

IDF School Guide

Information
about Students
with Primary
Immunodeficiency
Diseases



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.

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SECOND EDITION

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40 West Chesapeake Avenue • Suite 308 • Towson, Maryland 21204 • www.primaryimmune.org • idf@primaryimmune.org
(800) 296-4433 • (410) 321-6647 • fax (410) 321-9165

In the United States, approximately 250,000 people are diagnosed with a primary immunodeficiency disease. Thousands more go undetected. These diseases are chronic illnesses caused by hereditary or genetic defects in which part of the body's immune system is missing or does not function properly. Due to advances in treatment, most children diagnosed with a primary immunodeficiency disease are able to attend school, learn and socialize.

The Immune Deficiency Foundation (IDF) originally developed A Guide for School Personnel, Primary Immune Deficiency Diseases in 2005 in response to parents wanting 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 primary immunodeficiency diseases and associated special needs, legal rights of children with chronic disease and resource referrals. This second edition, renamed IDF School Guide, Information about Students with Primary Immunodeficiency Diseases, adds updated and expanded information on all these topics, as well as a glossary of medical and educational terms that should be helpful to school personnel and parents alike.

Primary immunodeficiency diseases affect each person differently with varying degrees of severity. Some children with a primary immunodeficiency disease will not experience any difficulties at school due to their particular condition and will not need any accommodations. Other children, with more substantial health concerns will need more assistance in the school setting. The information in the IDF School Guide should be used to fit each student's individual needs.

Perhaps most importantly, this guide can help facilitate effective communication between parents and school system personnel, including administrators, teachers and nurses. Meetings are crucial to ensure the health and well-being of children in the school setting and this publication is designed to serve as a basis for discussions at meetings. Used in conjunction with information on a student's specific diagnosis, personal medical history and current treatment, this guide will be a valuable reference throughout the school year.

Contributors/Editors

IDF School Guide

Daniel C. Antilla, MA

*Independent School District 15
St. Francis, MN*

Katherine A. Antilla, MAEd

*Immune Deficiency Foundation
Towson, MD*

Christine M. Belser

*Immune Deficiency Foundation
Towson, MD*

R. Michael Blaese, MD

*Immune Deficiency Foundation
Towson, MD*

Margaret Dodds, RN, MS, CPNP

*Texas Children's Hospital
Houston, TX*

John W. Seymour, PhD, LMFT

*Mankato State University
Mankato, MN*

Tarea Stout, MS, LPC

Madison, MS

Bradley J. Wing, MA

*Intermediate District 287
Plymouth, MN*

About the Immune Deficiency Foundation

One of the greatest challenges faced by individuals diagnosed with primary immunodeficiency disease is finding the right information and resources when they need it. With knowledge and foresight from their personal experience, the Immune Deficiency Foundation (IDF) was founded by families of children with primary immunodeficiency diseases and their physicians to help meet those needs. It is with the spirit and energy of this keen perspective that IDF exists today, thriving as an organization dedicated to individuals living with primary immunodeficiencies.

The Immune Deficiency Foundation is the national non-profit patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research. Since 1980, IDF has provided accurate and timely information for the nearly quarter-million Americans who have been diagnosed with a primary immunodeficiency disease. Governed by a Board of Trustees, and supported by a Medical Advisory Committee comprised of some of the world's leading clinical immunologists, as well as hundreds of grassroots volunteers and a compassionate,

professional staff, IDF has provided individuals and their families with vital knowledge and has made tremendous strides in:

- Helping the patient and medical communities gain a broader understanding of primary immunodeficiency diseases through education and outreach efforts.
- Addressing patient needs through public policy programs by focusing on issues such as insurance reimbursement, patient confidentiality, ensuring the safety and availability of immune globulin therapy, and maintaining and enhancing patient access to treatment options.
- Promoting, participating, and funding research that has helped characterize primary immunodeficiency diseases and given patients and physicians substantially improved treatment options.

Today, thousands of individuals and families affected by primary immunodeficiency diseases depend on IDF as the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.

IDF Resources and Services

Educational Publications

- Patient and Family Handbook for Primary Immunodeficiency Diseases
- Our Immune System
- IDF School Guide: Information about Students with Primary Immunodeficiency Diseases
- Diagnostic and Clinical Care Guidelines for Primary Immunodeficiency Diseases
- IDF Guide for Nurses on Immune Globulin Therapy For Primary Immunodeficiency Diseases
- Clinical Focus Monographs
- IDF Advocate— newsletter
- Primary Immune Tribune— e-newsletter

Services for Patients and Families

- Patient Advocacy inquiries related to diagnosis, treatment, health insurance, peer support and literature requests
- IDF Educational Meetings – local and regional patient meetings, national conference
- IDF Volunteer Network – Peer Support, Grassroots Advocacy and Fundraising
- Student Scholarships for post-secondary education

Services for Medical Professionals

- Consulting Immunologist Program (877.666.0866) provides physicians a free consult or second opinion on patients with primary immunodeficiency
- LeBien Visiting Professor Program offers Grand Rounds and clinical presentations at medical institutions throughout North America

- United States Immunodeficiency Network (USIDNET): IDF administers the NIH contract for research and mentoring for primary immunodeficiency diseases.
- National Patient Registries of Primary Immunodeficiency Diseases

Public Policy Initiatives

- Advocacy efforts on public policy issues that are critical to patients at national and state levels
- IDF Grassroots Advocacy Program mobilizes the primary immunodeficiency community to contact their government representatives to promote healthcare legislation that will positively affect the community
- Advocacy for increased funding for research on primary immunodeficiency diseases
- Work with other organizations on quality of care initiatives for users of plasma products

Survey Research

- Unique ability to reach national samples of patients and physicians with surveys
- Trusted as sole source/gold standard of information on patient characteristics, experiences and attitudes
- Information used to advocate for patients in federal and state legislation

Immune Deficiency Foundation

40 W. Chesapeake Ave., Suite 308,
Towson, MD 21204
Telephone: 800.296.4433 410.321.6647
E-mail: idf@primaryimmune.org
Website: www.primaryimmune.org

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What are Primary Immunodeficiency Diseases?

In the United States, there are approximately 250,000 people diagnosed with primary immunodeficiency diseases and thousands more go undetected. This means that in the United States, approximately 1 in 1,200 persons have a diagnosed primary immunodeficiency disease. Although many types of primary immunodeficiency diseases are present at birth, or symptoms occur in early childhood, some patients may develop a primary immunodeficiency in any decade of life.

Primary immunodeficiency diseases occur in persons with an immune system that is either absent or hampered in its ability to function. These diseases can affect anyone, regardless of age or sex. The World Health Organization recognizes a group of more than 150 rare disorders that are primary immunodeficiency diseases. Some affect a single cell within the immune system; others may affect one or more components of the system. Primary immunodeficiency diseases share one common feature: each one results from a defect in one or more of the functions of the body's normal immune system. Since one of the most important functions of the normal immune system is to protect us against infection, patients with primary immunodeficiency diseases commonly have an increased susceptibility to infection and without proper treatment, may endure recurrent health problems, often developing serious and debilitating illnesses.

