outlines the management of school healthcare services for students with significant or chronic health conditions; can stand alone or be part of a 504 Plan or an IEP; see **Chapter 7** for more details.
- **Emergency Care Plan (ECP):** a plan of action if an emergency related to a student's medical condition occurs in the school setting; see **Chapter 7** for more details.

What is the difference between a 504 plan and an IEP?

Both 504 plans and IEPs require a student to be identified as having a disability (as legally defined by the ADA/ADAAA, see **Chapter 3**) in order to be eligible. Most parents/guardians of children with PI do not view their child as having a disability. However, in order for a school to provide accommodations or modifications, the student must be "identified" as disabled. Both types of plans are legal documents between parents/guardians and the school.

Please note—the student does not need to apply or qualify for disability benefits provided by the Social Security Administration. The Americans with Disabilities Act (ADA) and the Social Security Administration define disability differently.

A student with a 504 plan is able to make effective progress in school without specialized instruction/related services. However, this student requires accommodations and/or modifications in order to gain the same access to instruction, school activities, and facilities as students without disabilities.

A student determined to be eligible for an IEP must be diagnosed with a disability that impairs their ability to make effective progress in school without specialized instruction. If a student only needs related services and not special education services, the student is not eligible for services under IDEA through an IEP. However, it is important to note that this student might still be eligible for services under Section 504 through a 504 plan. Also, note that an IEP has a due process clause should misunderstandings arise (see **Chapter 6**), whereas a 504 plan does not.

Accommodations and Modifications

For schools to provide an appropriate education for students with primary immunodeficiency (PI), accommodations and/or modifications may be necessary and can be included in a 504 plan or an IEP.

An **accommodation** is any technique that alters the academic setting or environment. A **modification** is any technique that in some way alters the work required to make it different from the work required of other students in the same class.

Accommodations are methods that help a student produce work equal to classmates, while modifications are used to change the rigor of the required assignments. Examples of both are listed below. These lists are not exhaustive and are dependent on each student's specific diagnosis and recommendations from the student's healthcare provider.

Example Accommodations

- A hall pass that the student keeps at all times.
- A space to rest or take medication near the nurse's office that is not used for ill students.
- Special restroom privileges due to gastrointestinal complications associated with some types of PI.
- A class schedule that includes a study period at the beginning or end of the day. When fatigue or other symptoms are an issue, attendance in the study period would be waived pending parental permission.
- Permission to stay in the nurse's office and return to class when possible or call parents/guardians if unable to remain at school due to fatigue or other symptoms.
- Permission to keep hand sanitizer accessible and use it as needed.
- A private room at boarding school.
- The opportunity to discreetly move to another seat if a nearby classmate is ill.
- Permission to eat outside of lunchtime to accommodate specialized nutrition.
- The provision of two sets of textbooks, one for home and one for school.
- When a class is missed, the student receives a copy of the notes, photocopies of any materials, and/or a recording of the lecture or discussion.
- A defined procedure for the student to receive missed assignments in a timely manner. Parents/guardians call or send an email to the case manager and each classroom teacher early enough in the day to allow assignments to be collected and picked up at school or sent to the parents/guardians or student via email.
- The opportunity to make up missed lab assignments and view videos presented during an absence. The teacher and student should mutually agree upon a time and the student should not miss opportunities to participate in recess or social activities.
- Virtual or homebound instruction (based on state law) if absences become problematic.

Example Modifications

- Exemption from completing certain parts of a physical education program due to fatigue or chronic infections.
- Shorter assignments focus on mastery of important material.
- Extended assignment deadlines or postponed test dates to account for absences.
- Waived participation points when the student is absent. The teacher has the option of assigning an additional, meaningful assignment based on the material missed or automatically awarding the points.
- Technology-based learning opportunities that replace or supplement classroom experiences when student health limits attendance. These opportunities may include online video conferencing between the classroom and a student's home, recorded lessons to be watched or listened to by the student, online courses for credit, online tutoring programs in specific subjects, and virtual schooling where available.

Chapter 5
Section 504 Plans

A Section 504 plan (504 plan) is a written document developed by the educational team, including the parents/guardians, student (if appropriate), and relevant school personnel, to provide accommodations and/or modifications that help a student with a disability succeed in school. The plan keeps everyone informed of the student's needs and includes accommodations and/or modifications not readily available to students without disabilities.

A student does not need to receive special education services to be eligible for services under Section 504 (see **Chapter 3**). However, it will be necessary to prove that the student has a disability and that accommodations and/or modifications are required in order for the student to receive an education equal to their classmates.

Please note—the student does not need to apply or qualify for disability benefits provided by the Social Security Administration. The Americans with Disabilities Act (ADA) and the Social Security Administration define disability differently.

Under Section 504, parents/guardians have the right to receive notice regarding the identification, evaluation, and/or placement of their child. They also have the right under FERPA to examine relevant educational records pertaining to their child.

Steps to Obtaining a 504 Plan

Parents/guardians interested in obtaining a 504 plan for their child should follow these steps.

1. **Contact the school**, in writing, to request a meeting with the appropriate school personnel. Typically, the written request should be sent to the 504 Coordinator. If the school does not have a 504 Coordinator, ask who should receive the request. In some situations, the responsible person may be a school counselor. A sample letter is included in **Chapter 10**.
    - School personnel at the meeting may include the 504 Coordinator (if applicable), a school counselor, a social worker, the principal, the student's classroom teacher(s), the school nurse, and/or a special education teacher.
2. **Prepare for the meeting** by gathering the following information:
    - A copy of the written request for a 504 plan.

- A completed copy of the Meeting/Conference Planner in **Chapter 10** of this guide.
- A letter from the student's healthcare provider that lists their medical condition, treatment/medication, and recommendations for accommodations and/or modifications. A sample letter is included in **Chapter 10**.
- Copies of the following IDF publications:

» This publication (*Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency*©).

» The chapter from the *Immune Deficiency Foundation Patient & Family Handbook for Primary Immunodeficiency Diseases - 6th Edition*© that describes your child's specific type of PI.

» *Our Immune System*©, a children's storybook that provides an easy-to-understand explanation of immune system function.

» *Is It Just an Infection?*© poster to be displayed in the school nurse's office to promote awareness of PI.

3. **Request a copy of the 504 plan** if one is developed. If a copy of the plan is not received by the expected date, contact the responsible person in writing.
4. **Review and sign the plan.** Parents/guardians will need to sign the plan if they agree with the accommodations and/or modifications before it can be implemented. Note that parents/guardians do not have to sign the plan immediately and can take time to review it in detail at home. In addition to returning a signed copy, parents/guardians should keep a copy of the plan for themselves.

   A 504 plan should:

   - List the necessary accommodations and/or modifications that will be provided.
   - Identify the staff member designated as the 504 Coordinator or as the "case manager." This staff member is responsible for checking in with the student and teachers on a regular basis to monitor progress, and is the main point of contact between home and school.
   - Identify the school personnel responsible for ensuring that the accommodations and/or modifications are provided.
   - Be distributed to relevant school personnel by the 504 Coordinator or case manager. A copy should also be readily available for substitute teachers.
   - Be filed in the student's school record.
   - Be updated as the student's needs change throughout the school year, if the student transfers to a different school, and before the beginning of a new school year.
5. **Develop a communication plan** with the 504 Coordinator and teachers. Communication should be ongoing to report progress or issues. It can take place via email, phone, letters/notes, or in-person meetings based on the preference of members of the 504 team. When the student is absent, the 504 Coordinator or case manager is responsible for notifying classroom teachers and collecting assignments to be completed by the student.

Managing Concerns Regarding a 504 Plan

Sometimes, the 504 team agrees to a particular plan, but accommodations and/or modifications are not implemented or are stopped for some reason. Parents/guardians can be their child's advocate by bringing the issue to school personnel's attention using the following escalation process.

