

Immune Deficiency Foundation

School Guide for Students with Primary Immunodeficiency Diseases



THIRD EDITION

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This book contains general medical information which cannot be applied safely to any individual case. Medical knowledge and practice can change rapidly. Therefore, this book should not be used as a substitute for professional medical advice.

IMMUNE DEFICIENCY FOUNDATION SCHOOL GUIDE FOR STUDENTS WITH
PRIMARY IMMUNODEFICIENCY DISEASES

THIRD EDITION

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Introduction

The Immune Deficiency Foundation (IDF), founded in 1980, is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases (PI) through advocacy, education and research. One way IDF fulfills this mission is by developing educational publications, such as this *Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency Diseases*, to provide accurate, useful information about these often unfamiliar diseases to patients, families, healthcare providers and others.

IDF originally developed *A Guide for School Personnel, Primary Immune Deficiency Diseases* in 2005 in response to parents seeking information to help their children in school. Parents wanted to be sure they were doing everything they could to help create an academic setting where their children's diseases were understood and they had the opportunity to succeed. The first edition included key medical points about PI and associated special needs, legal rights of children with chronic disease and resource referrals. The second edition, renamed *IDF School Guide: Information about Students with Primary Immunodeficiency Diseases*, added updated and expanded information on all these topics, as well as a glossary of medical and educational terms that are helpful to school personnel and parents alike. This third edition, *Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency Diseases*, is updated and includes additional information and samples of letters and forms to help parents and students advocate for themselves in the educational setting.

Students with PI should receive an education equal to their peers and be encouraged to maintain as normal a school life as possible. Some students with PI may not have trouble at school due to their particular condition and not require assistance. Others, who have more substantial health concerns, may need significant assistance in the school setting.

When PI affects a student's education, it is important for the parents or the student (if appropriate) to share information about their primary immunodeficiency with school personnel. In this case, school personnel, parents and the student (if appropriate) can work together and develop a plan to address issues that might arise during the school year.

IDF hopes this guide can help facilitate effective communication between parents, students and school personnel. Once again, it is important to note that PI can affect individuals differently. In addition to information from the student's healthcare providers and family, the information in this guide should be used to fit each student's individual needs.

Please remember that the information in this guide should not be used in place of a visit, consultation, or advice of your healthcare provider. Should you have any healthcare related questions, you should call or see your clinician.

Efforts have been made to ensure that the material presented in this guide is accurate, reliable and in accordance with current standards at the time of publication. However, as research and experience expands, recommendations for care, treatment and management may change. Please visit www.primaryimmune.org for updated information.

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School Guide for Students with Primary Immunodeficiency Diseases

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Table of Contents

Chapter 1	Getting Started	3
Chapter 2	What Are Primary Immunodeficiency Diseases?	6
	• Examples of Primary Immunodeficiency Diseases	
	• Medical Therapy for Primary Immunodeficiency Diseases	
Chapter 3	Special Considerations in the School Setting	10
	• Susceptibility to Infection	
	• Absenteeism	
	• Vaccinations	
	• Emotional & Social Issues	
Chapter 4	Possible Accommodations and Modifications for Students with PI.	14
Chapter 5	Educational Rights under Federal Law	16
	• Section 504 of the Rehabilitation Act of 1973 (Section 504)	
	• Americans with Disabilities Act of 1990 (ADA) & the ADA Amendments Act of 2008 (ADAAA)	
	• Individuals with Disabilities Education Act (IDEA)	
	• No Child Left Behind Act (NCLB)	
	• Family Education Rights and Privacy Act (FERPA)	
Chapter 6	Selecting and Developing a Plan	19
	• Section 504 Plan (504 Plan)	
	• Individualized Education Program (IEP)	
	• Individualized Healthcare Plan (IHP)	
	• Emergency Care Plan (ECP)	
Chapter 7	Managing Transitions	26
	• A New School Year	
	• A New School District	
	• Returning to School after an Extended Absence	
	• Preparing for Post-Secondary Education	
Chapter 8	Post-Secondary Education	28
	• Educational Rights	
	• What is a Disability?	
	• Disclosure	
	• Choosing a School	
	• Information for Students Receiving Immunoglobulin Therapy	
	• Campus Life	
Chapter 9	Sample Letters	32
	• Accommodation Letter from Healthcare Provider	
	• Letter Requesting Meeting with School Personnel	
	• Letter Requesting a Planning Meeting to Develop a 504 Plan or an Individualized Healthcare Plan (IHP) or Request an Assessment to Determine Eligibility for an Individualized Education Program (IEP)	
	• Student Letter to School Personnel	
Chapter 10	Sample Forms	37
	• Meeting/Conference Planner	
	• 504 Accommodation Plan	
	• Individualized Healthcare Plan (IHP)	
	Glossary of Medical Terms	47
	Glossary of Educational Terms	48
	Resources	50

Chapter 1 – Getting Started



To Parents

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

Since primary immunodeficiency diseases (PI) are a group of rare, chronic disorders, most people are not familiar with them, and school staff will likely need information. Below are ways to help your child receive the best opportunities to learn and participate.

Disclosing your child's diagnosis

One of the decisions faced by parents is whether to tell the school about the diagnosis of a primary immunodeficiency as well as the specific type. Disclosing a diagnosis of PI or any chronic illness is a very personal decision. There are some things to consider.

If PI does not affect the student's education, it is up to the parents and/or student whether to tell the school about the diagnosis. However, it will be important to tell the school in the following situations so students with PI can receive an education equal to other students.

- The student is absent or expects to be absent more than other students.
- The student takes medication at school.
- The student needs accommodations or modifications that are not available to other students.

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.

Share information regarding how your child’s diagnosis might affect their school experience.

Suggested materials to share with the school:

- 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 9.*
- Copies of IDF publications:
 - *Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency Diseases*
 - Chapter from the *Immune Deficiency Foundation Patient & Family Handbook for Primary Immunodeficiency Diseases* - 5th Edition that describes your child’s specific type of PI
 - *Our Immune System*, a children’s storybook, 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

Learn about your child’s educational rights. Information about laws to protect your child in the education setting are included in Chapter 5 of this guide. It is essential for parents 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.

Understand your child’s education or healthcare plan. Information about education and healthcare plans is included in Chapter 6 of this guide.

Help develop your child’s education or healthcare plan. As your child gets older, encourage them to provide input on their plan and advocate for themselves during the school day. However, until your child is 18, you will be responsible.

Communicate with school personnel. Parents and school personnel should develop a communication plan and regularly discuss your child’s progress. Parents should 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 a pre-established time, or an e-mail is all that is typically necessary to keep in contact.

Tips for Communicating in Writing

- Clearly state your request or concern.
- Include your child’s name, grade, teacher, and your contact information.
- 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.
- Always date the communication.
- Add a “thank you” at the end of the letter.

Tips for Meeting with School Personnel

Before the Meeting

- Prepare and know what you want.
- Complete the Meeting/Conference Planner, *included in Chapter 10 of this guide.*

During the Meeting

- Remain calm.
- Stick to the facts.
- Ask questions when you need more information.
- Take notes.

- o Complete paperwork provided by the school. If you need time to review the paperwork, it is okay to take it home and return it when you have had time to check it over.
- o Review and discuss the next step.
- o Request a follow up date.

After the Meeting

- o Follow up in writing to thank the school personnel for their help and discuss the next steps.
- o Keep in touch with key school personnel.

Keep good records. Communicate in writing as much as possible. Even after a phone call, follow up with a short note or e-mail outlining the call. Keep a copy of everything for your records in one place where it can be accessed easily.

In addition to keeping good records regarding your child’s education, it is vitally important to keep good records about your child’s health. The **IDF ePHR** is an online personal health record specifically for the PI community. Use it to organize all your child’s health records in one place. Conveniently access the health records from your computer, tablet or smartphone to track activities and information. Information is safe, secure and private, and there is no cost to you. Learn more about IDF ePHR at: www.idfephr.org.

Know your resources. IDF has staff available to help you navigate the school system. Contact IDF: www.primaryimmune.org/services/ask-idf/ or 800-296-4433.

Every state also has at least one Parent Training & Information Center (PTI) or Community Parent Resource Center (CPRC) that provides training and information to parents 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 of children with disabilities and to the professionals who work with them.

Some states have CPRCs and do the same work as PTIs. However, their focus is serving parents of children with disabilities in specific areas, including low-income parents, parents of children with limited English proficiency and parents with disabilities. Additional information about how PTIs and CPRCs can help parents is available at www.parentcenterhub.org/find-your-center/.

To 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 and school personnel before you turn 18 to learn how to advocate for yourself at school. In addition to information in this guide, below are some questions when advocating for yourself.

- 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, school personnel and IDF are here to help.

To 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.

Chapter 2 – What Are Primary Immunodeficiency Diseases?