The infections may be in the skin, the sinuses, the throat, the ears, the lungs, the brain or spinal cord, or in the urinary or intestinal tracts, and the increased vulnerability to infection may include repeated infections, infections that will not clear up or unusually severe infections. People with primary immunodeficiency diseases live their entire lives more susceptible to infections – enduring recurrent health problems and often developing serious and debilitating illnesses. In some cases the regulation of these immune processes is disrupted so that the immune system can actually attack normal body components (autoimmunity) resulting in skin rashes, arthritis, anemia, gastrointestinal or other serious complications.

Primary Immunodeficiency Disease is Not AIDS

Primary immunodeficiency diseases are caused by an inborn or congenital defect. 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. AIDS is a secondary immunodeficiency caused by the HIV virus. Irradiation, chemotherapy, malnutrition and burns can also cause secondary immune deficiencies.

Is it just an infection?

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 "bugs" and viruses. However, instances in which the body cannot recover may be an indication of a primary immunodeficiency disease.

You should be suspicious if you have an infection that is:

Recurrent - keeps coming back

Unusual - caused by an uncommon organism

Persistent - won't completely clear up or clears slowly

Runs in the

Severe - requires hospitalization or intravenous antibiotics

Family - others in your family have a similar susceptibility to infection

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

Typically, persons diagnosed with a primary immunodeficiency disease “look” healthy. Primary immunodeficiency diseases are hidden conditions as are asthma and diabetes. Schools are accustomed to making accommodations for students with asthma and diabetes. They may also need to make accommodations for students diagnosed with primary immunodeficiency diseases.

Examples of Primary Immunodeficiency Diseases

DISEASE	IMMUNE DEFECT	PRIMARY TREATMENT
X-Linked Agammaglobulinemia (XLA or Bruton's Disease)	B-Cell Defect/Antibody Deficiency	Immune globulin infusions, antibiotics
Common Variable Immune Deficiency (CVID)	B-Cell Defect/Antibody Deficiency	Immune globulin Infusions, antibiotics
Hyper IgM Syndrome	B-Cell Defect/Antibody Deficiency	Immune globulin Infusions, antibiotics
IgG Subclass Deficiency	B-Cell Defect/Antibody Deficiency	Antibiotics, immune globulin infusions in some cases
Selective IgA Deficiency	B-Cell Defect/Antibody Deficiency	Prophylactic antibiotic therapy
Wiskott-Aldrich Syndrome	Combined T-Cell and B-Cell Defect	Bone marrow or stem cell transplant, immune globulin infusions, splenectomy, antibiotics
Ataxia Telangiectasia (A-T)	Combined T-Cell and B-Cell Defect	Immune globulin infusions in those with antibody deficiencies, no specific therapy
Severe Combined Immune Deficiency (SCID)	Combined T-Cell and B-Cell Defect (Caused by multiple gene defects)	Bone marrow or stem cell transplant, immune globulin infusions, PEG-ADA injections for ADA deficiency SCID, antibiotics
Complement Component Deficiencies	Complement Defect (Over 30 different complement components)	Antibiotic therapy
Chronic Granulomatous Disease (CGD)	Phagocyte Function Defect	Gamma interferon, antibiotics, antifungals
DiGeorge Syndrome	T-Cell Defect/Thymic Aplasia	Thymic transplant, immune globulin Infusions

Medical Therapy for Primary Immunodeficiency Diseases

Therapies for B-Cell Defects and Antibody Deficiencies

Therapies for T-Cell or Combined B- and T-Cell Defects

There are a number of specific medical therapies available to individuals with primary immunodeficiency diseases. The type of therapy depends on the type and severity of the primary immunodeficiency disease.

It is important to discuss with the family the possible side effects experienced by the child and appropriate protocol in the event that illness is a result of medical therapy.

Following is an overview of specific medical therapies and an experimental type of therapy (gene therapy). Additional information about these therapies is available in the *IDF Patient & Family Handbook for Primary Immunodeficiency Diseases*.

Immune Globulin Replacement Therapy

Many individuals with antibody deficiencies receive immune globulin replacement therapy. Immune globulin refers to the fraction of blood plasma that contains immunoglobulins or antibodies. The immunoglobulin partly replaces what the body should be making but does not help the patient's own immune system make more. Therefore, the immunoglobulin only provides temporary protection. Consequently, repeat doses are required at regular intervals. Depending on the route of administration, this may be done by giving subcutaneous infusions (SCIG) under the skin as often as every 2 or 3 days, or larger intravenous infusions (IVIG) once every 3 or 4 weeks. Since it only replaces the missing end product, and does not correct the defect in antibody production, immunoglobulin replacement is usually necessary for the patient's whole life.

Intravenous Immune Globulin Replacement - IVIG

Most patients have no side effects from the intravenous infusions. However, a number of adverse events have been associated with IVIG. The severity of reactions can range from mild to severe. Sometimes a low-grade fever or headache will occur. Less often, patients experience hives or wheezing.

Other side effects are less likely, but may include drowsiness or general malaise, nausea and vomiting, dizziness, chills, abdominal cramps, chest tightness, swelling, sweating, heart rate changes, itching, backache or other body aches, anxiety and sensitivity to light. It is not uncommon for mild side effects to persist for 2 - 3 days following the IVIG treatment.

Subcutaneous Immune Globulin Replacement - SCIG

A low rate of reactions is reported from subcutaneous infusions. The most common side effect is a localized site reaction which includes discomfort, burning, itching, mild redness and/or swelling. In most cases, these symptoms resolve within 12 to 24 hours. Reactions such as headache, nausea, fever and chills are much less frequent.

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 the more serious primary immunodeficiency diseases. Success in this procedure is largely dependent on the donor and recipient sharing or being "matched" for their "tissue types" and originally, the most likely donors were "histocompatible" siblings of the affected patient. Without a match between the tissue types of the donor and patient, the donor cells can recognize that they are in a foreign host and begin to attack the host in a frequently lethal disorder known as graft versus host disease (GVHD). There is now a national registry of thousands of volunteers whose tissue types have been determined. This resource has made successful transplantation from "unrelated donors" a possibility for those patients who do not have a "matched" sibling donor.

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 effectively reverse the immunodeficiency by eliminating a toxin that causes the immune deficiency. Aside from the discomfort of an intramuscular injection, PEG-ADA has had no side effects.

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 primary immunodeficiency diseases 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. Neupogen® is usually kept in the refrigerator and is given by subcutaneous injection at home, several times a week, or everyday in some cases. The dose must be adjusted according to the resulting rise in the white blood cell count. Side effects may include local reactions at the injection sites, pain in the bones, and potentially, serious allergic reactions.

Gamma Interferon

Individuals with chronic granulomatous disease often receive gamma interferon three times weekly subcutaneously. Gamma interferon 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. Common side effects of gamma interferon therapy include; fever, muscle aches, headaches, and chills.

Antibiotic and Antifungal Therapy

While many of the primary immunodeficiency diseases 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 primary immunodeficiency diseases 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 those primary immunodeficiency diseases, in 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. An advantage of gene therapy is that the patient does not need to receive stem cells from another donor, and therefore, there is no risk of graft versus host disease (GVHD). Gene therapy has shown some early successes in the treatment of ADA deficiency SCID, X-linked SCID, CGD and the Wiskott-Aldrich syndrome, although it is still early in the use of this novel treatment. 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 primary immunodeficiency diseases.