1. **Contact the teacher.** The teacher is probably the person responsible for delivering the accommodations and/or modifications. There might be a misunderstanding or other reason why the 504 plan is not being followed. Document the

outcome of your communication with the teacher in your records. Also, send an email or letter to the teacher outlining your discussion. If the issue cannot be resolved, proceed to the next step.

2. **Contact the 504 Coordinator or case manager.** The 504 Coordinator or case manager, whichever one manages the student's 504 plan, should be aware of the student's needs. If parts of the plan cannot be implemented, it may need to be rewritten; and if it is workable, then pressure may be required to enforce it. Again, agree on a time period for the changes/implementation to take place, and follow up with a letter outlining the agreement. If progress is not made, contact the principal.

3. **Contact the principal.** Parents/guardians should explain that they have met with the teacher and 504 Coordinator (or case manager) to discuss the 504 plan and it is still not being followed. Submit a request, in writing, for what needs to be done based on previous conversations with the teacher and 504 Coordinator or case manager. Agree upon a time period to follow up regarding the accommodations and/or modifications. Follow up with the principal in writing outlining your conversation.

4. **Talk to a Parent Training & Information Center (PTI).** Although the 504 plan falls under federal and not state law, advocates may be familiar with how area schools have succeeded with 504 plans in the past. Call the nearest Parent Training & Information Center and discuss the problem with an advocate or staff member who has experience working with area school districts. Find a Parent Training & Information Center at www.parentcenterhub.org/find-your-center/.

5. **Contact the school district 504 Coordinator.** It is a parent/guardian's right to also file a complaint with the school district 504 Coordinator, and the district coordinator must investigate the allegations regarding Section 504.

6. **Contact the U.S. Department of Education, Office of Civil Rights.** The last resort for parents/guardians with 504 plan concerns is contacting the U.S. Department of Education, Office of Civil Rights to file a complaint at https://www2.ed.gov/about/offices/list/ocr/complaintintro.html.

Additional information about 504 plans is available at http://www2.ed.gov/about/offices/list/ocr/504faq.html.

Sample 504 Plan

504 Plan – Page 1 of 4

Student First Name	Student Last Name	Date of Birth	Age
Gender	School		Grade
Case Manager		Date of Meeting	

Describe the nature of the concern.

Describe the basis of determination of disability (observations, health screenings, test scores, medical reports, grade reports).

Describe how the disability affects one or more major life activity (see list in Chapter 3).

Based upon the above information, the student does/does not meet the guidelines for classification as an individual with a disability under Section 504 of the Rehabilitation Act.

Describe the accommodations and/or modifications that are necessary and will provide equal opportunity.

Instructional Accommodations/Modifications

Physical Accommodations/Modifications (schedule, desk, length of day, transportation—include an emergency evacuation plan)

Behavioral/Social Accommodations/Modifications

Accommodations/Modifications to Maintain Classroom Behavior

Accommodations/Modifications to Participate in Desired Extracurricular Activities

Accommodations/Modifications to Participate in State/District-Wide Testing

Medications

1.

Medication Name _____ Dosage & Frequency _____ Side Effect(s) _____

Start Date _____ Stop Date _____

2.

Medication Name _____ Dosage & Frequency _____ Side Effect(s) _____

Start Date _____ Stop Date _____

3.

Medication Name _____ Dosage & Frequency _____ Side Effect(s) _____

Start Date _____ Stop Date _____

4.

Medication Name _____ Dosage & Frequency _____ Side Effect(s) _____

Start Date _____ Stop Date _____

5.

Medication Name _____ Dosage & Frequency _____ Side Effect(s) _____

Start Date _____ Stop Date _____

6.

Medication Name _____ Dosage & Frequency _____ Side Effect(s) _____

Start Date _____ Stop Date _____

❑ Check if additional information is attached.

Physician Name _____ Phone Number _____

Emergency Information _____

Special Recommendations

Next 504 Plan Review Date

Team Members

Parent/Guardian Printed Name	Signature	
Parent/Guardian Printed Name	Signature	
Administrator or Designee Printed Name	Signature	Title
Case Manager Printed Name	Signature	Title
School Nurse Printed Name	Signature	Title
Teacher Printed Name	Signature	Title
Teacher Printed Name	Signature	Title

❑ Check if additional information is attached.

Chapter 6
Individualized Education Programs (IEP)

An Individualized Education Program (IEP) is a written document developed for a student, ages 3-21, who meets the educational qualifications for special education under the Individuals with Disabilities Education Act (IDEA, see **Chapter 3**). An IEP is created to meet the educational needs of an individual student, provides an opportunity for teachers, parents/guardians, school personnel, and students (when appropriate) to work together to improve educational results for the student, and is reviewed at least once per year.

Before an IEP is developed, a multidisciplinary IEP team must determine that the student is eligible for special education. By federal law, a multidisciplinary team must determine that:

1. The student has a disability.
2. The student's disability is negatively impacting their educational performance.
3. The student requires special education to receive a free, appropriate public education (FAPE).

Although requirements vary by state, in general, IEP teams must include the following members:

- Parents/guardians
- Student (if appropriate)
- General education teacher(s)
- Special education teacher(s)
- School system or local education agency (LEA) representative (often the school principal or an assistant principal, but can also be a case manager, child study team member, or district administrator)
- Individual who can interpret the evaluation results (for example, a school psychologist, speech, occupational, and/or physical therapist, board-certified behavior analyst, school nurse, or medical doctor)
- Others with knowledge about the student
- Anyone the parents/guardians would like to invite to the meeting, which may include legal representation in some cases

When constructing an appropriate educational program for a student with a disability, the IEP team considers the student's involvement and participation in three main areas of school life:

- General education curriculum
- Extracurricular activities
- Non-academic activities

Extracurricular and non-academic activities refer to school activities that fall outside the realm of the general curriculum.

Steps to Obtaining an IEP

IDEA mandates the following ten specific steps that must be followed to create an IEP. Parents/guardians have the right to request a due process legal hearing if they cannot come to an agreement with the school at any one of the steps below.

1. **Need is identified.** A parent/guardian or school can request an evaluation for a student believed to have a disability. (If the school initiates this step, they must have parental permission before an evaluation begins.) Parents/guardians should send a written request to the teacher or other school personnel requesting an evaluation to determine whether the student qualifies for special education services. A sample letter requesting an evaluation for special education is included in **Chapter 10**.

   After the school receives the request for an evaluation, they will contact the parents/guardians to schedule a meeting and discuss the next steps within 10 days. Prepare for the meeting by compiling the following information:

   - A copy of the written request for an evaluation.
   - A completed copy of the Meeting/Conference Planner in **Chapter 10** of this guide.
   - A letter from the student's healthcare provider that lists their medical condition, treatment/medication, and recommendations for accommodations and/or modifications. A sample letter is included in **Chapter 10**.
   - For older students, a letter from the student explaining how their PI affects their school day. A sample letter is included in **Chapter 10**.
   - Copies of the following IDF publications:
     - » This publication (*Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency*©).
     - » The chapter from the *Immune Deficiency Foundation Patient & Family Handbook for Primary Immunodeficiency Diseases - 6th Edition*© that describes your child's specific type of PI.
     - » *Our Immune System*©, a children's storybook that provides an easy-to-understand explanation of immune system function.
     - » *Is It Just an Infection?*© poster to be displayed in the school nurse's office to promote awareness of PI.

2. **Evaluation occurs.** If it is determined that an evaluation should be completed, the evaluation results will include the following information:
   - A determination regarding whether the student has a disability that requires special education and related services.
   - Information about the student's specific educational needs.
   - Specific special education and related services to be implemented that are appropriate for addressing the student's needs.

If parents/guardians disagree with evaluation results, they have the right to take the student for an independent educational evaluation (IEE) and request that the school pay for it. However, by law, the school does not have to accept the results of an independent evaluation.

3. **Eligibility is determined.** After the evaluation, a group of qualified professionals determines if the student is eligible for special education services as defined by IDEA (see **Chapter 3**).