Primary immunodeficiency diseases (PI) are a group of more than 220 rare, chronic disorders in which part of the body's immune system is missing or functions improperly. Because one of the most important functions of the normal immune system is to protect us against infection, patients with PI commonly have an increased vulnerability to infections, which can be recurrent, unusually severe, or won't clear up. People with PI can face frequent health problems and often develop serious and debilitating illnesses.

While not contagious, these diseases are caused by hereditary or genetic defects, and although some disorders present at birth or in early childhood, the disorders can affect anyone, regardless of age or gender. Some affect a single part of the immune system; others may affect one or more components of the system. And while the diseases may differ, they all share one common feature: each results from a defect in one of the functions of the body's normal immune system.

Years ago, a diagnosis of a PI meant extremely compromised lives, not just for the patients but for their families as well. Today, with early diagnosis and appropriate therapies, many patients diagnosed with a PI can live healthy, productive lives.

Primary immunodeficiency diseases are not contagious.

PI is caused by hereditary or genetic defects. They are not contagious. When the damage is caused by an extrinsic force, such as an environmental factor or agent, it is called a secondary immunodeficiency disease. PI is not AIDS. AIDS is a secondary immunodeficiency caused by the HIV virus. Irradiation, chemotherapy, malnutrition and burns are also causes of secondary immunodeficiencies.

What are the symptoms of PI?

Nearly everyone has suffered from a cold, the flu, and a sinus or an ear infection. Most people have experienced a cut, scrape or abrasion that became infected. Even in the case of more severe infections, such as pneumonia, we expect the cough and congestion to 'run its course,' aided by prescription antibiotics, over-the-counter symptom remedies, and our body's own immune system.

Recovery times vary, but the human body can usually rid itself of the infection-causing germs, and work to defend against future infections and viruses. However, instances in which the body cannot recover may be an indication of a PI.

IDF recommends that people ask, “Is it just an infection?” Individuals should be suspicious if they have an infection that is:

- **Severe** – requires hospitalization or intravenous antibiotics
- **Persistent** – won’t completely clear up or clears very slowly
- **Unusual** – caused by an uncommon organism
- **Recurrent** – keeps coming back or if it
- **Runs in the Family** – others in your family have had a similar susceptibility to infection

If any of these words describe the infection, IDF recommends that individuals should ask their healthcare providers to check for the possibility of PI. People with PI live their entire lives more susceptible to infections—enduring recurrent health problems and often developing serious and debilitating illnesses. Fortunately, with early diagnosis and proper medical care, many patients live full and independent lives.

According to IDF, there are approximately 250,000 people who are diagnosed with PI in the U.S., and thousands more go undetected. Although some disorders present at birth or in early childhood, the disorders can affect anyone, regardless of age or gender.

It is critical to get an early diagnosis and proper medical care if a PI is suspected. Do not hesitate to ask your healthcare provider to check for the possibility of this condition.

Typically, persons diagnosed with PI “look” healthy. These diseases are often described as hidden conditions, similar to asthma or diabetes. Schools are accustomed to making accommodations for students with asthma and diabetes, and they may also need to make accommodations for students diagnosed with PI.

Examples of Primary Immunodeficiency Diseases

Antibody Deficiencies

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

Cellular Immunodeficiencies

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

Innate Immune Disorders

- Chronic Granulomatous Disease (CGD) and Other Phagocytic Cell Disorders
- Hyper IgE Syndrome
- Complement Deficiencies
- Innate Immune Defects
- NEMO Deficiency

This information is excerpted from the *IDF Patient & Family Handbook for Primary Immunodeficiency Diseases - 5th Edition*. Copyright 2013 by Immune Deficiency Foundation, USA.

Additional information about the types of PI listed above is available in the *IDF Patient & Family Handbook for Primary Immunodeficiency Diseases - 5th Edition* and on the IDF website: www.primaryimmune.org/about-primary-immunodeficiencies/specific-disease-types/. For information about additional types, submit questions at www.primaryimmune.org/services/ask-idf.

Overview of Medical Therapy for Primary Immunodeficiency Diseases

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 disease. This information regarding specific medical therapy should be shared 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 receiving medical treatment, a plan to help the student keep up with classmates should be created.
- **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. The American Academy of Pediatrics has created *Guidelines for the Administration of Medication in School*. It is available at <http://pediatrics.aappublications.org/content/112/3/697.full>.

Medical Therapies at a Glance

Immunoglobulin Replacement Therapy

Many individuals with PI, specifically those with antibody deficiencies, receive immunoglobulin (Ig) replacement therapy, either intravenously (IVIG) or subcutaneously (SCIG). Immunoglobulin refers to the fraction of blood plasma that contains immunoglobulins or antibodies. The Ig partly replaces what the body should be making but does not help the patient's own immune system make more. Therefore, Ig only provides temporary protection and repeat doses are required at regular intervals.

Bone Marrow or Hematopoietic Stem Cell Transplantation

Stem cell transplantation is a form of treatment for individuals with T cell, granulocyte or combined defects. Stem cells from the bone marrow, cord blood or peripheral blood of a normal donor are transplanted intravenously to an immune deficient recipient. It is a highly specialized treatment that is used to treat some of types of PI.

Enzyme Replacement Therapy

Enzyme replacement therapy is used for individuals who are adenosine deaminase (ADA) deficient. Intramuscular injection of replacement enzyme (PEG-ADA) twice a week maintains enough ADA activity in the bloodstream of patients to remove toxins that causes the immune deficiency.

Granulocyte-Colony Stimulating Factor (G-CSF)

G-CSF is available as Neupogen® and in a slightly modified form called Neulasta®. They are 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 autoimmune diseases.

Interferon Gamma

Individuals with Chronic Granulomatous Disease (CGD) often receive interferon gamma three times weekly subcutaneously. Interferon gamma is one type of interferon that is found naturally in the body. Its use improves bacterial killing by phagocytes, which ingest microorganisms and other cell and foreign particles in the body.

Antibiotic and Antifungal Therapy

While many of types of PI are well controlled by replacement therapies, individuals can still experience recurrent bouts of infections, especially during the winter months of the year. For this reason, many individuals affected by PI are on numerous courses of antibiotics or antifungal medications throughout the year, depending on the types of infections experienced.

Gene Therapy

Gene therapy is being researched as a treatment for some types of PI for which the defective gene has been identified. With this treatment, a normal copy of the defective gene is inserted into the cells of the patient to correct the inherited gene defect. Gene therapy has shown some success in the treatment of ADA deficient SCID and X-linked SCID. There is great potential, as well as some risks involved in gene therapy, which must still be regarded as an experimental therapy whose “kinks” have not been completely worked out. It is hopeful that one day gene therapy will be the procedure of choice for some of the more serious types of PI.

Additional information about specific medical therapies for PI is available in the *IDF Patient & Family Handbook for Primary Immunodeficiency Diseases - 5th Edition* or on the IDF website: www.primaryimmune.org/treatment-information/.

Chapter 3 – Special Considerations in the School Setting



Susceptibility to Infection

Even with regular medical treatment, frequent infection is a possibility in students with primary immunodeficiency diseases (PI). They are more susceptible to developing an infection and tend to become more ill than their classmates when an infection develops. Individuals with PI who have developed an infection are no more contagious than those with normal immune systems with a similar infection.

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 and water before meals, after outings and after using the restroom, should become routine. When soap and water are not available, alcohol-based hand gels are an effective alternative. Individually wrapped and disposable hand wipes are excellent for school lunches and for outings. For younger students, periodic washing of toys may be beneficial.

It is important to note that some germs carried by classmates can be harmful to students with PI. Classmates with an illness should also use good hand hygiene and use a tissue when sneezing, coughing or blowing noses.

Situations that must be handled with care:

- Signs of illness expressed by the student or noticed by the teacher or other faculty member should be brought to the nurse's attention immediately. Parents need to be contacted to ensure that appropriate care is provided.
- Outbreaks of communicable diseases should be reported to the student's parents as soon as possible. Primary concerns are chickenpox, influenza, meningitis, MRSA, hepatitis and measles.
- Cuts or other wounds should receive immediate first aid treatment by the nurse. Parents need to be alerted about the incident so they can continue proper care at home.

Absenteeism

Students with PI often miss more school than their classmates. These absences are typically a result of illness, side effects from medication, regularly scheduled treatments, and appointments with healthcare providers.

If the student expects to have multiple absences or a concern arises about the number of days missed by a student, a meeting with the family and school will be important to identify how to meet the academic needs of the student. Establishing a Section 504 Plan or an Individualized Education Plan (IEP) may be helpful in this case. A 504 Plan, named for Section 504 of the Rehabilitation Act of 1973, is a written document developed by the educational team, including the parents and student (if appropriate), and relevant school personnel to provide accommodations and modifications that can help a student with a disability succeed in school. An IEP is a written document developed for a student, ages 3 to 22, 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, school personnel and students (when appropriate) to work together to improve educational results for the student and is reviewed at least once per year. 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 IEP. Homebound services may also be an option that should be discussed at this time. Additional information about these plans and possible accommodations and modifications *are included in Chapters 4, 5 and 6 of this guide.*

Frequent absences are not just a concern in regards to missed instruction and assignments, but they can be a source of major distress to students when they miss socializing with their peers. Some children worry that their friends have forgotten about them or do not like them anymore. It may be important for parents and school personnel to find ways to ease the child's anxiety during extended absences and about returning to their friends and school.