Therapies for Phagocytic Defects

Other Therapies

Communication: The Key to Success

Communication between school personnel, parents and students diagnosed with primary immunodeficiency diseases is of the utmost importance. It is essential for family members or school staff to initiate a meeting before the school year begins and maintain regular communication throughout the year. This guide can serve as the basis for that discussion and help to identify the individual needs of students and ways to meet those needs.

Meetings with school personnel and family members will facilitate an open dialogue regarding specifics about the individual student as well as foster an ongoing relationship to ensure that the student's needs are met and deal with issues that may arise throughout the year. In some cases, it may be helpful for school personnel to contact the student's healthcare provider for additional information, provided consent has been obtained from the student's parent or guardian.

A school healthcare team should be developed and include:

- School nurse
- Student (if appropriate)
- Parents
- Principal, administrator, or designee
- Teacher(s)
- Guidance counselor
- Other relevant staff
- Student's healthcare provider (if necessary)

Including the student's healthcare provider gives a tremendous amount of support to the family and allows the school to see that the parents are not being overprotective when it comes to their child's primary immunodeficiency disease. Otherwise, written information regarding the child's condition should be sufficient.

Successful communication depends upon the full participation of the school, family and the student's healthcare provider. The main contact person at school as well as the preferred method of communication (e-mail, phone, notes) between the school, family and healthcare provider should be determined and agreed upon by the team.

To be effective members of the healthcare team, school staff should learn about the child's particular primary immunodeficiency disease. Information may be obtained from the student's healthcare provider (with permission), family and publications from the Immune Deficiency Foundation. All IDF publications are available at www.primaryimmune.org or can be ordered from IDF at 800.296.4433.

Development and Implementation of the Educational or Healthcare Plan

The result of a meeting with the school healthcare team may be the development of an Emergency Care Plan (ECP) or an Individualized Healthcare Plan (IHP). This team, with the addition of a case manager, should also be part of the group that develops and implements the student's Section 504 Plan, Individualized Education Program (IEP) or other education plan if one is necessary. The *Educational & Healthcare Plans* section of this guide contains an overview of these plans. It may also be helpful to review the *Special Considerations for Students with Primary Immunodeficiencies* section since it contains information that may be used in an educational or healthcare plan.

Everyone should provide input during the plan's development and be fully involved during its implementation. If one component fails to follow through the plan will not work.

Federal laws make it possible for students with chronic health conditions, such as primary immunodeficiency diseases, to attend school and participate in the regular classroom. Their right to participate is protected by the following federal laws.

- Section 504 of the Rehabilitation Act of 1973 (Section 504)
- Americans with Disabilities Act of 1990 (ADA) – Amended 2008
- Individuals with Disabilities Education Act (IDEA)

It is important for school personnel to be aware of their responsibilities in the assuring that the needs of students with primary immunodeficiency diseases are met. The responsibilities of school personnel are listed below, followed by those of the parents and student. The lists are not representative of legal checklists of what must be done to comply with federal, state and local laws. They are simply steps that school personnel, parents, and students should take to ensure a positive school experience.

Superintendent, Student Services Coordinator or 504 Coordinator

- Learn about the student's primary immunodeficiency disease
- Provide leadership in assuring that all students' needs are met
- Understand and implement all federal and state laws
- Monitor schools attended by students with special needs
- Provide support to the student
- Meet with members of educational or healthcare teams when necessary
- Respect each student's confidentiality and right to privacy
- Allocate sufficient resources to manage the needs of all students

Principal, Administrator or Designee

- Notify the school nurse upon the enrollment of a student with a primary immunodeficiency disease
- Learn about the student's primary immunodeficiency disease
- Provide support to the student
- Participate in meetings of the educational/ healthcare team
- Support and facilitate ongoing communication between the school and family
- Identify staff members with a right to know about the student's condition
- Provide leadership in assuring that all students' needs are met
- Understand and implement all federal and state laws
- Respect each student's confidentiality and right to privacy
- Allocate sufficient resources to manage the needs of all students

School Nurse

The school nurse will be the key staff member who coordinates the healthcare plan for a student with a primary immunodeficiency disease. The nurse is also an active member of the student's education team if a 504 Plan or IEP is indicated.

- Obtain and review the student's healthcare information from the healthcare provider and family
- Facilitate the initial healthcare team meeting
- Learn about the student's primary immunodeficiency disease
- Obtain information from the parents, student and healthcare provider for the development of the healthcare plan
- Conduct periodic evaluations of the student's healthcare plan
- Obtain necessary medication and supplies from the parents
- Distribute the *IDF School Guide, Information about Students with Primary Immunodeficiency Diseases*, to relevant school personnel
- Provide education and act as a resource to school personnel that have responsibility for the student on a regular basis
- Practice universal precautions and infection control procedures during all student encounters.
- Notify the parents promptly if there is an outbreak of a contagious illness in the child's classroom or school
- Accurately document communication with the student, parents, school personnel and healthcare professional
- Obtain parental permission to act as the liaison between the school and the student's healthcare provider

Information for School Personnel

- Communicate with the teacher(s), guidance counselor, case manager or parents regarding concerns about the student
- Provide support to the student
- Encourage independence and self-care based upon the child's developmental level
- Understand and implement all federal and state laws
- Respect each student's confidentiality and right to privacy

Teachers

Once the essential accommodations and modifications have been determined, the teacher needs to consider the most efficient and effective implementation of the plan in relationship to their regular teaching duties.

- Participate in educational or healthcare team meetings
- Learn about the student's primary immunodeficiency disease
- Work with the educational or healthcare team to implement written plans
- Provide support to the student
- Notify the school nurse promptly if there is an outbreak of a contagious illness in the child's classroom
- Provide appropriate classroom accommodations/modifications to the student
- Provide instruction to the student if it is missed due to absence
- Provide information for substitute teachers
- Communicate with the school nurse, guidance counselor, case manager or parents regarding concerns about the student
- Treat the student the same as other students
- Respect each student's confidentiality and right to privacy

Guidance Counselor, School Psychologist or Social Worker

- Learn about the student's primary immunodeficiency disease
- Provide support to the student
- Treat the student the same as other students
- Recognize that students may rebel by discontinuing all or part of their medical treatment
- Encourage independence and self-care based upon the child's developmental level
- Be aware that some students are not comfortable sharing information about their condition with students and staff
- Participate in and provide input to the student's educational or healthcare team
- Communicate with the school nurse, teacher(s), case manager or parents regarding concerns about the student
- Respect each student's confidentiality and right to privacy

Information for Parents

Parents are a child's first teacher. When a child enters school, parents become partners with the school and are part of the child's educational team. The common goal between parents and schools should be to provide an education that enables the student to be successful in school and life.

Contact the school

Parents should contact the school principal and request a meeting to share essential information about their child's primary immunodeficiency disease. This meeting should be scheduled before the start of the school year or soon after the child is diagnosed.