4. **Student is eligible for services.** If the student is determined to be eligible for special education services, a team meeting (which includes the parents/guardians, general education teacher(s), special education teacher(s), and a school district or charter school representative), must be scheduled within 30 days to write the IEP. However, parents/guardians can waive this 30-day timeline and go directly to an IEP meeting after eligibility for special education services is determined.

5. **IEP meeting is scheduled by the school.** The school must:

    - Contact the participants, including the parents/guardians.
    - Notify parents/guardians in a timely manner regarding the purpose, time, and location of the meeting to make sure they have an opportunity to attend.
    - Schedule the meeting at a time and place agreeable to parents/guardians and the school.
    - Tell the parents/guardians who will be attending the meeting.
    - Tell the parents/guardians that they may invite people to the meeting who have knowledge or special expertise about the student.

6. **IEP meeting occurs and IEP is written.** The IEP team, which includes the parents/guardians and student (the student must be invited if they are age 14 or above, but any student may be invited to attend if appropriate), meets to develop an educational program that will help the student progress in the general curriculum. The IEP must include the supplementary aids and services (accommodations) that will be provided for the student and a statement, if necessary, of the program modifications (which change the rigor of the curriculum) needed to facilitate the student's progress and capability to be involved in the general curriculum.

By law, an IEP must include the following information:

- Present levels of educational performance.
- Goals for the year, broken down into short-term objectives or benchmarks.
- Special education and related services offered to the student.
- Amount of each school day spent outside of a general education classroom.
- Modifications necessary when state or district-wide tests are given, or if the team decides that state- or district-wide testing is not appropriate, the IEP must map out an alternate plan to test the student.
- When and where the school will start providing services to the student, how often the services will be provided, and how long the services are expected to last.
- How the school will measure the student's progress toward the IEP goals and how progress will be reported to parents/guardians.
- Transition services the student will need to prepare for life after finishing high school are mandated at age 14; however, the IEP team may start to address these skills as early as deemed appropriate for the student.

IDEA requires certain information to be included in the IEP but does not specify how the IEP should look. Because states and local school systems may include additional information, forms differ from state to state and may vary between school systems within a state.

The parents/guardians have the right not to agree with the IEP. In this case, they may discuss their concerns with other members of the team and try to work out an agreement. If parents/guardians still disagree, they can request mediation. Mediation may also be offered by the school.

Parents/guardians may also file a complaint with the state education agency or a due process complaint. A due process complaint is a letter filed by an individual or organization on matters of conflict related to the identification, evaluation, or educational placement of a student, or the provision of a free appropriate public education (FAPE) to a student. This is the first step in requesting a due process hearing where mediation must be available. See the "Contesting an Evaluation or IEP" section of this chapter for more information.

7. **Special education services are provided.** Parents/guardians receive a copy of the IEP. The school implements the student's IEP as it was written. All of the student's teachers and service providers have access to the IEP and understand their responsibilities for carrying out the IEP including the accommodations, modifications, and supports that must be provided to the student.
8. **Progress reports** are shared with the parents/guardians at least as often as they are shared with parents/guardians of children not receiving special education services.
9. **Review of IEP.** The IEP team, which includes the parents/guardians and student (if appropriate or age 14 or older), reviews the IEP at least once a year and whenever necessary throughout the year as requested by the parents/guardians or IEP team.
10. **Reevaluation of the student** must occur periodically to determine if special education services continue to be required. Timelines for revaluation vary from state to state. Check with your specific state department of education to determine the relevant timeline.

Considerations for Students with PI and Developmental Disabilities

Developmental disabilities are a group of conditions that affect a person's physical, intellectual, emotional, and/or social development. Examples include autism spectrum disorder, intellectual disability, and behavioral disorders, and students with these types of disabilities typically have IEPs. Although school personnel may be familiar with developmental disabilities, a student with a developmental disability that has a co-diagnosis of PI merits special consideration.

Circumstances that Increase Exposure to Germs

Students with PI who also have a developmental disability may be at greater risk of exposure to germs than neurotypical students with PI due to their cognitive and behavioral challenges. According to the Kennedy Krieger Institute, self-injurious behavior (SIB) is behavior that could result in physical injury to one's own body. Although behaviors that increase exposure to germs or illness are not typically considered SIB, in a student with PI, they may lead to serious health outcomes.

Therefore, behaviors and activity patterns that increase exposure to germs must be examined to determine if they need to be treated as SIB within an IEP. A few examples include:

- The need to repeatedly touch people or surfaces.
- Pica (eating non-food items such as paper or dirt).
- Frequently putting hands and fingers in mouth, nose, or eyes.

In addition, students with developmental disabilities may have a limited understanding of infection control and hygiene techniques. For example, while neurotypical students may know to move away from a person displaying signs of infection/illness, a student with a developmental disability may not. The student also may not be able to communicate problems or report if school personnel are following the IEP.

Likewise, due to the nature of special education classrooms, classmates may not be able to follow proper hygiene techniques such as covering a cough, using tissues, and washing hands properly. They also may exhibit behaviors that increase their likelihood of spreading germs or may not be able to communicate when they are feeling ill, remaining in class when neurotypical students would be dismissed.

These circumstances all increase a student with PI's exposure to germs and risk of serious illness.

Special Circumstance Instructional Aide (SCIA)

PI is a serious disease and general class staff may not be able to monitor students with PI closely in an active classroom setting. For students with a developmental disability and PI, an instructional aide or paraeducator who provides 1-on-1 support, known as a Special Circumstance Instructional Aide (SCIA), may be required, depending on the functioning and awareness level of the student. Note that school districts typically have an assessment process separate from the IEP process for assigning a SCIA, as they are obligated to provide the least restrictive environment (LRE) for the student. However, a SCIA may allow some students to remain in school rather than receive homebound instruction.

SCIAs for students with PI should be properly trained and familiar with PI. The aide can facilitate proper teaching and behavior modification techniques that aid in skill development and reduce behaviors that may lead to exposure to germs. The aide may need to directly intervene to ensure exposure is prevented. Intervention can include, but is not limited to:

- Cleaning desks, keyboards, doorknobs, or other surfaces.
- Making sure the student washes their hands frequently and properly.

- Moving the student to a different seat or location.
- Ensuring safety during bus/transportation services.
- If face masks are needed, ensuring the mask is worn properly throughout the day and during transportation services.

It should be noted that the SCIA should work to increase independence at school. A person well-trained in behavior techniques is likely required. This expertise will help to ensure the student acquires these skills as part of their daily living routine.

Individuals with PI frequently experience fatigue. In those with developmental disabilities, this may lead to irritability or behavioral issues. A significant percentage of individuals with PI also suffer from comorbid autoimmune disorders. These can, in some cases, result in fluctuating behavioral issues that result from pain and discomfort. Neurological issues such as tics can also occur. In addition, fluctuations in learning, attention, or loss of skills can occur. In these cases, a SCIA may be needed to assist the student in keeping up with their current classroom activities or for safety issues.

Additional IEP Suggestions

Below are some ideas for items to include in an IEP for a student with both a developmental disability and PI:

1. Behavioral goals that include hygiene skills.
2. Review of hygiene skills with classmates.
3. Supervision to make sure that the student is thoroughly and properly washing/sanitizing hands throughout the day.
4. Classroom teacher(s) wash their hands frequently and sanitize their hands after working with another student, especially one who shows signs of illness/infection.
5. Personnel clean shared equipment such as computer keyboards, iPads, and occupational therapy equipment prior to the student using them.
6. Parents/guardians are notified of potential exposure as a result of close contact in and outside of the classroom, shared bathrooms, lunchrooms, occupational therapy room, gym, etc., and temporary accommodations are provided for the student to use another bathroom (faculty/staff), eat someplace else, etc.
7. Classroom teacher(s) or the school nurse informs parents/guardians of illness in the class as soon as possible. During infectious disease outbreaks, daily communication is likely required. The student may also need leeway to be late for school during these times so the teacher and nurse have an idea of what the illness situation looks like on that particular day.
8. If the class has an individual with signs of infection, the student with PI is moved to another classroom if they lack the understanding to stay away from people who are sick. Additional considerations for moving the student to a different classroom include lack of hygiene skills by others in the class and seating assignments/class setup.
9. The school encourages sick students to stay home.