It is the responsibility of the parents and students to become familiar with the attendance policy and work with the school to follow the policy or a written plan developed with the school if increased absenteeism is an issue.

Vaccinations

Students receiving regular immunoglobulin (Ig) replacement therapy, either intravenously or subcutaneously, for their PI are protected from infection by the antibodies contained in the Ig and should not need, and probably would not respond to, any commonly used or required vaccinations (live or killed vaccines). Similarly, individuals receiving Ig replacement would not be susceptible to contracting infection from someone else that recently received a live vaccine. The one exception is the influenza virus, because Ig products do not contain antibodies to the current year's strain of influenza. If there are cases of influenza in the school or if the student with PI is suspected of having contracted influenza, they should be tested right away and started on a medication called Tamiflu.

Live vaccines can potentially harm some individuals with PI who have severely impaired immune systems. Administering a live vaccine (such as the rotavirus, chickenpox, MMR and intranasal influenza vaccines) to persons with severe types of PI, including SCID, WAS, CID, complete DiGeorge, could result in an infection with the organism in the vaccine which then causes them to contract a serious form of the illness. Individuals with CGD are considered to be safe with all live vaccines except BCG and typhoid fever, and those vaccines are not commonly used in the U.S. and Canada.

Under no circumstances should a student be administered a vaccination without written parental permission. In addition, parents and students should be notified of any vaccination program within the school system even if the student with PI will not be involved. Untreated students with severe types of PI may be at some theoretical risk of contracting infection from another individual who has recently received a live virus vaccination. However, the IDF Medical Advisory Committee has completed a thorough review of the medical literature on this topic and concluded that, in actuality, there are no reported instances of patients with PI acquiring a vaccine virus infection (specifically rotavirus, MMR and chickenpox vaccines) from a recently immunized household contact, with the notable exception of oral polio vaccine which is no longer in use in the U.S. or Canada. The complete article can be viewed at www.primaryimmune.org/immunizations. Specific recommendations for immunization of children and adolescents with PI are included in the following chart.

Chapter 3 – Special Considerations at School

Category and Examples	Recommended	Contraindicated (Should Not Receive)
B-LYMPHOCYTE (HUMORAL) DEFECTS		
<ul style="list-style-type: none"> • Common Variable Immune Deficiency (CVID) • X-Linked Agammaglobulinemia (XLA) • Antibody Deficiencies 	<ul style="list-style-type: none"> • Effectiveness of any vaccine is uncertain 	<ul style="list-style-type: none"> • Oral Polio vaccine • Chickenpox, live influenza (inhaled) • Yellow Fever • MMR
<ul style="list-style-type: none"> • Less severe antibody deficiencies • Selective IgA Deficiency • IgG Subclass Deficiencies 	<ul style="list-style-type: none"> • All vaccines are probably effective • All routine vaccines are recommended • Live viral vaccine other than those contraindicated are probably safe 	<ul style="list-style-type: none"> • Oral Polio vaccine • BCG vaccine • Yello Fever
T-LYMPHOCYTE (CELLULAR) DEFECTS		
<ul style="list-style-type: none"> • Complete DiGeorge Syndrome 	<ul style="list-style-type: none"> • All vaccines are probably ineffective 	<ul style="list-style-type: none"> • Any live vaccine
<ul style="list-style-type: none"> • Combined defects - pre-transplant Severe Combined Immune Deficiency (SCID) and pre-transplant Combined Immune Deficiency 	<ul style="list-style-type: none"> • All vaccines are probably ineffective 	<ul style="list-style-type: none"> • Any live vaccine
<ul style="list-style-type: none"> • Post-Transplant Severe Combined Immune Deficiency (SCID) 	<ul style="list-style-type: none"> • Effectiveness of vaccines depends on degree of immune suppression and reconstitution 	<ul style="list-style-type: none"> • Any live vaccine
Partial defect such as: <ul style="list-style-type: none"> • Most patients with DiGeorge Syndrome • Wiskott-Aldrich Syndrome (WAS) • Ataxia-Telangectasia (A-T) 	<ul style="list-style-type: none"> • Effectiveness of vaccines depends on degree of immune competence 	<ul style="list-style-type: none"> • Any live vaccine
COMPLEMENT DEFICIENCIES		
<ul style="list-style-type: none"> • C3, C4, C2 Deficiencies • Factor B Deficiency 	<ul style="list-style-type: none"> • All routine vaccines are effective • Pneumococcal, meningococcal recommended 	<ul style="list-style-type: none"> • None
PHAGOCYtic FUNCTION DEFECTS		
<ul style="list-style-type: none"> • Chronic Granulomatous Disease (CGD) • Leukocyte Adhesion Defects 	<ul style="list-style-type: none"> • All inactivated vaccines are safe and probably effective • Live viral vaccines are probably safe and effective 	<ul style="list-style-type: none"> • BCG and Salmonella

If for some reason a student with one of the more severe types of PI is not protected by regularly receiving Ig replacement, the parents and student should keep in regular contact with the school to learn if any individuals in the school have recently become ill with a potentially serious infectious illness (such as measles, chickenpox, meningitis, hepatitis, influenza) or have recently received a rarely used live viral vaccine. If this is the case, immediately speak with the healthcare provider and decide whether it is necessary to temporarily remove the student from school or to consider whether anti-viral or anti-bacterial medications are available for either prophylaxis or treatment if the student does become infected.

FluMist is the name given to the intranasal seasonal influenza virus vaccine. It is a live attenuated influenza virus vaccine that is administered by droplets given into the nose. FluMist has an excellent safety record, and there is no direct evidence that it poses a threat to individuals with PI. However, as a live virus, it retains some theoretical risk for patients with defective immunity, and it is the general recommendation that patients with PI not be given live agent vaccines. Similarly, there is only a small chance that the vaccine virus in FluMist will spread from an immunized individual to a close contact, so special precautions to separate most patients with PI from someone recently immunized with FluMist are probably unnecessary.

In the situation where a family member has the most severe immune defect (an infant with untreated SCID), IDF recommends that exposure to anyone who has been recently immunized with FluMist, chickenpox or rotavirus vaccine be restricted until more experience is acquired with this unusual circumstance to better understand the potential risk.

The key to preventing the spread of influenza among contacts in the home, school or workplace is widespread immunization and the development of herd immunity to limit the amount of virus in the environment. IDF recommends that in families with someone who has PI, all members of the family group should be immunized each year with the inactivated influenza vaccine.

In the event that a student is unable to receive immunizations required by state law for entry into the school system, appropriate documentation from the student's healthcare provider must be submitted to the school.

Emotional and Social Issues

The challenge of living with a chronic illness such as PI 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 more serious psychological concerns. This recognition and awareness can help the student and family seek appropriate interventions in a timely manner.

The school nurse, social worker, counselor, case manager and teacher can assist with the psychosocial and academic needs of the student. If necessary, they can meet with other school personnel, a class or a group of peers to provide information about PI and the student's needs. Of course, it is imperative that permission is given from the parents and student before discussing a medical condition with others.

Students with PI want to be treated like their peers. They do not want to be defined by their illness. It is vital to allow the student to decide whom they want to tell about their condition and when they want to share this information.

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 parent or student should mention it to the teacher immediately.

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

- Before the school year begins, older students might want to write a letter to their instructors. The letter would include information about the student's PI and how it affects their school day. *A sample student letter is included in Chapter 9.*
- Parents should discuss their child's 504 Plan or Individualized Education Plan (IEP) with them at home. *(Additional information about these plans are included in Chapter 6.)*
- Ask your child for input regarding accommodations or modifications to the plan.
- Invite your child to attend a planning meeting. If the student is not interested in attending, encourage input and assure them that you and school personnel support the student.

Chapter 4 – Possible Accommodations and Modifications for Students with PI



For schools to provide an appropriate education for students with primary immunodeficiency diseases (PI), accommodations and modifications may be necessary and can be included in a 504 Plan or 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, which 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. The list is not exhaustive and is dependent on each student's specific diagnosis and recommendations from the student's healthcare provider.

Healthcare

- Nutrition and diet may play an important part in the management of some individuals. Frequent meals or special nutritional needs due to intestinal malabsorption or other associated nutritional disorder may be required.
- Special restroom privileges due to gastrointestinal complications associated with some types of PI may be required. The student will be given a hall pass to keep at all times.
- Hall passes or visits with the school nurse may be needed for medication administration during school hours. The student will be given a hall pass to keep at all times.
- Physical limitations might prevent a student from participating in certain physical education activities. For example, many children with PI have chronic ear infections, which may limit them from participating in swimming class as part of a physical education program.
- The student is allowed to bring a water bottle to school and drink from it when desired.
- A private room is provided for the student at boarding school.
- The student has the opportunity to discretely move to another seat if a nearby classmate is ill.