Be Prepared

Parents should share the following information with the school.

- *IDF School Guide, Information about Students with Primary Immunodeficiency Diseases*
- *IDF Patient & Family Handbook for Primary Immunodeficiency Diseases* or a copy of the chapter describing the child's primary immunodeficiency disease
- Information from your child's physician
- Medications or procedures required during school
- Special needs: medical, academic, dietary, transportation
- Emergency plan and procedures
- Provide the school with necessary medication and medical supplies

Give Consent

Parents will be asked to sign a release form that gives the school permission to contact the child's healthcare provider. The healthcare provider will also need the parent's written permission to discuss the child's condition with the school. If the child requires medication or special procedures at school, they must receive specific written instructions from the healthcare provider. This information must be given to all appropriate school personnel. The school will instruct parents in the proper procedures to facilitate communication between school and medical personnel.

Keep in Touch

Parents and school personnel should regularly discuss the child's progress and immediately inform school staff of any changes in the child's health status. A phone call, during the teacher's free time or a pre-established time, or e-mail is all that is typically necessary to assure that the child is progressing and things are going well.

Understand Your Child's Educational Rights

It is important for parents to understand the federal, state and local laws. An overview of federal laws is included in this guide.

Every state has at least one Parent Training and Information Center (PTIs) or Community Parent Resource Center (CPRCs) that provides training and information to parents of children with disabilities and to professionals who work with them. This assistance helps parents to participate more effectively with professionals in meeting their children's educational needs. The Parent Centers work to improve outcomes for children, ages birth to 26 years, with all 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 professionals who work with them. Some states have CPRCs. CPRCs do the same work as PTIs. However, their focus is serving parents of children with disabilities in specific areas of the state, including low-income parents, parents of children with limited English proficiency and parents with disabilities.

The PTI/CPRC will help parents in the following ways:

- understand your child's disability and special needs
- learn about federal laws and what they mean for your child
- learn about options, programs, services and resources for your child and family
- learn how to communicate with your child's school
- actively participate on your child's educational team
- work with your child's school to develop an educational program
- assist with resolving disagreements with your child's school
- provide information to school personnel
- help your child understand his/her educational rights

A list of parent centers in the United States is available at the following Website: www.taalliance.org/ptidirectory

Information for Students

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. They 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. Following, are some ways students can learn to be self-advocates.

- Learn about their primary immunodeficiency disease
- Learn the name, dose and purpose of medications
- Wear a medical ID bracelet (if appropriate)
- Know which staff person to contact and how to contact the individual if you have concerns
- Tell school personnel when feeling ill
- Ask teachers for assistance with assignments missed due to absenteeism
- Participate in educational or healthcare plan meetings
- Learn about their educational rights

With support and advance planning the transition into adulthood can be an exciting time when self-advocacy has been practiced.

Special Considerations for Students with Primary Immunodeficiencies in the School Setting

Susceptibility to Infection

Even with regular medical treatment, it is important to be aware that frequent infection is a possibility in children with primary immunodeficiency diseases. These children are more susceptible to developing an infection and tend to become more ill than their peers do when an infection develops. Children with primary immunodeficiency diseases who have developed an infection are no more contagious than individuals with normal immune systems with a similar infection.

One of the most important things a child with a primary immunodeficiency disease can do to stay healthy is to minimize exposure to germs. Good hand hygiene, including washing one's 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 children, periodic washing of toys may be beneficial.

It is important to note that germs carried by classmates can be harmful to children with primary immunodeficiency diseases. A classmate with an illness should use good hand hygiene and use a tissue when sneezing, coughing or blowing his or her nose. Alcohol based hand gels should be freely available throughout the educational setting.

The following situations must be handled with care:

- Signs of illness expressed by the child 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.
- 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.

Vaccinations

Live vaccines can harm some individuals who have impaired immune systems. Administering a live vaccine to persons with primary immunodeficiency diseases could cause them to contract a serious form of the illness. **Under no circumstances should a student be administered a vaccination without written parental permission.** In addition, parents should be notified of any vaccination program within the school system even if their own child will not be involved.

Children with primary immunodeficiency diseases may be at risk of contracting infection from another individual who has received a live vaccination such as varicella-zoster, MMR, or rotavirus vaccine. Parents of children with primary immunodeficiency diseases should be notified if individuals who have close contact with their child have received or will receive one of these vaccinations. In certain cases, it may be necessary to remove the student temporarily from the school. A plan should be discussed with the parents and student's physician.

FluMist, a live attenuated influenza virus vaccine that is administered by droplets given into the nose, has an excellent safety record and there is no direct evidence that it poses a threat to patients with primary immunodeficiency. However, as a live virus, it retains some theoretical risk for patients with defective immunity and it is the general recommendation that patients with primary immunodeficiencies 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 that special precautions to separate most patients with primary immunodeficiency diseases from someone recently immunized with FluMist are probably unnecessary. However, in the situation where a family member has the most severe immune defect such as an infant with SCID, IDF continues to recommend that exposure to a recently FluMist immunized individual be restricted.

The key to preventing the spread of influenza amongst contacts in the home, school or workplace remains 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 a primary immunodeficiency disease, all members of the family group should be immunized each year with the inactivated influenza vaccine.

In the event that a child is unable to receive immunizations required by state law for entry into the school system, parents must present appropriate documentation from the child's physician to school personnel.

Students with primary immunodeficiency diseases often miss more school than their classmates. These absences are typically a result of illness, side effects from medication, regularly scheduled treatments and doctor's appointments.

If a concern arises about the number of days missed by a student, a meeting with the child's family would be important to identify how to meet the academic needs of the student. Establishing a 504 Plan or an IEP may be helpful in this case. 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. Additional information about these plans and possible accommodations and modifications are included in the *Educational and Healthcare Plans* and *Accommodations and Modifications* sections of this guide.

Frequent absences are not only a concern in regards to missed instruction and assignments. Absenteeism can be a source of major concern 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. Therefore, it may be important for parents and school personnel to discuss ways to ease the child's anxiety during extended absences and about returning to their friends and school.

Absenteeism

Emotional/ Social Issues

The challenge of living with a chronic illness can cause significant stress and have a great impact on the psychological well being of the student affected by one of these diseases. Depression is more commonly seen in individuals affected by chronic illnesses such as primary immunodeficiency diseases. Consequently, it is important for all school personnel associated with a student affected by a primary immunodeficiency disease to pay close attention to signs of more serious psychological concerns, such as clinical depression, and bring those to the attention of the student's parents. This recognition can help the student and his or her family seek appropriate interventions in a timely manner.

The school nurse, social worker, counselor or case manager 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 primary immunodeficiency diseases and the student's needs. Of course, it is imperative that permission is given from the parents and student before discussing a child's medical condition with others.

Children with primary immunodeficiency diseases want to be treated like their peers. They do not want to be defined by their illness. It is important to allow the child 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.

Possible Accommodations and Modifications

For schools to provide an appropriate education for students with primary immunodeficiency diseases, accommodations and modifications may be necessary. 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 commensurate with 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.