Contesting an Evaluation or IEP

If parents/guardians disagree with the initial evaluation or the IEP, they can follow a formal grievance process.

- Request an independent evaluation.
- File a written complaint.
- Participate in due process hearings.
- Participate in mediation.
- File a complaint with the state education agency, if mediation is not successful.

The Center for Appropriate Dispute Resolution in Special Education (CADRE) works to increase the nation's capacity to effectively resolve special education disputes, reducing the use of expensive adversarial processes. CADRE works with state and local education and early intervention systems, parent centers, families, and educators to improve programs and results for children with disabilities. CADRE is funded by the Office of Special Education Programs at the U.S. Department of Education to serve as the National Center on Dispute Resolution in Special Education. More information is available at: https://www.cadreworks.org/.

Additional information about IEPs is available through individual school districts or at the Center for Parent Information and Resources website: https://www.parentcenterhub.org/.

Chapter 7

Individualized Healthcare Plans and Emergency Care Plans

Individualized Healthcare Plan (IHP)

An Individualized Healthcare Plan (IHP) is a written healthcare plan adapted specifically for the school setting. An IHP outlines the management of school healthcare services for students with significant or chronic health conditions.

A student's IHP is developed by the school nurse in collaboration with the parents/guardians, student (if appropriate), relevant school personnel, and the student's healthcare provider. The plan ensures quality, comprehensive care of the student's health needs. It also promotes continuity of care and communication between relevant school personnel and the family.

The need for an IHP is based upon a student's need for nursing care while they are at school or participating in a school activity. It is not based upon educational entitlement, such as Section 504 or IDEA.

Students with specialized healthcare needs may need an emergency care plan (ECP) in addition to an IHP. An IHP may also be included in a 504 plan or an IEP.

Individualized Healthcare Plan (IHP)

IHP – Page 1 of 6

School Year _____ to _____

Student First Name | Student Last Name | Gender | Date of Birth | Age

School | Grade | Teacher

Parent/Guardian First Name | Last Name | Home Phone | Cell Phone

Street Address | City | State | Zip | Email Address

Parent/Guardian First Name | Last Name | Home Phone | Cell Phone

Street Address | City | State | Zip | Email Address

Physician Name | Office Phone

Physician Street Address | City | State | Zip

Hospital Emergency Room (ER) | Phone

Hospital ER Street Address | City | State | Zip

Ambulance Service | Phone

School Nurse | Phone

Medical Condition(s)

Symptoms Student May Report

Allergies to Medications

Background Information/Nurse Assessment

Brief Medical History

❑ Check if additional information is attached.

Special Healthcare Needs

❑ Check if additional information is attached.

Social/Emotional Concerns

❑ Check if additional information is attached.

Academic Achievement

❑ Check if additional information is attached.

Medications

1.

Medication Name | Dosage & Frequency | Side Effect(s)

Start Date | Stop Date

2.

Medication Name | Dosage & Frequency | Side Effect(s)

Start Date | Stop Date

3.

Medication Name | Dosage & Frequency | Side Effect(s)

Start Date | Stop Date

4.

Medication Name | Dosage & Frequency | Side Effect(s)

Start Date | Stop Date

5.

Medication Name | Dosage & Frequency | Side Effect(s)

Start Date | Stop Date

6.

Medication Name | Dosage & Frequency | Side Effect(s)

Start Date | Stop Date

❑ Check if additional information is attached.

Special Dietary Needs

❑ Check if additional information is attached.

Transportation

_____

_____

❑ Check if additional information is attached.

Classroom/School Modifications

_____

_____

❑ Check if additional information is attached.

Necessary Healthcare Procedures at School

_____

_____

_____

Equipment (List necessary equipment/supplies) Provided by Parent Provided by School

1. _____
2. _____
3. _____

Healthcare Action Plan

Attach physician's order and other standards for care.

Procedures and Interventions

Procedure	Equipment	Administered by	Trained by
1.			
2.			
3.			

Safety Measures

_____

_____

_____

❑ Check if additional information is attached.

Substitute/Backup Staff (when primary staff is not available)

_____

_____

Possible Problems to be Expected

_____

_____

Training

_____

_____

Emergency Plan _____ ❑ Attached Training Plan_____ ❑ Attached

Plan Review

Next Review Date of Individualized Healthcare Plan (IHP): _____

Team Members

We have participated in the development of this Individualized Healthcare Plan (IHP) and agree with its contents.

Plan Review

Administrator or Designee Printed Name	Signature	Date
School Nurse Printed Name	Signature	Date
Teacher Printed Name	Signature	Date

Parent/Guardian Authorization for Special Health Services

We (I), the undersigned who are the parents/guardians of _____ request and approve this Individualized Healthcare Plan. We (I) understand that a qualified designated person(s) will be performing the healthcare service. It is our understanding that in performing this service the designated person(s) will be using a standardized procedure which has been approved by the student's healthcare team/physician.

We (I) will notify the school immediately if the health status of _____ changes, there is a change or cancellation of any procedure or we change physicians.

We (I) agree to provide the following medical equipment, supplies or medication.

❑ **No equipment required.**

Parent/Guardian Printed Name	Signature	Date
Parent/Guardian Printed Name	Signature	Date

Emergency Care Plan (ECP)

An Emergency Care Plan (ECP) ensures that a plan of action is in place if an emergency related to a student's medical condition occurs in the school setting. The ECP includes who should be contacted and specific actions that should be followed to maintain the student's health and safety during an emergency.

An ECP is developed by the school nurse, the student (if appropriate), parents/guardians, relevant school personnel, and the student's healthcare provider. The school nurse shares the ECP with pertinent school personnel and provides training to these individuals.

The ECP is not a replacement for an IHP. The IHP focuses on healthcare needs. The ECP focuses on emergency care. The ECP should flow from the IHP.

EMERGENCY ACTION PLAN

Health Condition _____

Student Name: _____ DOB: _____ Grade: _____

Student Picture

Contact Information:

Parent/Guardian Name: _____ Phone: _____

Parent/Guardian Name: _____ Phone: _____

Emergency Contact: _____ Phone: _____

Additional Contacts: _____ Phone: _____

Building Health Office/School Nurse: _____ Phone: _____

AN EMERGENCY MAY INCLUDE ANY OR ALL OF THESE SYMPTOMS:

_____

If you see this:	DO THIS:

Preferred hospital: _____

Doctor's Name: _____ Date: _____

Emergency Plan written by: _____ Date: _____

Parent/Guardian Signature: _____ Date: _____

The parent/guardian signature authorizes the nurse to share this information with school staff on a "need to know" basis. In the event of an emergency, care will be initiated and parents will be contacted.

This plan is in effect for the current school year only.

Allergy & Asthma NETWORK **SN CHAT®** School Nurse Chronic Health Assessment Tool

AllergyAsthmaNetwork.org

Reprinted from the School Nurse Health Assessment Tool (SN CHAT) with permission from the Allergy and Asthma Network (https://allergyasthmanetwork.org/).

Chapter 8
Managing School Transitions

Returning to School after an Extended Absence

It is essential to help students stay connected to their classmates during extended absences. Parents/guardians, classroom teachers, the school counselor, and other school personnel can work together to make the transition back to school easier. Inviting friends to visit the student's home or hospital will help keep the student connected to peers, as will linking to the classroom or classmates via video chat.

At the end of an extended absence, it is important to work with teachers or other school personnel to prepare everyone for the student's return to school. If more than one teacher is involved in the student's education, then a single person should be appointed as the main liaison. In cases where the student has a 504 plan, this would be the 504 Coordinator/case manager. For students with an IEP, designate one of the IEP team members for this role.