- Students with PI may experience fatigue which may limit stamina. This fatigue may wax and wane over the course of the school year. A rest period in the nurse's office might be necessary. Another option would be to schedule a study period at the beginning or end of the day. When fatigue is an issue, attendance in the study period would be waived pending parental permission.
- Outbreaks of communicable diseases should be reported to the student's parents as soon as possible. Primary concerns are chickenpox, influenza, meningitis, MRSA, hepatitis and measles.
- Signs of illness expressed by the student or noticed by the teacher or other faculty member should be brought to the nurse's attention immediately. Parents need to be contacted to insure that appropriate follow-up care is provided.
- Cuts or other wounds should receive immediate first aid treatment by the nurse. Parents need to be alerted about the incident so they can continue proper care at home.
- The student is provided with a space near the nurse's office that will not be used for children with visible illnesses. This space is reserved for rest or taking medication.
- The student is allowed to stay in the nurse's office and return to class when possible or call parents if unable to remain at school.
- The student is allowed to keep hand sanitizer in their desk or locker and use it when appropriate.

Absenteeism

- The school provides two sets of textbooks, one for home and one for school. If an additional set of textbooks is not available, provide a photocopy of the chapter or book.
- Shorten assignments to focus on mastery of important material.
- Extend assignment deadlines or postpone a test date.
- When a lecture is missed, provide a copy of the notes or a recording of the lecture.
- Develop a procedure for the student to receive missed assignments in a timely manner. Perhaps, the parent or student calls or sends an e-mail to the case manager, and each teacher early enough in the day to allow assignments to be collected and picked up at school or sent to the parents or student via e-mail.
- Participation points may not be denied when the student is absent and will not be held against the student at grading time. The instructor has the option of assigning an additional, meaningful assignment based on the material missed or automatically awarding the points.
- Provide an opportunity for the student to make up missed lab assignments and view videos presented during an absence. The teacher and student should mutually agree upon a time. The student should not miss opportunities to participate in recess or social activities. If possible, arrange for a parent to supervise the student while the assignment is completed at home.
- Provide the student with homebound instruction (based on state law) if absences become problematic.
- Technology-based learning opportunities may be used to replace or supplement classroom experiences when student health limits attendance. Technology-based opportunities may include online video conferencing between the classroom and a student's home, taped lessons to be watched or listened to by the student, online courses for credit, and online tutoring programs in specific subjects.

Chapter 5 – 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 diseases (PI). Parents, students, and school personnel should be aware of the laws that ensure equal opportunities to individuals with disabilities for the following reasons:

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

This section provides an overview of some federal laws that protect students with disabilities in the educational setting.

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, such as the Department of Education (ED). Individuals with disabilities are defined as persons with a physical or mental impairment, which substantially limits one or more major life activities.

In the education setting, Section 504 entitles students with disabilities to receive an equal opportunity to participate in academic, nonacademic, and extracurricular activities. In addition, this law requires school districts, K through grade 12, to identify students with disabilities and to provide them with a free appropriate public education (FAPE). To be appropriate, educational programs for students with disabilities must be designed to meet their individual needs to the same extent that the needs of nondisabled students are met. An appropriate education may include regular or special education and/or related aids and services needed in order to accommodate the unique needs of individuals with disabilities.

Section 504 describes a process for schools to use in 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.

A student does not need to qualify for special education services under IDEA, the Individuals with Disabilities Education Act, to receive accommodations or other educational services under Section 504.

Additional information about Section 504 of the Rehabilitation Act of 1973 is available at the following website: www2.ed.gov/about/offices/list/ocr/504faq.html#introduction.

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

The ADA is civil rights law for individuals with disabilities. Unlike Section 504, the ADA applies to public and private schools, although private schools affiliated with a religious organization not receiving federal funds are exempt. However, laws have been created in some states to address disabilities in religious schools.

According to the legal definition from the Americans with Disabilities 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 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.

It is important to remember that each individual is different, and a diagnosis of PI does not ensure that everyone will be identified as an individual with a disability.

Additional information about the Americans with Disabilities Amendments Act of 2008 is available on the U.S. Department of Education website: www2.ed.gov/about/offices/list/ocr/docs/dcl-504faq-201109.html.

Individuals with Disabilities Education Act (IDEA)

IDEA is our nation's special education law. Congress originally enacted it in 1975 to ensure that children with disabilities have the opportunity to receive a free appropriate public education, just like other children. The law 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

Chapter 5 – Educational Rights under Federal Law

A diagnosis from a doctor or mental health professional alone is not enough to qualify for special education services. Eligibility for special education services under IDEA is a two-pronged process. The team of qualified professionals and the parent must determine that the student meets both of these criteria in order to be eligible for special education services:

- **Prong One:** The student must be determined to have one (or more) of the 13 disability areas listed in the IDEA; and
- **Prong Two:** The student must, as a result of that disability, need special education in order to make progress in school and in order to receive benefit from the general educational curriculum.

Part B of IDEA: Services for School-Aged Children

Part B ensures that all children (ages 3 to 22) with a disability will have available to them a free appropriate public education (FAPE) that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living. The Office of Special Education Programs (OSEP) in the office of Special Education and Rehabilitative Services (OSERS) in the U.S. Department of Education oversee IDEA.

To fully meet the definition as a *child with a disability*, a child's educational performance *must be adversely affected* due to the disability. A child with a chronic health condition may qualify for services under the category *other health impairment* if the condition adversely affects the child's educational performance.

IDEA requires school districts to identify all students with disabilities and to provide them with a free appropriate public education (FAPE). 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 Educational Program (IEP). The IDEA regulations specify how school personnel and parents work together to develop and implement an IEP. Additional information about IEPs is included in the Educational and Healthcare Plans section of this guide.

No Child Left Behind Act (NCLB)

The No Child Left Behind (NCLB) Act, Public Law (PL) 107-110, was enacted in 2001. NCLB was an important piece of legislation for all families, including those with children with disabilities. The main themes of the law are accountability for results, emphasis on doing what works based on scientific research, increased parental options, and increased local control and flexibility.

Since 2001, the U.S. Department of Education has offered each state educational agency an opportunity to request flexibility regarding specific requirements of the NCLB Act of 2001 in exchange for rigorous and comprehensive state developed plans designed to improve educational outcomes for all students, close achievement gaps, increase equity and improve the quality of instruction.

Since children with disabilities are included in statewide testing and accountability measures, it is important for parents to be aware of their rights and the intersection of No Child Left Behind and the Individuals with Disabilities Education Act (IDEA). Information about the No Child Left Behind Act is available at the U.S. Department of Education website: www2.ed.gov/nclb/.

Family Education 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 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 does not allow schools to disclose personal identifiable information, without obtaining consent, to school personnel who have a legitimate educational interest for the child. FERPA also allows parents of students, or students 18 and older, to inspect and review the student's educational records. Additional information about the Family Education Rights and Privacy Act is available at the U.S. Department of Education website: www2.ed.gov/policy/gen/guid/fpco/ferpa/.

Chapter 6 – Selecting and Developing a Plan



Some students diagnosed with primary immunodeficiency diseases (PI) may need a written 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. This section provides information about the following plans.

- Section 504 Plan (504 Plan)
- Individualized Education Program (IEP)
- Individualized Healthcare Plan (IHP)
- Emergency Care Plan (ECP)

Section 504 Plan (504 Plan)

A 504 Plan is a written document developed by the educational team, including the parents and student (if appropriate), and relevant school personnel to provide accommodations and modifications that can help a student with a disability succeed in school. The plan will keep everyone informed of the student’s needs and includes accommodations not readily available to students without disabilities. Developing a procedure that allows the student to keep up with assignments due to absenteeism is one example of an accommodation that might be listed in a 504 Plan for a student with PI.

A student does not need to receive special education services to be eligible for services under Section 504. However, it will be necessary to prove that the student has a disability, and accommodations will be required in order for the student to receive an education equal to their classmates. *A sample 504 Plan is included in Chapter 10. Please note—this does not mean that the student needs to apply/qualify for disability benefits provided by the Social Security Administration. It simply means that the individual fits the ADA’s legal definition of having a disability listed on page 17.*

Chapter 6 – Selecting and Developing a Plan

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

Steps to Obtaining a 504 Plan

Parents 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 will be sent to the 504 Coordinator. If your school does not have a 504 Coordinator, find out who should receive the request. In some situations, the responsible person might be a school counselor. *A sample letter is included in Chapter 9.*

- School personnel at the meeting might include the 504 Coordinator, counselor, social worker, principal, classroom teacher(s), school nurse and/or special education teacher.