- Nutrition and diet may play an important part in the management of some individuals with primary immunodeficiency diseases. Frequent meals or special nutritional needs due to intestinal malabsorption or other associated nutritional disorder may be required for some students.
- Special restroom privileges due to gastrointestinal complications associated with the primary immunodeficiency disease may be required for some students.
- Hall passes or scheduled nursing visits may be needed for medication administration during school hours.
- Class assignments and tests may need to be rescheduled or reorganized due to regularly scheduled treatments, doctor's visits, or increased absence from school due to illnesses.
- Some students may have physical limitations that might prevent them from participating in certain physical education activities. For example, many children with primary immunodeficiency diseases have chronic ear infections, which may limit them from participating in swimming class as part of a physical education program.
- Provide two sets of textbooks, one for home and one for school.
- Shorten assignments to focus on mastery of important material missed due to absence.
- Extend assignment deadlines or postpone a test date due to absence.
- Provide a copy of the teacher's or another student's notes due to absence during lectures.
- The student may bring a water bottle to school and drink from it when desired.

Possible Accommodations and Modifications

- Develop a procedure for the student to receive missed assignments due to an absence in a timely manner. Perhaps, the parent calls or sends an e-mail to each teacher early enough in the day to allow the teacher to prepare work to be picked up by the parent, or the teacher sends the assignment to the parent 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.
- Provide an opportunity for the student to make up lab assignments and view videos missed due to 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 he/she completes the assignment at home.
- Provide the student with a tutor should absences become problematic.
- Provide a private room for the student at college or boarding school.
- Students with primary immunodeficiency diseases may experience fatigue which may limit stamina. This fatigue may wax and wane over the course of the school year. Assignments made need to be adjusted to accommodate this additional condition.
- 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, online courses for credit, and online tutoring programs in specific subjects.

It is essential that students with primary immunodeficiency diseases be allowed to maintain as normal a school life as possible and receive an education equal to their peers. Some children with a primary immunodeficiency disease will not experience any difficulties at school due to their particular condition. Other children, with more substantial health concerns will need significant assistance in the school setting. School personnel, parents and the student can develop a plan that will work to address concerns of reducing exposure to infection, coordinating schoolwork during absences, and providing certain modifications of schoolwork when needed.

Federal laws include requirements and guidelines for how schools should respond if a student's learning is impacted by a health condition. 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 and school personnel work together on behalf of the student.
- The laws enable families to effectively advocate for their child and participate as a member of their child's educational team.
- The laws assist school personnel in understanding all the services available to students, ensure protection of civil rights and improve collaboration with families and other agencies.

Following is an overview of the federal laws that have been enacted to protect students with disabilities and information about educational plans/programs available under the laws.

Section 504 of the Rehabilitation Act of 1973 (Section 504) and Americans with Disabilities Act of 1990 (ADA)

Section 504 is a federal law designed to protect the rights of individuals of all ages with disabilities in programs and activities that receive federal financial assistance from the U.S. Department of Education. Title II of the ADA protects the rights of individuals with disabilities in all public entities, regardless of whether it receives federal funds. In schools, these laws are enforced by the Office for Civil Rights (OCR) in the U.S. Department of Education.

Educational Rights under Federal Law

**Section 504
of the
Rehabilitation
Act of 1973
(Section 504)
and Americans
with Disabilities
Act of 1990
(ADA)**

According to the legal definition from the Americans with Disabilities Act of 1990 (ADA), including changes made by the ADA Amendments Act of 2008 (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, or
- being regarded as having such an impairment

A child with a disability that does not qualify for special education services under IDEA, the Individuals with Disabilities Education Act, may still be entitled to accommodations or other educational services under Section 504.

Section 504 describes a process for schools to use in determining whether a student has a disability and deciding 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 a student's needs are unique.

Section 504 also entitles students with disabilities to be given an equal opportunity to participate in academic, nonacademic and extracurricular activities. In addition, this law requires school districts to identify all 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 related aids and services to accommodate the unique needs of individuals with disabilities.

Additional information about Section 504 of the Rehabilitation Act of 1973 is available at the following Website: <http://www.ed.gov/about/offices/list/ocr/504faq.html>

**IDEA – the
Individuals with
Disabilities
Education Act**

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

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 administers IDEA.

There are 14 disability categories included in 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. Information about IEPs is included in the *Educational & Healthcare Plans* section of this guide.

The No Child Left behind (NCLB) Act, Public Law (PL) 107-110, is the nation's latest general education law. NCLB is 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 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). Parent centers can help parents understand their options. Additional information about the No Child Left Behind Act is available at the following Website: www.ed.gov/nclb

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 following Website: <http://www.ed.gov/policy/gen/guid/fpco/ferpa/index.html>

No Child Left Behind Act (NCLB)

Family Education Rights and Privacy Act (FERPA)

Educational & Healthcare Plans

Some children diagnosed with primary immunodeficiency diseases may need one or more of the following plans in order to attend school and participate in classroom activities.

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 family, student (if appropriate), teacher(s), other relevant school personnel and the student's healthcare provider. The plan ensures quality, comprehensive care of the child's healthcare needs. It also promotes continuity of care and communication of the child's needs to relevant school personnel and parents.

The need for an IHP is based upon a student's need for nursing care while he or she is 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. Sections of an IHP may be included in an Individualized Education Program (IEP) or 504 Plan. An IHP may also be included as an attachment to either of these documents. A sample IHP is included in the Appendix 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 whom to call 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) Website provides sample and blank emergency care forms. They refer to emergency care plans as emergency information forms. The forms are available at <http://www.aap.org/advocacy/emergprep.htm>

Section 504 Plan (504 Plan)

A student does not need to receive special education services to be eligible for services under Section 504. Administering medication, allowing the student to carry a water bottle, make frequent phone calls to parents, or developing a procedure that allows the student to keep up with assignments due to absenteeism are examples of related aids or services (accommodations) that may be provided to a student with a primary immunodeficiency disease. To keep everyone informed, a written document should be developed that lists a student's accommodations and modifications. This document may be a Section 504 Plan or 504 Plan.

A 504 Plan is developed by the educational team, which includes the parents and student (if appropriate) and relevant school personnel. The plan should include any accommodations that may not be readily available to students without disabilities.

The types of accommodations offered by a 504 Plan are often informal agreements between parents and school personnel developed sometime during the child's educational experience. Although outlining accommodations and modifications may not seem necessary, it is always best to put things in writing to ensure consistency among all interested parties. A sample 504 Plan is included in the Appendix of this guide.

A child, ages 3 to 22, who receives special education must meet the educational qualifications of special education and have an Individualized Education Program (IEP) developed to meet the educational needs of the individual student. The IEP provides an opportunity for teachers, parents, school personnel and students (when appropriate) to work together to improve educational results for a child with a disability.

To create an effective IEP, the educational team (parents, special and regular educator(s), a representative of the school system, someone to interpret evaluation results, others with knowledge about the student and the student) meet and discuss the student's unique needs.

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

The team designs 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.

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 not appropriate – If these tests are not administered the IEP must state 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
- 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

Both Section 504 Plans and an IEP are legal documents between parents and the schools. However, 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, the Individuals with Disabilities Education Act. This child might still be eligible for services under Section 504.