The liaison works with teachers and the student to determine how the student will catch up on missed work. This includes collecting assignments from teachers to pass along to the student and working with everyone to agree on the priority order for completing missed work. Returning to school after a prolonged absence is usually quite stressful for a student with PI and decreasing confusion and stress regarding missed assignments will help everyone in the long run.

A New School Year or a New School in the Same District

Before the school year begins, parents/guardians of students with PI should schedule a time to meet with their child's new teacher(s). If the student has a 504 plan or an IEP, the 504 Coordinator/case manager, IEP team, and other relevant school personnel should also attend the meeting. A copy of the student's 504 plan or IEP should be shared with all attending.

Parents/guardians should be prepared to share the following information:

- A letter from the student's healthcare provider that lists their medical condition, treatment/medication, and any recommendations for accommodations/modifications. A sample letter is included in **Chapter 10**.
- Older students might want to write a letter to their teachers. The letter should include information about the student's PI and how it affects their school day. A sample letter is included in **Chapter 10**.

- Copies of the following IDF publications:
  - » This publication (*Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency*©).
  - » The chapter from the *Immune Deficiency Foundation Patient & Family Handbook for Primary Immunodeficiency Diseases - 6th Edition*© that describes your child's specific type of PI.
  - » *Our Immune System*©, a children's storybook that provides an easy-to-understand explanation of immune system function.
  - » *Is It Just an Infection?*© poster to be displayed in the school nurse's office to promote awareness of PI.

If appropriate, the student may be included in the meeting.

A New School District

If the student has a 504 plan, the process to initiate a new 504 plan (see **Chapter 5**) will need to be followed.

If the student has an IEP, district officials must provide an education comparable to the one received in the previous district or implement a new IEP. Before the move, parents/guardians should get information from the current IEP team on how to begin a new IEP process. It will be important to schedule a meeting with the new school as soon as possible after the student is enrolled.

Parents/guardians should be prepared to share the following information:

- A copy of the IEP or 504 plan from the previous school district.
- Contact information for the individual responsible for managing the plan at the previous school.
- A copy of the letter requesting a meeting.
- A letter from the student's healthcare provider that lists their medical condition, treatment/medication, and any recommendations for accommodations/modifications. A sample letter is included in **Chapter 10**.
- Older students might want to write a letter to their teachers. The letter should include information about the student's PI and how it affects their school day. A sample letter is included in **Chapter 10**.
- Copies of the following IDF publications::
  - » This publication (*Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency*©).
  - » The chapter from the *Immune Deficiency Foundation Patient & Family Handbook for Primary Immunodeficiency Diseases - 6th Edition*© that describes your child's specific type of PI.
  - » *Our Immune System*©, a children's storybook that provides an easy-to-understand explanation of immune system function.
  - » *Is It Just an Infection?*© poster to be displayed in the school nurse's office to promote awareness of PI.

Preparing for Secondary Education and Beyond

Self-advocacy is an important step toward becoming an adult. Self-advocacy skills include the ability to communicate one's needs, make decisions, and ask for help when necessary. These skills allow a student to be more successful in high school and beyond.

By the end of middle school, many young people are ready to practice self-advocacy. Some ways students can learn to be self-advocates include:

- Learning about their type of PI.
- Learning the name, dosage, and purpose of medications.
- Knowing which staff person to contact and how to contact the individual if they have concerns.
- Telling school personnel when they feel ill.
- Asking teachers for assistance with assignments missed due to absenteeism.
- Participating in educational or healthcare plan meetings.
- Learning about their educational rights.

When self-advocacy has been practiced with support from parents/guardians, healthcare providers, and school personnel, and with advance planning, the transition into adulthood can be an exciting time. For more in-depth information, including skills checklists for ages 12 and up, see *IDF's Transition Guide: Pediatric to Adult Care©*, *https://primaryimmune.org/publication/patients-and-families/immune-deficiency-foundation-transition-guide-pediatric-adult-care*.

Chapter 9
Post-Secondary Education

Many high school students with PI continue their education in post-secondary schools, including vocational and career schools, two- and four-year colleges, and universities, and they can have amazing careers.

Educational Rights

Students should become knowledgeable about their rights and responsibilities, as well as the responsibilities of post-secondary schools. This knowledge will ensure that students have the opportunity to enjoy the benefits of the educational experience without confusion or delay.

For students who had an IEP in high school, it is important to know that the Individuals with Disabilities Education Act (IDEA) does not apply to post-secondary schools. Post-secondary education students, however, are entitled to services and accommodations through Section 504 of the Rehabilitation Act of 1973 and the ADA/ADAAA.

Section 504 and ADA/ADAAA prohibit post-secondary schools from searching for information about a student's disability status and ensure that students will not be discriminated against due to a disability during the admissions process or in any areas of programming. A student who meets the essential requirements for admission to a post-secondary school may not be denied admission based upon a disability.

Although post-secondary schools are required to comply with Section 504, there are significant differences in the responsibilities of school districts and post-secondary schools. For example, in post-secondary education, it is the student's responsibility to notify the school if they need an accommodation. Post-secondary schools, unlike K-12 schools, are not required to identify students with disabilities.

Most individuals with PI do not view themselves as having a disability. However, if a student with PI wants a post-secondary school to provide an academic adjustment, they must "identify" themselves as having a disability.

Please note—the student does not need to apply or qualify for disability benefits provided by the Social Security Administration. The Americans with Disabilities Act (ADA) and the Social Security Administration define disability differently.

The Pacer Center publishes resources that include the most updated information about federal laws and establishing academic adjustments in a post-secondary school. For more information and to request a copy of this guide, see: https://www.pacer.org/transition/learning-center/postsecondary/.

Legal Definition of a Disability

The legal definition of a disability in post-secondary education is the same as that in K-12 education and is defined by the ADA/ADAAA as:

- A physical or mental impairment that substantially limits one or more major life activities of an individual:
  - **Major life activities include**, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, **learning**, reading, concentrating, thinking, communicating, and working.
  - **A major life activity also includes the operation of a major bodily function, including but not limited to, functions of the immune system**, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.
- A record of such an impairment.
- Being regarded as having such an impairment.

Disclosure

It is up to the student with PI to decide whether they choose to disclose their medical condition at the post-secondary level. This is a very personal decision and will be based on whether the student is requesting accommodations, modifications, or special services.

If a student chooses to disclose their PI, the school will request documentation of the diagnosis and the need for the accommodations, modifications, or services the student is requesting. Documentation might include a letter from the student's healthcare provider, in addition to other documentation required by the school. There are differences between the required documentation and how accommodations, modification, or services are provided at each school, but the ultimate goal is that the student with PI receives the same educational opportunity as others.

Appropriate adjustments will be made based on the student's individual needs. Examples of academic adjustments in post-secondary education include:

- Providing classroom recordings or a note-taker due to an absence caused by illness.
- Extended time for completion of assignments or testing due to an absence caused by illness.
- No penalty for missing classes over the amount allotted per instructor for the semester.

In providing an academic adjustment, the post-secondary school is not required to lower their academic requirements. The school is also not required to provide a service or program that would result in undue financial or administrative burdens.

Students interested in an academic adjustment should contact the Office of Disability Services, or the equivalent department, during their initial campus visit and upon being accepted to discuss adjustments and how they might be provided.

The Office of Disability Services will not disclose a student's specific diagnosis to instructors. The information shared with instructors simply states, "chronic health condition." Since instructors are told very limited information, a student may want to write to each instructor at the beginning of the semester explaining their PI and how it might affect their attendance and/or schoolwork. It is also recommended that the student meet with each instructor to discuss their situation. Students should work with their instructors to formulate a plan of action should the student become sick during the semester.

If the student chooses not to disclose their chronic health condition and they do become ill, it will be important to notify instructors immediately. Instructors understand that illness happens and will typically work with students, as long as they have made the effort to communicate.