2. Prepare for the meeting by compiling the following information:

- Copy of the written request for a 504 Plan.
- A completed copy of the Meeting/Conference Planner located in Chapter 10 of this guide.
- Letter from your child's healthcare provider, which lists the medical condition, treatment/medication and recommendations for accommodations/modifications. *A sample letter is included in Chapter 9.*
- Copies of the following IDF publications.
 - *Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency Diseases*
 - Chapter from the *IDF Patient & Family Handbook for Primary Immunodeficiency Diseases - 5th Edition* that describes your child's specific type of PI.
 - *Our Immune System*, a children's storybook, provides an easy to understand explanation of immune system function.
 - Is It Just an Infection? Poster.

3. Request a copy of the plan. If a 504 Plan is developed, you will need to sign the plan before it can be implemented. Ask when you will receive the copy. When you receive and review the plan, and if you agree with the accommodations, sign and return it. Keep a copy for yourself. If you do not receive a copy of the plan by the expected date, contact the responsible person in writing.

Your child's 504 Plan should...

- List the necessary accommodations that will be provided.
 - Identify the school personnel responsible for ensuring that the accommodations are provided.
 - Be distributed to relevant school personnel by the 504 Coordinator/Guidance Counselor/responsible school personnel. A copy should also be readily available for substitute teachers.
 - Be filed in your child's school record.
 - Be updated as your child's needs change throughout the school year, if the child transfers to a different school and before the beginning of a new school year.
- 4. Develop a communication plan** with the 504 Coordinator and teachers. Communication should be ongoing to report progress or issues. It can take place via e-mail, phone, letters/notes or in-person meetings based on the preference of members of the 504 team.

Managing Concerns Regarding a 504 Plan

- 1. Contact the teacher.** The teacher is probably the person responsible for delivering the accommodations or modifications. There might be a misunderstanding or other reason why the 504 Plan is not being followed. If the issue cannot be resolved with the teacher, proceed to the next step. Document the outcome of your communication with the teacher in your records. Also, send an e-mail or letter to the teacher outlining your discussion.
- 2. Contact the 504 Coordinator or School Counselor.** The 504 Coordinator or school counselor, whichever one manages your child's 504 Plan, should be aware of your child's needs. If parts of your child's 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. It is a parent's right to file a complaint with the school district 504 Coordinator, and the coordinator will investigate the allegations regarding Section 504. If progress is not made, contact the principal.
- 3. Contact the principal.** Explain that you have met with the teacher and 504 Coordinator to discuss how some of the accommodations or modifications on your child's 504 Plan are not being followed. Tell the principal that you are not confident that the plan will/can be followed. List the reasons why you believe the plan will not be followed and submit your request, in writing, for what needs to be done based on your conversation with the teacher and 504 Coordinator and your child's needs. Agree upon a time period to follow up regarding the accommodations/modifications being followed. Follow up with the principal in writing outlining your conversation.
- 4. Talk to your state Parent Training & Information Center (PTI).** Although the 504 Plan falls under federal and not state law, advocates in your area may be familiar with how schools have succeeded with 504 Plans in the past. You should be able to call your local Parent Training & Information Center and discuss your problem with an advocate or staff member who has experience working with school districts in your area. Find your local Parent Training & Information Center at www.parentcenterhub.org/find-your-center/.
- 5. Contact the U.S. Department of Education Office of Civil Rights.** If you have not made progress with your local school district after following the steps outlined above, contact the U.S. Department of Education Office of Civil Rights at <https://wdcrobcolp01.ed.gov/CFAPPS/OCR/contactus.cfm>.

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

Chapter 6 – Selecting and Developing a Plan

Individualized Education Program (IEP)

An Individualized Education Program (IEP) is a written document developed for a student, ages 3 to 22, 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, 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 team (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 requires special education and related services to benefit from the general education program.

The IEP team must include the following members:

- Parent
- Student (if appropriate)
- General education teacher(s)
- Special education teacher
- School system representative (Local Education Agency representative)
- Individual who can interpret the evaluation results
- Others with knowledge about the student
- Anyone the parent would like to invite to the meeting

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

- General education curriculum
- Extracurricular activities
- Nonacademic activities

Steps to an IEP

The IDEA (Individuals with Disabilities Education Act) mandates that the following ten specific steps that must be followed to create an IEP.

- 1. Need is identified.** A parent or school can request an evaluation for a child believed to have a disability. (If the school initiates this step, they must have parental permission before an evaluation begins.) Parents should send a written request to the teacher or other school personnel requesting an evaluation to determine whether your child qualifies for special education services. *A sample letter requesting an evaluation for special education is included in Chapter 9.*

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

- Copy of the written request for an IEP with a list of suggested accommodations.
- Letter from your child's healthcare provider, which lists the medical condition, treatment/medication and recommendations for accommodations/modifications. *A sample letter is included in Chapter 9.*
- Older students might want to write a letter to their instructors. The letter would include information about the student's PI and how it affects their school day. *A sample letter is included in Chapter 9.*

- Copies of the following IDF publications:
 - *Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency Diseases.*
 - Chapter from the *IDF Patient & Family Handbook for Primary Immunodeficiency Diseases - 5th Edition* that describes your child's specific type of PI.
 - *Our Immune System*, a children's storybook, provides an easy to understand explanation of immune system function.
 - Is It Just an Infection? Poster.

2. Evaluation occurs. If it is determined that an evaluation should be completed, the evaluation results will include the following information.

- Determination regarding whether the student has a disability that requires special education and related services
- Information about the child's specific educational needs
- Specific special education services and related services, which will be implemented and are appropriate for addressing the student's needs

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

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 the IDEA. The parents have the right to request a hearing if they do not agree with the decision.

4. Student is eligible for service. If the student is determined to be eligible for special education services, a team meeting (which includes the parent, general education teacher, special education teacher and LEA (local education agency), must be scheduled within 30 days to write the IEP. However, parents can waive this 30 day time line and roll 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.
- Notify parents in a timely manner to make sure they have an opportunity to attend.
- Schedule the meeting at a time and place agreeable to parents and the school.
- Notify the parents regarding the purpose, time, and location of the meeting.
- Tell the parents who will be attending the meeting.
- Tell the parents that they may invite people to the meeting who have knowledge or special expertise about the child.

6. IEP meeting occurs, and IEP is written. The IEP team, which includes the parents 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 child's progress and capability to be involved in the general curriculum. Extracurricular and nonacademic activities refer to school activities that fall outside the realm of the general curriculum.

Chapter 6 – Selecting and Developing a Plan

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 NOT PARTICIPATING with children without disabilities.
- Modifications necessary when state or district-wide tests are given, or explanation of why taking the tests is 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.
- 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.

The 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 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 still disagree, they can request mediation. Mediation may also be offered by the school. Parents may also file a complaint with the state education agency or a due process complaint, which is a letter filed by an individual or organization on matters of conflict related to the identification, evaluation, or educational placement of a child, or the provision of a free appropriate public education (FAPE) to the child. This is the first step in requesting a due process hearing where mediation must be available.

- 7. Special education services are provided.** The school assures that the student's IEP is followed as it was written. Parents receive a copy of the IEP. All of the child's teachers and service providers has access to the IEP and understands their responsibilities for carrying out the IEP. This includes the accommodations, modifications, and supports that must be provided to the student based on the IEP.
- 8. Progress reports** are shared with the parents at least as often as they are shared with parents of children not receiving special education services.
- 9. Review of IEP.** The IEP team, which includes the parents and student (if appropriate), reviews the IEP at least once a year and whenever necessary throughout the year when requested by the parents or IEP team.
- 10. Reevaluation of student** must occur every three years to determine if special education services are required. However, some state timelines may be different (a re-evaluation must take place every two years for students identified with an intellectual disability in the state of Pennsylvania). The parents or school can request a reevaluation more often than every three years.

If parents 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: www.directionservice.org/cadre/about.cfm.

Additional information about IEPs is available through your local school district or at the Center for Parent Information and Resources website: www.parentcenterhub.org.

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

Both Section 504 Plans and an IEP are legal documents between parents and the schools. However, an IEP, or special education, has a due process clause should misunderstandings arise.

If a child only needs related services and not special education services, the child would not be eligible for services under IDEA. However, it is important to note that this child might still be eligible for services under Section 504.

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/related services.

A student with a 504 Plan is able to make effective progress in school without specialized instruction/related services. However, this student requires accommodations in order to gain equal access to the instruction or facility. A 504 Plan will provide accommodations that allow the student with a disability/impaired major life activity to receive the same access to instruction, school activities and facilities as students without disabilities.

Individualized Healthcare Plan (IHP)

The 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 healthcare conditions.

The IHP is developed by the professional school nurse in collaboration with the parents, student (if appropriate), relevant school personnel and the student's healthcare provider. The plan ensures quality, comprehensive care of the student's healthcare 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 of the Rehabilitation Act of 1973 or special education.