Additional information about the Individualized Education Program is available through your local school district or at the following U.S. Department of Education Website: www.ed.gov/index.jhtml

Post-Secondary Education and Employment

The period of transition between high school and college or entering the work force can be a stressful time for students, but particularly difficult for individuals affected by chronic illnesses. Academic and social stressors are a big concern for high school students with primary immunodeficiency diseases. Practical considerations about choosing a career and maintaining good health insurance after leaving their parents' policies might be foremost in their minds. Anticipating these concerns and working together with the student and the established school healthcare team can help ease this transition period.

Post-Secondary Education

Many high school students with primary immunodeficiency diseases continue their education in post-secondary schools, including vocational and career schools, two- and four- year colleges and universities. Students should become knowledgeable about their rights and responsibilities as well as the responsibilities that post-secondary schools have toward the student. This knowledge will ensure that the student has the opportunity to enjoy the benefits of the post-secondary education experience without confusion or delay.

When planning campus visits to prospective schools, parents and students may want to work with the admissions office to identify the contact person at the school that can provide information on how to plan for academic adjustments at the college level.

Most individuals with a primary immunodeficiency do not view themselves as having a disability. However, if a student wants the school to provide an academic adjustment, they must identify themselves as having a disability. Remember, according to the legal definition from the Americans with Disabilities Act of 1990 (ADA), including changes made by the ADA Amendments Act of 2008 (P.L. 110-325), a disability is:

- a physical or mental impairment that substantially limits one or more major life activities of an individual
 - o 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.
 - o **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, or
- being regarded as having such an impairment

The appropriate adjustment will be made based on the student's individual needs. Examples of academic adjustments are:

- A reduced course load
- Providing note takers
- Extended time for testing

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

Post-secondary schools are not required to identify students with disabilities. Students interested in requiring an academic adjustment should contact the school as soon as possible since some adjustments take time to provide. In addition, the school may request documentation that proves the student has a disability. It is important to know that a student who meets the essential requirements for admission to a post-secondary school may not be denied admission based upon a disability.

While post-secondary schools are still required to comply with the Section 504 law, there are significant differences in the responsibilities of secondary school districts and post-secondary schools. 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 a Section 504 in a post-secondary school.

For more information and to request a copy of this guide, please go to the OCR Website: <http://www.ed.gov/about/offices/list/ocr/transition.html> or call the OCR office at 800.421.3481.

Section 504 of the Rehabilitation Act of 1973

Vocational Rehabilitation (VR) Programs

Under Title I of the Rehabilitation Act of 1973, states receive federal grants to operate a comprehensive VR program. Vocational Rehabilitation is an eligibility program designed to assist people with disabilities to obtain, regain, or maintain employment. This program assesses plans, develops and provides VR services to eligible individuals with disabilities, consistent with their strengths, resources, priorities, concerns, abilities, capabilities, interests and informed choice.

To be eligible for VR services, an individual must:

- Be an “individual with a disability,” meaning a person who (1) has a physical or mental impairment which constitutes or results in a substantial impediment to employment for the individual; and (2) can benefit from VR services to achieve an employment outcome.
- Require VR services to prepare for, secure, retain, or regain employment.

Individuals who receive Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI) benefits are presumed to be eligible for VR services leading to employment, if the individual does intend on obtaining employment.

A student with primary immunodeficiency disease may be eligible to participate in their state VR program, depending on the diagnosis and level of disability as described by limitations of functional capacities.

Overview of the steps of the vocational rehabilitation process:

- **Application** – An individual will be considered to have “submitted an application” when he or she “requests” VR services and provides sufficient information for the VR agency to determine eligibility.
- **Eligibility** – This is to be determined within 60 days of application unless the VR counselor and individual agree to an extension.
- **Services** – For eligible individuals, a Plan for Employment is jointly developed between the VR counselor and the individual ensuring that the individual is informed of their choices available. This plan serves as a road map of services needed for employment. Possible services might be: Vocational Evaluation Assistive Technology, Counseling and Guidance, Educational Assistance, Personal and Work Adjustment, Prosthetic and Orthotic Devices, Transition Services, and Job Training and Placement.
- **Employment** – When the individual finds employment, the case remains open for a minimum of 90 days to ensure success on the job.
- **Successful Rehabilitation** – The case is closed due to the successful employment of the individual.
- **Post- Employment Services** – If issues arise and/or minor services are required after an individual case is closed, they can still be provided in Post-Employment Services.

For additional information, please refer to the following Websites:

- www.ed.gov/about/offices/list/osers/rsa/index.html for general information
- www.ed.gov/about/offices/list/osers/rsa/faq.html for frequently asked questions about VR programs
- <http://www.jan.wvu.edu/cgi-win/TypeQuery.exe?902> for a list of state Vocational Rehabilitation Agencies

Most young adults in this country are covered under a group insurance plan offered by one of their parent's employers. Many of these employer sponsored plans end dependent coverage when the dependent child turns 19, if not attending college, or to age 23 or 25, if enrolled in school full-time. When dependent children are no longer eligible for group insurance under a parent's plan, they are entitled for up to 36 months of COBRA coverage (if the employer has 20 or more employees). Some plans continue to cover totally disabled dependents as “adult disabled children” beyond the usual end date for dependent children. To know how dependents are covered under the employer sponsored health plan, the parents should ask their human resources department for a copy of the Summary Plan Description (SPD). A SPD is a requirement of the law (ERISA) that sets the terms of each employee benefit plan in a written plan document.

Medicaid, usually available through the state's Children's Health Insurance Plan (CHIP), is another form of insurance that usually ends when the dependent child turns 19. Medicaid for disabled Supplemental Security Income (SSI) can end if the young adult is no longer designated as disabled or if income or assets exceed the allowable limits.

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.*
- ATAXIA:** *An unsteady gait caused by neurological abnormalities.*
- BACTERIA:** *Single cell organisms (microorganisms) that can be seen only under a microscope. While bacteria can be useful, many bacteria can cause disease in humans.*
- B-LYMPHOCYTES (B-CELLS):** *White blood cells of the immune system derived from bone marrow and involved in the production of antibodies.*
- BONE MARROW:** *Soft tissue located in the hollow centers of most bones that contain developing red blood cells, white cells, platelets and cells of the immune system.*
- CHRONIC:** *Term used to describe an illness or infection that may be recurrent or last a long time.*
- COMBINED IMMUNODEFICIENCY:** *Immunodeficiency when both T- and B-lymphocytes cells are inadequate or lacking.*
- COMPLEMENT:** *A complex series of blood proteins that act in a definite sequence to affect the destruction of bacteria, viruses and fungi.*
- CONGENITAL:** *Present at birth.*
- FUNGUS:** *Member of a class of relatively primitive microorganisms including mushrooms, yeast, and molds.*
- GAMMA GLOBULINS:** *The protein fraction of blood that contains immunoglobulins or antibodies.*
- GAMMA INTERFERON:** *A cytokine primarily produced by T-lymphocytes that improves bacterial killing by phagocytes; used as treatment for Chronic Granulomatous Disease.*
- 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.*
- GRANULOCYTE:** *A white cell of the immune system characterized by the ability to ingest (phagocytize) foreign material; neutrophils, eosinophils, and basophils are examples of granulocytes.*
- HYPOGAMMAGLOBULINEMIA:** *Lower than normal levels of gamma globulins or immunoglobulins (or antibodies) in the blood.*
- IGA:** *An immunoglobulin found in blood and secreted into tears, saliva, and on the mucous membranes of respiratory and intestinal tracks.*
- IGD:** *An immunoglobulin whose function is poorly understood at this time.*
- IGE:** *An immunoglobulin found in trace amounts in the blood and responsible for allergic reactions.*