Choosing a Post-Secondary School

There are many factors involved in choosing a post-secondary school. Selecting a school that suits the student's academic goals is top of the list. However, for students with PI, it is also important to consider healthcare needs. Note that this section provides only an overview; for more in-depth information, see *IDF's Transition Guide: Pediatric to Adult Care*© https://primaryimmune.org/publication/patients-and-families/immune-deficiency-foundation-transition-guide-pediatric-adult-care.

Some factors to consider:

- **Accessibility to medical providers with knowledge of PI**. Once the list of post-secondary schools has been narrowed, students will want to discuss healthcare options with their current medical team. Depending on how far the school is from the current medical team, a transition of care might be necessary. If so, the current medical team may know a provider familiar with PI in the area. IDF also has a Clinician Finder tool that may be helpful: https://primaryimmune.org/clinician-finder.
- **Support for students**. All post-secondary schools provide accommodations and support. However, some schools offer more staff and resources for students with disabilities. During campus visits, visit with the Office of Disability Services and the Student Healthcare Center. If you plan on living on campus, you will also want to visit the Housing & Residential Life Department.
- **Continuation of treatment**. Students planning to live on campus and receive immunoglobulin (Ig) therapy or other injectable drugs will need to make arrangements for their products and supplies to be shipped and stored. The Office of Disability Services, Housing & Residential Life Department, or Student Healthcare Center will be able to provide information regarding the shipment and storage of medication and supplies.

Students Receiving Immunoglobulin, PEG-ADA, or Interferon Gamma Therapy

Students who receive immunoglobulin (Ig), either intravenously (IVIG) or subcutaneously (SCIG), PEG-ADA, or interferon gamma may want to communicate with their roommates about their PI and their therapy. This will avoid confusion and concern that illegal drugs are being used. In addition to notifying roommates, students living on campus will want to notify their Resident Assistant (RA). The RA can also work with students to assure that treatment continues while living on campus.

Keep in mind that it may not be necessary for students relocating or going away to school to change infusion providers. Students receiving infusions or injections through a specialty pharmacy in a homecare setting may be able to continue with the same provider. Check with the current infusion provider several months before moving to determine whether service can continue. If a change is needed, the current provider should participate in coordinating the transition to the new provider.

For students receiving infusions or injections in a clinic or outpatient hospital setting, it will be key to coordinate care in advance with as much notice as possible. For example, some colleges or universities may not allow infusions or injections to be given in a dormitory and arrangements may have to be made for infusions at the student health center or a local hospital/infusion center. Additionally, the receiving clinic will likely need to get a new insurance authorization to provide care. Failure to obtain a new authorization could result in denied claims or delays in therapy.

Campus Life

Many young adults with PI choose to live the typical college life in a dormitory or apartment setting with one or more roommates. However, a healthcare provider may want some students with PI to have a private room, so students should discuss options with their healthcare provider. Whether in a dorm or apartment, on or off campus, with roommates or without, students should carefully consider their options when choosing living arrangements.

Advantages for students with PI living on campus in a dorm or apartment:

- **Convenience** – Living on campus enables students to walk to classes, libraries, and dining halls, avoiding the stress that a commute can create. Lowering stress is always good for physical and emotional wellbeing.
- **Social Life** – Students living on campus are around more people and have more opportunities to make friends. On-campus living offers RAs that are older students. The RAs' role is to provide support and information to the students living in their unit.
- **Nutrition** – Colleges and universities offer meal plans to all students whether they live on campus or off campus. Living on campus makes it easier to eat a balanced diet when meals are prepared.

Drawbacks for students with PI living on campus:

- **Privacy** – There is very little privacy living in a dorm. Most dorm rooms involve living in cramped quarters and sharing bathrooms.
- **Questions** – Students receiving treatment on campus will probably need to answer questions from curious roommates. This is not necessarily bad unless someone "doesn't get it." So, be prepared to answer questions about PI.
- **Infectious Disease Outbreaks** – On-campus housing, and dorms in particular, are notorious for infectious disease outbreaks such as COVID-19, meningitis, and influenza. Be aware that it may be difficult to avoid sick individuals if an outbreak occurs within your building.

Students requesting a private room will need documentation from their healthcare provider that states this accommodation. The student will also need to work with the Office of Disability Services and the Housing & Residential Life Department to make these arrangements. Remember that requesting a private room might involve disclosing a chronic health condition to the Office of Disability Services and Housing & Residential Life Department. Outside of these departments, it is the student's decision to share information about their health condition.

Chapter 10
Sample Letters and Forms

Sample Letter from a Healthcare Provider

<Medical Facility Letterhead>

<Date>

To Whom It May Concern:

<First and last name> has been diagnosed with <list type of PI, e.g., CVID, SCID, CGD>, which is a primary immunodeficiency (PI), a group of over 400 rare disorders. These conditions, in which part of the body's immune system is missing or functions improperly, are caused by hereditary or genetic defects and are not contagious.

PI is a chronic illness, and even with regular medical care and treatment with <list treatment(s) and medication(s)>, this student's educational performance may be impacted by an increased risk of illness or treatment side effects.

Therefore, I recommend the following accommodations and/or modifications. [Possible accommodation/modifications are listed in **Chapter 4**.]

Thank you for your assistance and cooperation regarding this student. Please contact me if you have any questions.

Sincerely,

<Signature of Healthcare Provider>

Sample Letter Requesting a Meeting with School Personnel

<Date>

Dear <School Staff Person>,

My child, <first and last name>, is diagnosed with a primary immunodeficiency (PI), specifically <list type of PI, e.g., CVID, SCID, CGD>. This is a genetic condition, not contagious to others, in which my child's immune system does not function properly.

Having a PI causes an increased risk of infection for my child, which might impact <their/his/her> educational performance. Therefore, I would like to schedule a 15-30 minute meeting with you and other staff involved in my child's education to discuss <child's name>'s diagnosis and issues that might arise at school.

Thank you for your consideration of my request. I would like to schedule the meeting within the next 14 days. I look forward to hearing from you at your earliest convenience.

Sincerely,

<Signature>

<Name: First & Last>

<Phone>

<Email Address>

Sample Letter Requesting a Planning Meeting to Develop a 504 Plan, an IHP, or an ECP, or Request an Assessment to Determine Eligibility for an Individualized Education Program (IEP)

<Date>

Dear <School Staff Person>,

My child, <first and last name>, is diagnosed with a primary immunodeficiency (PI), specifically <list type of PI, e.g., CVID, SCID, CGD>. This is a genetic condition, not contagious to others, in which my child's immune system does not function properly.

Having a PI causes an increased risk of infection for my child, which might impact <his/her/their> educational performance in the following ways, which are also listed in the letter from <child's name> physician.

<List examples: increased absenteeism, fatigue, etc.>

In order to help my child succeed in school, I am requesting <development of a 504 plan, an Individualized Healthcare Plan, or an Emergency Care Plan, or assessment to determine eligibility for an Individualized Education Program (IEP)>.

Thank you for your consideration of my request. I look forward to hearing from you within 14 days.

Sincerely,

<Signature>

<Name: First & Last>

<Phone>

<Email Address>

Sample Student Letter to School Personnel

<Date>

Dear <School Staff Person>,

I am a student with a primary immunodeficiency (PI), specifically <list your type of PI, such as CVID, XLA, SCID, CGD>. This is a genetic condition, not contagious to others, in which my immune system does not function properly. There are over 400 types of PI, which are rare, chronic conditions. Since PI is rare, you may not have had a student with this diagnosis in your class before. Therefore, I would like to share the following information about myself with you.

<List the issues, based on the letter from your doctor, that affect your school day. For example, illness, fatigue, medical appointments, side effects from medication.>

Throughout the school year, I want to participate in educational and extracurricular activities just like my friends do. However, there might be times when accommodations or modifications listed on my <504 plan, IEP> are necessary. I also have an <IHP, EHP> with important information on maintaining my health at school. Thank you for your understanding and support.