Students with specialized healthcare needs may need an emergency care plan (ECP) in addition to an IHP. An IHP may be included in an Individualized Education Program (IEP) or 504 Plan. *A sample IHP is included in Chapter 10 of this guide.*

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.

The ECP is developed by a professional school nurse, the student (if appropriate), parents, relevant school personnel, the student's health provider, hospital emergency department and community first responders. 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.

The American Academy of Pediatrics (AAP) provides sample and blank emergency care forms. They refer to "ECP" as emergency information forms. The forms are available at: www.aap.org/advocacy/emergprep.htm.

Chapter 7 – Managing Transitions



A New School Year

Before the school year begins, parents of students with primary immunodeficiency diseases (PI) should schedule a time to meet with their child's new teacher(s). If the child has a 504 Plan or an Individualized Education Plan (IEP), the 504 Coordinator/Case Manager and other relevant school personnel will also attend the meeting. A copy of your child's 504 Plan or IEP will be shared with all attending.

Parents will want to be prepared to share the following information:

- Letter from your child's healthcare provider, which lists the medical condition, treatment/medication and recommendations for accommodations/modifications. *A sample letter is included in Chapter 9.*
- Older students might want to write a letter to their instructors. The letter would include information about the student's PI and how it affects their school day. *A sample letter is included in Chapter 9.*
- Copies of the following IDF publications:
 - *Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency Diseases.*
 - Chapter from the *IDF Patient & Family Handbook for Primary Immunodeficiency Diseases - 5th Edition* that describes your child's specific type of PI.
 - *Our Immune System*, a children's storybook, provides an easy to understand explanation of immune system function.
 - Is It Just an Infection? Poster.

If appropriate, you may want to include your child in the meeting.

A New School District

If the child 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 should get information from the current IEP team regarding 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 child is enrolled in the new school.

If the child has a 504 Plan, the process to initiate a new 504 Plan will need to be followed.

Parents will want to be prepared to share the following information:

- Copy of the IEP or 504 Plan from the previous school district.
- Contact information for the individual responsible for managing the plan in the previous school.
- Copy of your letter requesting a meeting.
- Letter from your child's healthcare provider, which lists the medical condition, treatment/medication and recommendations for accommodations/modifications. *A sample letter is included in Chapter 9.*
- Older students might want to write a letter to their instructors. The letter would include information about the Student's PI and how it affects their school day. *A sample letter is included in Chapter 9.*
- IDF has developed a series of Transition Skills Checklists, which can help children, ages 12 and up, learn about their care and transition to taking on more responsibility. Download the checklists at www.primaryimmune.org/teens/more-resources/.
- Copies of the following IDF publications:
 - *Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency Diseases.*
 - Chapter from the *IDF Patient & Family Handbook for Primary Immunodeficiency Diseases - 5th Edition* that describes your child's specific type of PI.
 - *Our Immune System*, a children's storybook, provides an easy to understand explanation of immune system function.
 - Is It Just an Infection? Poster.

Returning to School after an Extended Absence

It is essential to help children stay connected to their classmates during extended periods of absence. Parents, the classroom teacher, school counselor and other school personnel can work together to make the transition back to school easier. Inviting friends to visit the child's home or hospital will help keep your child connected to peers, and don't forget about linking to the classroom or classmates via Skype, FaceTime or other technology.

At the end of an extended absence, it is important to work with the teacher or other school personnel to prepare everyone for the child's return to school.

Preparing for Post-Secondary Education

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 if 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 self-advocates include:

- Learning about their type of PI
- Learning the name, dose and purpose of medications
- Knowing which staff person to contact and how to contact the individual if they have concerns
- Telling school personnel when feeling 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, healthcare providers and school personnel and with advance planning, the transition into adulthood can be an exciting time.

Chapter 8 – Post-Secondary Education



Many high school students with primary immunodeficiency diseases (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 the student has the opportunity to enjoy the benefits of the education experience without confusion or delay.

For students who had an Individualized Education Plan (IEP) in high school, it is important to know that 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 Americans with Disabilities Act of 1990. These laws prohibit post-secondary schools from searching for information about a student's disability status and ensure that students will not be discriminated against during the admissions process and in all areas of programming due to a disability.

Although post-secondary schools are required to comply with the Section 504 law, there are significant differences in the responsibilities of secondary 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, also known as an academic adjustment.

Most individuals with PI do not view themselves as having a disability. However, if a student with PI wants the school to provide an academic adjustment, they must “identify” themselves as having a disability. **Please note—this does not mean that the student needs to apply/qualify for disability benefits provided by the Social Security Administration. It simply means that the individual fits the ADA’s legal definition of having a disability.**

What is a disability?

According to the legal definition from the Americans with Disabilities Act of 1990 (ADA), including changes made by the ADA Amendments Act of 2008 (ADAAA), a disability is:

- 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 upon whether the student is requesting accommodations or special services.

If a student chooses to disclose their PI, the school will probably request documentation that proves the diagnosis and the accommodations or services you are requesting. Possible documentation might be a letter from your healthcare provider in addition to other documentation required by the school. There may be differences between the required documentation and how accommodations or services are provided at each school, but the ultimate goal is that the student receives the same educational opportunity as others.

Appropriate adjustments will be made based on the student’s individual needs. Examples of academic adjustments are:

- Providing note takers due to an absence caused by illness
- Extended time for completion of assignments or testing due to an absence caused by illness

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 acquiring an academic adjustment should contact the Office of Disability Services, or applicable department, during the campus visit and upon being accepted to discuss your accommodations and how they might be provided.

The Office of Disability Services will not disclose the name of your condition. The information shared with your instructors simply states, “chronic health condition.” If you choose not to disclose that you have a chronic health condition and you do become ill, it will be important to notify your instructors immediately. They understand that illness happens and will typically work with you as long as you have made the effort to communicate with them.

A student who meets the essential requirements for admission to a post-secondary school may not be denied admission based upon a disability.

The Office of Civil Rights (OCR) division of the U.S. Department of Education publishes a comprehensive guide specifically on “Students with Disabilities Preparing for Post-Secondary Education” that includes the most updated information about this federal law and establishing academic adjustments in a post-secondary school.

For more information and to request a copy of this guide, please go to the OCR Website: www.ed.gov/about/offices/list/ocr/transition.html or call the OCR office at 800-421-3481.

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 on the top of the list. However, for students with PI it is also important to consider healthcare needs. Some factors to consider:

- **Accessibility to medical providers with knowledge about PI.** Once the list of post-secondary schools has been narrowed down, students will want to discuss healthcare options with their current medical team. Depending upon how far school is from the current medical team, a transition of care might be necessary. If so, the current medical team will probably know a provider familiar with PI in the area and assist in the transition of care. IDF can also help with physician location. Contact IDF at www.primaryimmune.org/services/ask-idf/ or 800-296-4433.
- **Support for students.** All post-secondary schools have the ability to provide accommodations and support. However, some schools will offer more staff and resources for students with disabilities. During campus visits, visit with the Office of Disability Services and 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 drug will need to make arrangements for their product 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 and 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 primary immunodeficiency 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 the 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 always be necessary for students relocating or going away to school to change 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 your 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 care and transition to the new provider.

For students receiving infusions or injections in a clinic or outpatient hospital setting, it will be key to coordinate the 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 might want some students with PI to have a private room. 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 will probably enable students to walk to classes, libraries, and cafeterias. Time and money isn't wasted on riding a bus or driving to school, finding a parking space and consequently avoiding the stress that a commute can create. Lowering stress is always good for physical and emotional well-being.
- **Social Life** – Students living on campus will be around more people and have more opportunities to make friends. On-campus living offers residential advisors (RAs) that are older students. The RA's 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.

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.

No matter where you choose to live, it is vitally important to keep good records. The IDF ePHR is an online personal health record specifically for the PI community. Use it to organize all your health records in one place. Conveniently access your health records from your computer, tablet or smartphone to track your medical activities. Your information is safe, secure and private and there is no cost to you. Information about IDF ePHR is available at www.idfephr.org.

Chapter 9 – Sample Letters



- Sample Accommodation Letter from Healthcare Provider
- Sample Letter Requesting Meeting with School Personnel
- Sample Letter Requesting a Planning Meeting to Develop a 504 Plan or an Individualized Healthcare Plan (IHP) or Request an Assessment to Determine Eligibility for an Individualized Education Program (IEP)
- Sample Student Letter to School Personnel

Sample Accommodation Letter from Healthcare Provider

<Medical Facility Letterhead>

<Date>

To Whom It May Concern:

_____ has been diagnosed with _____, which is a primary immunodeficiency disease (PI), a group of over 220 different rare disorders. While not contagious, these diseases are caused by hereditary or genetic defects, in which part of the body's immune system is missing or functions improperly.

PI is a chronic illness, and even with regular medical care and treatment with _____, this student's educational performance might be impacted by an increased risk of illness.