IGG: *The most abundant and common of the immunoglobulins. IgG functions mainly against bacteria and some viruses. It is the only antibody that can cross the placenta from the mother to the developing fetus.*

IGM: *An immunoglobulin found in the blood. IgM functions in much the same way as IgG but is formed earlier in the immune response. It is also very efficient in activating complement.*

IMMUNE RESPONSE: *The response of the immune system against foreign substances.*

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.*

INTRAVENOUS IMMUNOGLOBULIN (IVIG): *Gamma globulin 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.*

PHAGOCYTE: *A general class of white blood cells that ingest microbes and other cells and foreign particles; monocytes, macrophages, and neutrophils are types of phagocytes.*

PLASMA CELLS: *Antibody-producing cells descended from B-lymphocytes.*

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.*

PROTEIN: *A class of chemicals found in the body made up of chains of amino acids (building blocks); immunoglobulins (antibodies) are proteins.*

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

SEPSIS: *An infection of the blood.*

SPLEEN: *An organ in the abdominal cavity; it is directly connected to the blood stream and like lymph nodes contains B-lymphocytes, T-lymphocytes, and macrophages.*

STEM CELLS: *Cells from which all blood cells and immune cells are derived, bone marrow is rich in stem cells.*

SUBCUTANEOUS INFUSION (SCIG): *Administration of gamma globulin in which it is infused slowly directly under the skin with a small pump.*

TELANGIECTASIA: *Dilation of the blood vessels.*

THYMUS GLAND: *A lymphoid organ located behind the upper portion of the sternum (breastbone). The thymus is the chief educator of T-lymphocytes. This organ increases in size from infancy to adolescence and then begins to shrink.*

T-LYMPHOCYTES (OR T-CELLS): *Lymphocytes that are processed in the thymus; they are responsible in part for carrying out the immune response.*

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.*

VIRUS: *A submicroscopic microbe causing infectious disease; can reproduce only in living cells.*

X-LINKED RECESSIVE INHERITANCE: *A form of inheritance where the characteristic, or disease, is inherited on the X-chromosome.*

Glossary of Educational Terms

- ACADEMIC:** *Having to do with subjects such as reading, writing, math, social studies and science.*
- 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.*
- CHILD STUDY TEAM (CST):** *A group of professional personnel who meet to discuss concerns relative to a student's school functioning. Concerns can be academic, behavioral, emotional and/or social.*
- COMMUNITY PARENT RESOURCE CENTERS (CPRCS):** *A resource for parents of children with disabilities in some states that do the same work as a 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.*

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, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.

A-T Children's Project

www.communityatcp.org/Page.aspx?pid=1200

800.5.HELP.A.T

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 lethal genetic disease that attacks children, causing progressive loss of muscle control, cancer and immune system problems.

CGD Café

<http://cgd.cultivatecommunity.com>

This is a community supported site that provides a place for family, friends and patients with chronic granulomatous disease to share information, stories and ideas.

Hereditary Angioedema Association

www.hereditaryangioedema.com/

866.798.5598

An organization that provides education, research and support for hereditary angioedema, a type of primary immune deficiency disease.

International Patient Organization for Primary Immunodeficiencies (IPOPI)

www.ipopi.org

IPOPI is an international organization whose members are national patient organizations for the primary immunodeficiencies.

The Jeffrey Modell Foundation

www.jmfworld.org

866.INFO.4.PI

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

Severe Combined Immunodeficiency (SCID) Homepage

www.scid.net

This site contains information about SCID with links to journal articles, latest research developments, and patient support.

Understanding XLP

www.xlp.ca

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

Velo-Cardio-Facial Syndrome Educational Foundation, Inc.

www.vcfsef.org

866.VCFSEF5

An international not-for-profit organization dedicated to providing support and information to individuals who are affected by Velo-Cardio-Facial syndrome, their families, physicians and other practitioners. This website includes information on DiGeorge Syndrome, which can include primary immune deficiency disease as one of the symptoms.

Education Issues

Education.com

www.education.com

Education.com provides parents of school-aged children with free access to information and resources.

HEATH Resource 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.

National Association of School Nurses

www.nasn.org

NASN is the leader in advocacy for student health and professional development of school nurses.

National Information Center for Handicapped Children and Youth (NICHY)

www.nichcy.org

NICHY is a national information and referral center that provides information on disabilities and disability-related issues for families, educators and other professionals. Specific information on early intervention programs, special education, individualized education programs, education rights and transition to adult life can be found through this organization.

NICHY: State Specific Information

www.nichcy.org/pages/statespecificinfo.aspx

Information about state-level offices that will put families in touch with resources in their community and provide information and assistance about disability issues in each state.

National Center on Secondary Education and Transition

www.ncset.org

The National Center on Secondary Education and Transition (NCSET) coordinates national resources, offers technical assistance, and disseminates information related to secondary education and transition for youth with disabilities in order to create opportunities for youth to achieve successful futures.

U.S. Department of Education

www.ed.gov/index.jhtml

This site contains information for parents about education for children of all ages and abilities.

College.gov

www.college.gov/wps/portal

This site is intended to be the go-to source for information and resources about planning, preparing and paying for postsecondary education (such as 2- or 4-year colleges and universities, as well as vocational or career schools).

Disability and Business Technical Assistance Center (DBTAC)

www.adata.org

A national Network of ADA Centers comprised of 10 regional centers that provide information, training and technical assistance on the Americans with Disabilities Act. The centers are funded by the National Institute on Disability and Rehabilitation Research under the U.S. Department of Education.

Education Resources Information Center (ERIC)

www.eric.ed.gov

This is the largest digital library of education literature in the world.

No Child Left Behind (NCLB)

www.ed.gov/nclb

This site includes detailed information about the No Child Left Behind Act.

Office for Civil Rights (OCR)

www.ed.gov/about/offices/list/ocr/index.html?src=mr

The mission of the Office for Civil Rights is to ensure equal access to education and to promote educational excellence throughout the nation through vigorous enforcement of civil rights.

Office of Post Secondary Education

www.ed.gov/about/offices/list/ope/index.html

The Office of Postsecondary Education (OPE) formulates federal postsecondary education policy and administers programs that address critical national needs in support of our mission to increase access to quality postsecondary education.

Office of Special Education Programs' (OSEP's) IDEA Web Site

<http://idea.ed.gov/explore/home>

The site provides searchable versions of IDEA and the regulations, access to cross-referenced content from other laws (e.g., the No Child Left Behind Act (NCLB), the Family Education Rights and Privacy Act (FERPA), etc.), video clips on selected topics, topic briefs on selected regulations, links to OSEP's Technical Assistance and Dissemination (TA&D) Network and a Q&A Corner where you can submit questions, and a variety of other information sources.