My parents/guardians and I will update you throughout the school year if there are changes in my health. Please feel free to contact us any time you have questions or concerns.

I am including a letter from my doctor that includes more information about me, and I have also enclosed some information about PI from the Immune Deficiency Foundation.

Thank you for letting me share information about myself. I look forward to <being in your class, attending your school>.

Sincerely,

<Student Name>

Meeting/Conference Planner

For parents, guardians, and students: use this form to make notes prior to a school meeting or conference.

Student First Name _____ Student Last Name _____ Meeting Date _____

My Concerns:

- _____
- _____
- _____
- _____
- _____

My Requests:

- _____
- _____
- _____
- _____
- _____

My Questions:

- _____
- _____
- _____
- _____
- _____

Meeting Outcome/Results:

- _____
- _____
- _____
- _____
- _____

Glossary of Medical Terms

ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS): A secondary immunodeficiency caused by the HIV virus.

ADENOSINE DEAMINASE (ADA): An enzyme essential for the development of the immune system.

AGAMMAGLOBULINEMIA: An almost total lack of immunoglobulins or antibodies.

ANTIBODIES: Protein molecules that are produced and secreted by certain types of white blood cells (B cells) in response to stimulation by an antigen; their primary function is to fight bacteria, viruses, toxins, and other substances foreign to the body.

CHRONIC: Descriptive term used to describe an illness or infection that may be recurrent or last a long time.

GENE: A unit of genetic material (DNA).

GENE THERAPY: Treatment of genetic conditions by providing the correct form of the gene causing the disease.

IMMUNODEFICIENCY: A state of either a congenital (present at birth) or an acquired abnormality of the immune system that prevents adequate immune responses.

IMMUNOGLOBULINS (Ig): Another name for antibodies.

INTERFERON GAMMA: A chemical primarily produced by T cells that improves bacterial killing by phagocytes; used as a treatment for Chronic Granulomatous Disease (CGD).

INTRAVENOUS IMMUNOGLOBULIN (IVIG): Immunoglobulin therapy that is infused directly into the vein.

LIVE VACCINES: Vaccines that contain live, but weakened germs; live vaccines (particularly oral polio) can transmit the disease they were designed to prevent to immunocompromised individuals.

MICROORGANISMS: Living organisms and infectious particles, such as bacteria and viruses, that can only be seen with a microscope; germs.

PRIMARY IMMUNODEFICIENCY: Immunodeficiency that is intrinsic to the cells and tissues of the immune system, not due to another illness, medication, or outside agent damaging the immune system.

PROPHYLACTIC: Medical therapy to prevent or guard against disease or infection.

SECONDARY IMMUNODEFICIENCY: Immunodeficiency due to another illness or agent, such as human immunodeficiency virus (HIV), cancer, or chemotherapy.

SUBCUTANEOUS IMMUNOGLOBULIN (SCIG): Administration of immunoglobulin therapy infused slowly directly under the skin with a small pump.

VACCINE: A substance that contains either whole microorganisms or components from a microorganism that stimulates an immune response in order to protect against subsequent infection by that microorganism.

Glossary of Educational Terms

504 PLAN: A written plan listing accommodations and modifications that enable a student who does not qualify for special education or an IEP to participate fully in the classroom.

ACCOMMODATION: A different way of doing something that takes into account the student's disability to help a student produce work commensurate with classmates.

AMERICANS WITH DISABILITIES ACT (ADA): A federal law enacted in 1990 to protect people with disabilities from discrimination.

COMMUNITY PARENT RESOURCE CENTERS (CPRCs): A resource for parents/guardians of children with disabilities in some states that do the same work as a Parent Training and Information Center (PTI), but focused on reaching underserved parents/guardians of children with disabilities who live in specific areas of the state.

DISABILITY: A problem or condition that makes it difficult for a student to learn or do things in the same ways as most other students. A disability may be short term or permanent.

ELIGIBILITY: The determination of whether a student qualifies to receive services based upon meeting established criteria.

EMERGENCY CARE PLAN (ECP): A written plan of action for any emergency situations related to a student's medical condition that occur in the school setting.

FAMILY EDUCATIONAL RIGHTS AND PRIVACY ACT (FERPA): A federal law first enacted in 1974 that protects the privacy of student education records.

FREE APPROPRIATE PUBLIC EDUCATION (FAPE): The words used in federal law (Section 504 and IDEA) to describe the right of students with disabilities to an education that will meet the student's individual learning needs at no cost to the student's parents.

HOMEBOUND INSTRUCTION: Educational instruction given in the student's home when the student is unable to attend school due to medical or other reasons.

INDIVIDUALIZED EDUCATION PROGRAM (IEP): A written plan for a student receiving special education services.

INDIVIDUALIZED HEALTHCARE PLAN (IHP): A written healthcare plan adapted specifically for the school setting.

INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA): A federal law first enacted in 1975 that provides funds to states to support special education and related services for children with disabilities. To be eligible for services under IDEA, a student's disabilities must impair the student's educational performance such that the student requires special education and related services.

LEAST RESTRICTIVE ENVIRONMENT (LRE): Part of the federal law that deals with determining the placement of students with disabilities. This includes that, to the maximum extent appropriate, students with disabilities shall be educated with students who do not have disabilities. The removal of a student from the regular school environment occurs only when the disability is such that the student cannot be satisfactorily educated in regular classes with the use of aides and services.

MAJOR LIFE ACTIVITY: These are activities that an average person can perform with little or no difficulty. Examples include walking, seeing, hearing, speaking, breathing, learning, performing manual tasks, caring for oneself, and working. Other activities such as sitting, standing, lifting, or reading are also major life activities, as is the proper functioning of major bodily systems.

MODIFICATION: Any technique that alters the work required in some way that makes it different from the work required of other students in the same class. Modifications are used to change the rigor of the required assignments.

OTHER HEALTH IMPAIRMENT (OHI): Term used in IDEA – having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome; and adversely affects a child's educational performance.

Glossary of Educational Terms *Continued*

PARENT TRAINING AND INFORMATION CENTER (PTI): An information resource for parents/guardians of children with disabilities. Every state has at least one PTI.

REHABILITATION ACT OF 1973 (SECTION 504): A nondiscrimination statute. Section 504 of the Act stipulates that individuals with disabilities may not be excluded from participating in programs and services receiving federal funds. It also prohibits job discrimination against people with disabilities in any program receiving federal financial assistance.

POST-SECONDARY EDUCATION: The next level of education after high school, such as college/university coursework or vocational/technical training.

SPECIAL CIRCUMSTANCE INSTRUCTIONAL AIDE/ASSISTANCE (SCIA): A specially trained instructional aide or paraeducator who provides 1-on-1 classroom support for a student with a disability. Typically, there is a separate evaluation process for SCIA beyond the IEP process.

Additional Resources

Immune Deficiency Foundation

Ask IDF: Contact IDF for free, individualized assistance on questions about living with primary immunodeficiency (PI) through the IDF website: https://primaryimmune.org/ask-idf.

Get Connected Groups: Designed to connect individuals diagnosed with PI and family members in their local communities: https://primaryimmune.org/idf-get-connected-groups.

IDF Friends: A web forum hosted by IDF and built for patients and caregivers to connect to others.

Publications: All IDF publications can be downloaded at https://primaryimmune.org/resource-center. You can also order free hard copies if they are available. Specific publications that are helpful for conversations with school personnel include:

- This publication (*Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency*©).
- The chapter from the *Immune Deficiency Foundation Patient & Family Handbook for Primary Immunodeficiency Diseases - 6th Edition*© that describes your child's specific type of PI.
- *Our Immune System*©, a children's storybook that provides an easy-to-understand explanation of immune system function.
- *Is It Just an Infection?*© poster to be displayed in the school nurse's office to promote awareness of PI.