Therefore, the following accommodations are recommended. (Possible accommodations are listed in the Immune Deficiency Foundation School Guide 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 Meeting with School Personnel

(Send via email, postal mail or deliver in-person)

<Date>

Dear <School Staff Person>,

My child, <first and last name>, is diagnosed with a primary immunodeficiency disease (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> 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>

<Address>

<Address>

<Phone>

<Email Address>

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

(Send via email, postal mail or deliver in-person)

<Date>

Dear <School Staff Person>,

My child, <first and last name>, is diagnosed with a primary immunodeficiency disease (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> 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 or an Individualized Healthcare Plan (IHP) 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 15 days.

Sincerely,

<Signature>

<Name: First & Last>

<Address>

<Address>

<Phone>

<Email Address>

Sample Student Letter to School Personnel

(Send via email, postal mail or deliver in-person)

<Date>

Dear <Name of Teacher, School Nurse, Administrator>,

I am a student with a primary immunodeficiency disease (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 220 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, IHP> are necessary. Thank you for your understanding and support during these times.

My parents and I will update you throughout the school year if there are changes in my health. Please feel free to contact us anytime 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>

Chapter 10 – Sample Forms



- Meeting/Conference Planner
- 504 Accommodation Plan
- Individualized Healthcare Plan (IHP)

Meeting/Conference Planner

For Parents, Guardians and Students

Use this form to make notes prior to a school conference.

Student First Name

Student Last Name

Meeting Date

My Concerns:

- _____
- _____
- _____
- _____
- _____

My Requests:

- _____
- _____
- _____
- _____
- _____

My Questions:

- _____
- _____
- _____
- _____
- _____

Meeting Outcome/Results:

- _____
- _____
- _____
- _____
- _____

Sample 504 Accommodation Plan

504 Accommodation 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 a major life activity (selfcare, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, working, 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).

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 of 1973.

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

Instructional Accommodations

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

Behavioral/Social Accommodations

Accommodations to Maintain Classroom Behavior

Accommodations to Participate in Desired Extra Curricular Activities

Accommodations to Participate in State/Districtwide Testing

Medications

1.	_____	_____	_____
	Medication Name	Frequency	Side Effect (s)
	_____	_____	
	Start Date	Stop Date	
2.	_____	_____	_____
	Medication Name	Frequency	Side Effect (s)
	_____	_____	
	Start Date	Stop Date	
3.	_____	_____	_____
	Medication Name	Frequency	Side Effect (s)
	_____	_____	
	Start Date	Stop Date	
4.	_____	_____	_____
	Medication Name	Frequency	Side Effect (s)
	_____	_____	
	Start Date	Stop Date	
5.	_____	_____	_____
	Medication Name	Frequency	Side Effect (s)
	_____	_____	
	Start Date	Stop Date	
6.	_____	_____	_____
	Medication Name	Frequency	Side Effect (s)
	_____	_____	
	Start Date	Stop Date	
7.	_____	_____	_____
	Medication Name	Frequency	Side Effect (s)
	_____	_____	
	Start Date	Stop Date	
8.	_____	_____	_____
	Medication Name	Frequency	Side Effect (s)
	_____	_____	
	Start Date	Stop Date	

Physician Name Phone Number

Emergency Information

Individualized Healthcare Plan (IHP)

IHP - Page 1 of 4

School Year _____ to _____

Student First Name Student Last Name Gender Date of Birth Age

School Grade Teacher

Mother First Name Mother Last Name Home Phone Cell Phone

Mother Street Address City State Zip Mother E-mail Address

Father First Name Father Last Name Home Phone Cell Phone

Father Street Address City State Zip Father E-mail 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

Medications

Allergies to Medications

Necessary Healthcare Procedures at School

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.

Healthcare Action Plan

Attach physician's order and other standards for care.

Procedures and Interventions

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

Medications

1. _____	Medication Name	Frequency	Side Effect (s)
	Start Date	Stop Date	
2. _____	Medication Name	Frequency	Side Effect (s)
	Start Date	Stop Date	

Healthcare Action Plan
(Continued)

3.	_____	_____	_____
	Medication Name	Frequency	Side Effect (s)
	_____	_____	
	Start Date	Stop Date	
4.	_____	_____	_____
	Medication Name	Frequency	Side Effect (s)
	_____	_____	
	Start Date	Stop Date	
5.	_____	_____	_____
	Medication Name	Frequency	Side Effect (s)
	_____	_____	
	Start Date	Stop Date	
6.	_____	_____	_____
	Medication Name	Frequency	Side Effect (s)
	_____	_____	
	Start Date	Stop Date	
7.	_____	_____	_____
	Medication Name	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.

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

1.	_____		
2.	_____		
3.	_____		

Glossary of Medical Terms

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

ACUTE: A descriptive term used to describe an illness, which is usually short in duration and of recent onset.

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 cells (B-lymphocytes) 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.

CONGENITAL: Present at birth.

GENE: A unit of genetic material (DNA).

GENE (OR GENETIC) TESTING: Testing performed to determine if an individual possesses a specific gene or genetic trait.

GENE THERAPY: Treatment of genetic diseases by providing the correct or normal form of the abnormal gene causing the disease.

GRAFT-VERSUS-HOST DISEASE: A reaction in which transplanted immunocompetent cells attack the tissue of the recipient.

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

IMMUNOGLOBULINS (Ig): Another name for antibody; there are five classes: IgA, IgD, IgG, IgM, and IgE.

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

INTRAVENOUS IMMUNOGLOBULIN (IVIG): Immunoglobulin therapy injected directly into the vein.

LIVE VACCINES: Live viruses are used in the vaccine; live vaccines (particularly oral polio) can transmit the disease they were designed to prevent in immunocompromised individuals.

MICROORGANISMS: Minute living organisms, usually one-cell organisms, which include bacteria, protozoa, and fungi.

NEUTROPENIA: A lower than normal amount of neutrophils in the blood.

NEUTROPHILS: A type of granulocyte, found in the blood and tissues that can ingest microorganisms.

OPPORTUNISTIC INFECTION: An infection that occurs only under certain conditions, such as in immunodeficient individuals.

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 initiated 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 INFUSION (SCIG): Administration of immunoglobulin in which it is infused slowly directly under the skin with a small pump.

VACCINE: A substance that contains components from an infectious organism which stimulates an immune response in order to protect against subsequent infection by that organism.

Glossary of Educational Terms

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

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

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

DEVELOPMENTAL DELAY: An infant or child is developing slower than normal.

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): Ensures that a plan of action is in place if an emergency situation related to a student's medical condition occurs in the school setting.

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

FREE APPROPRIATE PUBLIC EDUCATION (FAPE): The words used in federal law (IDEA) to describe the right of a student with disabilities to a special education which 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 that provides funds to states to support special education and related services for children with disabilities, administered by the Office of Special Education Programs in the U.S. Department of Education. To be eligible for services under IDEA, a student's disabilities must impair the student's educational performance so 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 child from the regular school environment occurs only when the disability is such that the child cannot be satisfactorily educated in regular classes with the use of aids 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.

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.

PARENT TRAINING AND INFORMATION CENTER (PTI): An information resource for parents 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 course work or vocational/technical training.

SECTION 504 PLAN: A written plan listing accommodations and modifications that enable a student who does not have an IEP to participate fully in the classroom.

VOCATIONAL REHABILITATION: A comprehensive system that assists individuals with temporary or permanent disabilities in the areas of assessment, counseling, training, physical rehabilitation and job placement.

Immune Deficiency Foundation

www.primaryimmune.org, 800-296-4433, idf@primaryimmune.org

Services for Patients and Families

- **Ask IDF:** Contact IDF with questions about living with primary immunodeficiency diseases (PI) through the IDF website: www.primaryimmune.org/ask-idf. IDF has a vast reserve of innovative resources and individualized assistance to help with the unique aspects of living with PI. From learning more about the diseases, to understanding insurance coverage, to lifestyle issues and more, be sure to Ask IDF.
- **Locate a Physician:** Contact IDF to find a physician in your area who is an expert on PI.
- **Peer Support:** Connecting people and patients who share similar relationships to PI.
- **Patient Assistance Resources:** Individualized assistance is available for patients experiencing problems with insurance denials for treatment, reimbursement issues, concerns with Medicare or Medicaid, disability, and accessing copayment and premium assistance. Resources and tools are available to help tackle insurance challenges.
- **Information about Patient Rights:** Patients can contact IDF to learn about their rights concerning product choice and treatment options, employment and school issues, as well as fair treatment, privacy or other rights.
- **IDF ePHR:** An electronic personal health record designed for the PI community to help organize health information in one place.
- **PI CONNECT:** The IDF Patient-Powered Research Network brings together the information patients enter in the IDF ePHR with the United States Immunodeficiency Network (USIDNET) patient-consented registry, which contains clinical data on several thousand patients with PI. PI CONNECT gives patients access to an exclusive research forum to discuss research related to PI.