Education Resources

Center for Appropriate Dispute Resolution in Special Education (CADRE) | https://www.cadreworks.org/

CADRE works to increase the nation's capacity to effectively resolve special education disputes, reducing the use of expensive adversarial processes. CADRE works with state and local education and early intervention systems, parent centers, families, and educators to improve programs and results for children with disabilities. CADRE is funded by the Office of Special Education Programs at the U.S. Department of Education to serve as the National Center on Dispute Resolution in Special Education.

Center for Parent Information and Resources | https://www.parentcenterhub.org/

The Center for Parent Information and Resources (CPIR) facilitates communication, resource development, and access to Parent Training & Information (PTI) Centers and the Community Parent Resource Centers (CPRCs). Find a center near you at https://www.parentcenterhub.org/find-your-center/.

Every state has at least one PTI or CPRC that provides training and information to parents/guardians of children, ages birth-26, with disabilities. Although each PTI has a different name, they all have the same goal—to provide training and information to parents/guardians of children with disabilities and to the professionals who work with them.

Some states have CPRCs that do the same work as PTIs. However, their focus is on serving parents/guardians of children with disabilities in specific areas, including low-income parents/guardians, parents/guardians of children with limited English proficiency, and parents/guardians with disabilities.

Franklin County Law Library: Education of Students with Disabilities: Federal and State Laws

https://fclawlib.libguides.com/specialeducation

The Franklin County Law Library in Columbus, Ohio, maintains an online legal research guide on federal and state laws and regulations pertaining to the education of students with disabilities. Resources include a table of laws and regulations in all 50 states.

HEATH Resource Center at the National Youth Transitions Center | https://www.heath.gwu.edu/

The HEATH Resource Center is the national clearinghouse on post-secondary education for individuals with disabilities. It provides information about educational support services, policies, procedures, adaptations, and opportunities at college campuses, vocational-technical schools, and other post-secondary training sites.

Home School Legal Defense Association | https://hslda.org/

The Home School Legal Defense Association is a member-based, non-profit advocacy organization that offers resources and support for families who choose to homeschool their children.

PACER Center | https://www.pacer.org/

Through more than 30 projects, PACER provides individual assistance, workshops, publications, and other resources to help families make decisions about education and other services for their child or young adult with disabilities. PACER is the Minnesota Parent Training and Information Center, funded by the U.S. Department of Education's Office of Special Education Programs.

U.S. Department of Education, Office of Civil Rights | https://www2.ed.gov/about/offices/list/ocr/index.html

OCR's mission is to ensure equal access to education and to promote educational excellence through vigorous enforcement of civil rights in our nation's schools.

U.S. Department of Education, Office of Special Education and Rehabilitative Services

https://www2.ed.gov/about/offices/list/osers/index.html

OSERS' mission is to improve early childhood, educational, and employment outcomes and raise expectations for all people with disabilities, their families, their communities, and the nation.

U.S. Department of Education, Student Privacy Policy Office

https://www2.ed.gov/about/offices/list/opepd/sppo/index.html

SPPO is responsible for the administration and enforcement of federal laws relating to the privacy of students' education records, and for the provision of technical assistance on student privacy issues for the broader education community.

Public Health Resources

U.S. Centers for Disease Control and Prevention, Types of Masks Guidance

https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/types-of-masks.html

This page describes different types of masks and respirators that you can use to protect yourself and others from getting and spreading COVID-19 and other infectious diseases.

U.S. Centers for Disease Control and Prevention, Ventilation in Schools and Childcare Programs Guidance

https://www.cdc.gov/coronavirus/2019-ncov/community/schools-childcare/ventilation.html

This page provides recommendations on how to increase air flow and air quality in school and childcare settings.

Primary Immunodeficiency Organizations

International Patient Organization for Primary Immunodeficiencies | https://ipopi.org/

International Patient Organization for Primary Immunodeficiencies (IPOPI) is an international organization whose members are national patient organizations for primary immunodeficiency diseases. The website provides general information on primary immunodeficiency diseases and resource contacts for patients and professionals worldwide.

The Jeffrey Modell Foundation | http://www.info4pi.org/

The Jeffrey Modell Foundation is dedicated to early and precise diagnosis, meaningful treatments, and, ultimately, cures for primary immunodeficiency.

Primary Immune Deficiency Treatment Consortium

https://www.rarediseasesnetwork.org/spotlight/v9i1/PIDTC

The Primary Immune Deficiency Treatment Consortium (PIDTC) is a part of the Rare Diseases Clinical Research Network (RDCRN) funded by the National Institute of Allergy and Infectious Diseases (NIAID) and the National Center for Advancing Clinical and Translational Sciences (NCATS).

Disease-Specific Organizations

A-T Children's Project | https://www.atcp.org/

The A-T Children's Project is a nonprofit organization that raises funds to support and coordinate biomedical research projects, scientific conferences, and a clinical center aimed at finding a cure for Ataxia-Telangiectasia (A-T), a lethal genetic disease that attacks children, causing progressive loss of muscle control, cancer, and immune system problems.

APS Type 1 Foundation | https://apstype1.org/

The APS Type 1 Foundation was started by a group of dedicated parents who were determined to ensure that their children received the best care possible and that no one should have to wait for a diagnosis or treatment for Autoimmune Polyglandular Syndrome Type 1. The foundation supports education, awareness, and fundraising for critical research in APS Type 1.

CGD Association of America | https://cgdaa.org/

The CGD Association of America is an independent, nonprofit organization that is committed to advocating for patients and carriers with chronic granulomatous disease.

Chronic Granulomatous Disease Association | http://www.cgdassociation.org/

The Chronic Granulomatous Disease Association (CGDA), founded in 1982, is a non-profit international support group for persons with chronic granulomatous disease (CGD), their families, and physicians. The organization networks patients with similar CGD-related illnesses or infecting organisms. It provides research grants aimed at finding a cure for CGD.

Hereditary Angioedema Association, Inc. | https://www.haea.org/

Founded and staffed by HAE patients and HAE patient caregivers, U.S. Hereditary Angioedema Association, Inc. (US HAEA) is a nonprofit patient advocacy organization dedicated to serving persons with angioedema. The association provides HAE patients and their families with a support network and a wide range of services including physician referrals, and individualized patient support.

Hyper IgM Foundation | https://hyperigm.org/

The Hyper IgM Foundation's mission is to improve the treatment, quality of life and long-term outlook for children and adults living with Hyper IgM.

International 22q11.2 Foundation | https://22q.org/

The International 22q11.2 Foundation is a nonprofit organization dedicated to supporting the needs of families and individuals affected by chromosome 22q11.2 differences by promoting awareness, state-of-the-art clinical care, cutting edge research endeavors, and solidarity with related associations around the globe.

Liam'sLighthouse Foundation | https://www.liamslighthousefoundation.org/

Liam's Lighthouse Foundation (LLF), a non-profit, tax-exempt organization, was established to create and provide educational material and awareness about Hemophagocytic Lymphohistiocytosis (HLH) including Histiocytic Disorders, and to distribute unbiased, factual information to physicians, hospitals, and the community regarding this disease.

SCID Angels for Life | http://www.scidangelsforlife.com/

SCID Angels for Life is a nonprofit organization that increases awareness, benefits research, and provides parent and family education for those affected by Severe Combined Immune Deficiency (SCID).

Wiskott-Aldrich Foundation | http://www.wiskott.org/

This site provides information about Wiskott-Aldrich Syndrome (WAS). The links on this site include information for patients and families, the latest research related to WAS, and financial support.

XLA Life | https://www.xla.life/

XLA Life's mission is to improve the quality of life for those affected by X-Linked Agammaglobulinemia (XLA).

XLP Research Trust | www.xlpresearchtrust.org

This organization promotes and funds research into the cause, management, symptoms, and cure for X-linked Lymphoproliferative (XLP) disease; raises awareness of the disease; and is a point of contact and support for families affected by XLP.

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Immune Deficiency Foundation

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