Programs for Patients and Families

- **Local Education Meetings:** Education programs featuring local experts and networking opportunities.
- **Family Conference Days:** While parents attend educational meetings with local experts, youth enjoy fun, age-appropriate activities and sessions plus time to meet others in the PI community.
- **Get Connected Meetings:** Designed to connect individuals diagnosed with PI and family members in their local communities.
- **Operation Outreach:** Education meetings designed to strengthen underserved areas.
- **IDF Retreats:** Weekend events for all ages that feature medical and life management sessions.
- **IDF Youth Programs:** Designed for children diagnosed with PI or have a family member with this condition.
- **IDF Teen Escape:** Weekend program developed to acquaint teens diagnosed with PI.
- **IDF National Conference:** The world's largest gathering of families affected by PI.
- **Volunteer:** Network of volunteers who provide peer support, create awareness, help host educational meetings, advocate for public policy, visit plasma centers and organize fundraising events throughout the country.
- **Scholarship Program:** Awards for students living with PI who plan on completing their secondary education.
- **IDF Plasma Partners Program:** Awareness and fundraising initiatives within plasma centers across the country arranged by IDF that highlights the work of plasma center staff members, plasma donors and IDF volunteers.

Services for Healthcare Professionals

www.primaryimmune.org/healthcare-professionals

- **IDF Medical Advisory Committee:** Comprised of prominent immunologists to support the mission of the IDF. Available as a resource for clinicians diagnosing and treating patients with PI.
- **IDF Nurse Advisory Committee:** Comprised of exceptional nurses to support the mission of the IDF. Available as a resource for nurses administering immunoglobulin therapy or treating patients with PI.
- **IDF Online Continuing Education Course for Nurses (English): Primary Immunodeficiency Diseases and Immunoglobulin Therapy:** A free, 5-hour, U.S. accredited course for nurses that provides an update on PI, immunoglobulin therapies and the nurse's role with these therapies:
www.primaryimmune.org/healthcare-professionals/continuing-education-course-for-nurses.
- **IDF Video Translations for Nurses (French, German, Spanish): Primary Immunodeficiency Diseases and Immunoglobulin Therapy:** A free, non-credit video series translated into French, German and Spanish. The series is based on the IDF Online Continuing Education Course for Nurses, which provides an update on PI, immunoglobulin therapies and the nurse's role with these therapies: www.primaryimmune.org/healthcare-professionals/idf-video-series-for-nurses.
- **IDF Consulting Immunologist Program:** A free service for physicians which provides consults with expert clinical immunologists on issues of diagnosis, treatment and disease management.
- **United States Immunodeficiency Network (USIDNET):** The United States Immunodeficiency Network (USIDNET) is a research consortium established to advance scientific research in the field of primary immunodeficiency diseases. The current focus of this initiative is on the primary immunodeficiency disease registry, and education and mentoring for young investigators. USIDNET, a program of the Immune Deficiency Foundation (IDF), is funded in part by the National Institute of Allergy and Infectious Diseases (NIAID) and the National Institutes of Health (NIH) an agency of the Department of Health & Human Services. NIAID supports research to advance the understanding of transplantation and to prevent, diagnose and treat infections and immune-mediated illnesses.
- **IDF & USIDNet LeBien Visiting Professor Program:** Promote improved knowledge by providing faculty at teaching hospitals with a Visiting Professor with expertise in PI and offers Grand Rounds and clinical presentations at medical institutions throughout North America.

Publications

All publications can be downloaded and printed at www.primaryimmune.org. Alternatively, you can order a hard copy (if it is available).

For patients and families:

- *IDF Patient & Family Handbook for Primary Immunodeficiency Diseases - 5th Edition*
- *Our Immune System* (Children's Book)
- *Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency Diseases*
- Bill of Rights for Patients with Primary Immunodeficiency Disease
- IDF Presents: In Tune with your Immune System, Battle of the Bands Comic Book

For healthcare providers:

- *IDF Diagnostic & Clinical Care Guidelines for Primary Immunodeficiency Diseases 3rd Edition*
- *IDF Guide for Nurses on Immunoglobulin Therapy for Primary Immunodeficiency Diseases 3rd Edition*
- *Clinical Focus on Primary Immunodeficiencies:*
 - “Chronic Granulomatous Disease”
 - “Clinical Update in Immunoglobulin Therapy for Primary Immunodeficiency Diseases”
 - “Subcutaneous IgG Therapy in Immune Deficiency Diseases”
 - “Primary Humoral Immunodeficiency Optimizing IgG Replacement Therapy”
 - “The Clinical Presentation of Primary Immunodeficiency Diseases”
 - “Treatment and Prevention of Viral Infections in Patients with Primary Immunodeficiency Diseases”
 - “IgG Subclass Deficiency”
 - “Immunization Of The Immunocompromised Host”

Communications and Online Resources

- **IDF ADVOCATE:** Newsletter, published three times per year.
- **Primary Immune Tribune:** E-newsletter, published monthly.
- **IDF Friends, www.idffriends.org:** A social network exclusively for the PI community.
- **IDF Common Ground, www.idfcommonground.org:** An online community for teens with PI.
- **IDF TV, www.primaryimmune.org/idf-tv:** A web-based TV channel that brings issues that affect the PI community to life.
- **IDF Arcade, www.primaryimmune.org/idf-arcade:** Games designed for children ages 4 to 12 that are a great way to have fun, while learning about the immune system.
- **IDF Reel Stories, www.primaryimmune.org/idf-reel-stories:** IDF Reel Stories is a patient-generated video community designed to encourage and empower fellow patients and their loved ones.
- **IDF Blog, www.primaryimmune.org/blog:** Includes updates on IDF programs and services as well as important issues. Users can comment, submit news, and share posts about awareness activities, advocacy initiatives, fundraising events and more.
- **IDF SCID Newborn Screening Blog, www.idfscidnewbornscreening.org:** Documents the fight to establish Severe Combined Immunodeficiency (SCID) newborn screening programs in all 50 states. Babies with SCID appear healthy at birth, but without early treatment, most often by bone marrow transplant from a healthy donor, these infants cannot survive. Testing for SCID is not currently included in the newborn screening panels of all states.

Resources – Public Policy Initiatives

Public Policy Initiatives

- Advocacy efforts monitor public policy issues that are critical to patients at national and state levels, including Medicare Patient IVIG Access Act, SCID Newborn Screening, Health Insurance Ig guidelines and more.
- Grassroots advocacy program mobilizes members of the PI community to contact their government representatives to promote healthcare legislation that will positively affect the community.
- IDF Advocacy Center features Action Alerts, enabling users to easily voice their concerns to decision makers, and the IDF Advocacy Channel, featuring patient and caregiver stories: www.primaryimmune.org/idf-advocacy-center.

Education Resources

Center for Appropriate Dispute Resolution in Special Education (CADRE)

www.directionservice.org/cadre/about.cfm

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

www.parentcenterhub.org

The Center for Parent Information and Resources (CPIR) serves as a central resource of information and products to the community of Parent Training Information (PTI) Centers and the Community Parent Resource Centers (CPRCs), so that they can focus their efforts on serving families of children with disabilities.

HEATH Resource Center at the National Youth Transitions Center

www.heath.gwu.edu

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

U.S. Department of Education

www.ed.gov

The U.S. Department of Education's mission is to promote student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access.

Information about Primary Immunodeficiencies

Immune Deficiency Foundation

www.primaryimmune.org
800-296-4433

The Immune Deficiency Foundation, founded in 1980, is the national non-profit patient organization dedicated to improving the diagnosis and treatment of patients with primary immunodeficiency diseases through research, education and advocacy.

International Patient Organization for Primary Immunodeficiencies

www.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

www.jmfworld.org
866-INFO-4-PI (866-463-6474)

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

Disease Specific Patient Groups and Organizations

A-T Children's Project

www.atcp.org

The A-T Children's Project is a non-profit 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.

Chronic Granulomatous Disease Association

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.

www.haea.org

Founded and staffed by HAE patients and HAE patient caregivers, U.S. Hereditary Angioedema Association, Inc. (US HAEA) is a non-profit 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.

Resources – Disease Specific Patient Groups and Organizations, cont.

Living with CGD – The IDF Resource for the Chronic Granulomatous Disease Community

www.livingwithCGD.org

An IDF website for those living with Chronic Granulomatous Disease (CGD) that provides the latest information and news, and connects members of this rare disease community.

Severe Combined Immune Deficiency

www.scid.net

This site contains information about Severe Combined Immune Deficiency (SCID) with links to journal articles, latest research developments and patient support.

SCID Angels for Life

www.scidangelsforlife.com

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

Understanding XLP

www.xlp.ca

This site provides families and patients with X-linked Lymphoproliferative Disorder (XLP) a means of communication.

Wiskott-Aldrich Foundation

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.

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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