Office of Special Education and Rehabilitative Services (OSERS)

www.ed.gov/about/offices/list/osers/index.html

The Office of Special Education and Rehabilitative Services (OSERS) is committed to improving results and outcomes for people with disabilities of all ages.

The National Early Childhood Technical Assistance Center

www.nectac.org

NECTAC is supported by the U.S. Department of Education's Office of Special Education Programs.

NECTAC serves all 50 states and 10 jurisdictions with an array of services and supports to improve service systems and outcomes for infants, toddlers, and preschool aged children with special needs and their families.

Wrightslaw

www.wrightslaw.com

This Web site is dedicated to helping individuals advocate for children with disabilities with regard to the education system and legal issues.

U.S. Department of Health and Human Services (HHS)

www.hhs.gov

HHS is the U.S. government's principal agency for protecting the health of all Americans and providing essential human services. The Web site contains information on the department's numerous federal programs.

Federal Organizations

Centers for Disease Control and Prevention (CDC) – Vaccines and Immunizations

www.cdc.gov/vaccines

The Vaccine and Immunization division of the CDC provides information on general vaccinations and specific precautions for individuals affected with primary immunodeficiencies.

Centers for Medicare & Medicaid Services (CMS)

www.cms.hhs.gov

800.633.4227

CMS provides information for individuals receiving services from Medicare, Medicaid or SCHIP.

Equal Employment Opportunity Commission (EEOC)

www.eeoc.gov

800.669.4000

EEOC is the federal agency whose mission is to promote equal opportunity in employment through administrative and judicial enforcement of the federal civil rights laws and through education and technical assistance. The Web site contains information on the agency, its current activities and legislative documents such as “The Americans with Disabilities Act.”

Healthfinder

www.healthfinder.gov

Healthfinder.gov is a Federal Web site for consumers, developed by the U.S. Department of Health and Human Services together with other Federal agencies. It is a key resource for finding government and nonprofit health and human services information on the Internet.

National Institutes of Health (NIH)

www.nih.gov

NIH provides information on advances in health, science and medical issues.

National Institute of Allergy and Infectious Diseases (NIAID)

www.niaid.nih.gov

301.496.5717 Office of Communications

NIAID is a division of NIH that provides information on allergy and infectious diseases, but also primary immunodeficiencies.

National Institute of Child Health and Human Development (NICHD)

www.nichd.nih.gov

NICHD is a division of the NIH that provides general information on children’s health issues, including an in-depth booklet on primary immunodeficiencies.

National Library of Medicine (NLM)

www.nlm.nih.gov

NLM is the world’s largest medical library. The library collects materials and provides information and research services in all areas of biomedicine and healthcare.

NIH Health Information

www.health.nih.gov

A-Z index of NIH health resources, clinical trials, MedlinePlus, health hotlines.

NIH Office of Rare Diseases (ORD)

www.rarediseases.info.nih.gov

The goals of ORD are to stimulate and coordinate research on rare diseases and to support research to respond to the needs of patients who have any one of the more than 6,000 rare diseases known today.

U.S. Department of Food and Drug Administration

www.fda.gov

The FDA is responsible for protecting the public health by assuring the safety, efficacy, and security of human and veterinary drugs, biological products, medical devices, our nation's food supply, cosmetics, and products that emit radiation. The FDA is also responsible for advancing the public health by helping to speed innovations that make medicines and foods more effective, safer, and more affordable; and helping the public get the accurate, science-based information they need to use medicines and foods to improve their health.

U.S. Department of Justice: Americans with Disabilities Act (ADA)

www.ada.gov

800.514.0301

This division of the government provides information to assist persons with disabilities and to help communities better serve these individuals.

U.S. Department of Labor

www.dol.gov

The Department of Labor fosters and promotes the welfare of the job seekers, wage earners, and retirees of the United States by improving their working conditions, advancing their opportunities for profitable employment, protecting their retirement and healthcare benefits, helping employers find workers, strengthening free collective bargaining, and tracking changes in employment, prices, and other national economic measurements. In carrying out this mission, the Department administers a variety of Federal labor laws including those that guarantee workers' rights to safe and healthful working conditions; a minimum hourly wage and overtime pay; freedom from employment discrimination; unemployment insurance; and other income support.

Job Accommodation Network (JAN)

www.jan.wvu.edu

800.526.7234

JAN is a free consulting service through the Office of Disability Employment Policy within the U.S. Department of Labor. It is designed to increase the employability of people with disabilities.

U.S. Social Security Administration

www.ssa.gov

This Web site contains complete information about Social Security.

American Academy of Allergy, Asthma, and Immunology (AAAAI)

www.aaaai.org

AAAAI is a professional organization for physicians who treat patients with allergies, asthma and immunologic disorders. The organization provides a worldwide referral system for physicians in various geographical regions.

American Academy of Pediatrics (AAP)

www.aap.org

AAP is a professional organization for pediatricians. It is committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults.

Clinical Immunology Society

www.clinimmsoc.org

The mission of the Clinical Immunology Society is to facilitate education, translational research and novel approaches to therapy in clinical immunology to promote excellence in the care of patients with immunologic/ inflammatory disorders.

National Organizations

Federation of Clinical Immunology Societies (FOCIS)

www.focisnet.org

FOCIS exists to improve human health through immunology by fostering interdisciplinary approaches to both understand and treat immune-based diseases.

Infusion Nurses Society (INS)

www.ins1.org

INS is dedicated to exceeding the public's expectations of excellence by setting the standard for infusion care.

National Marrow Donor Program (NMDP)

www.marlow.org

NMDP is a non-profit organization that facilitates unrelated marrow and blood stem cell transplants for patients with life-threatening diseases who do not have matching donors in their families.

Children's Defense Fund

www.childrensdefense.org

The Children's Defense Fund is a non-profit organization devoted to children's issues, including the Children's Health Insurance Program. The Web site provides information on these topics.

Disability Rights Education and Defense Fund (DREDF)

www.dredf.org

The Disability Rights Education and Defense Fund, founded in 1979, is a leading national civil rights law and policy center directed by individuals with disabilities and parents who have children with disabilities.

Families USA

www.familiesusa.org

Families USA is a non-profit organization dedicated to the achievement of high-quality, affordable health and long-term care for all Americans. The Web site contains state and national resources.

Family Voices

www.familyvoices.org

Family Voices is a national organization that provides information and education concerning the healthcare of children with special health needs.

Genetic Alliance

www.geneticalliance.org

The Genetic Alliance is an international coalition of families, health professionals, and genetic support organizations that provide information, support and advocacy to those affected by genetic conditions, including primary immunodeficiencies.

Gene Tests

www.geneclinics.org

At this site, one can enter a diagnosis and pull up scholarly articles about many primary immunodeficiency diseases.

National Disabilities Rights Network (NDRN)

www.ndrn.org

NDRN is a non-profit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP) for individuals with disabilities.

National Family Caregivers Association (NCFA)

www.nfcacares.org

NCFA is a grass roots organization created to educate, support, empower and speak up for millions of Americans who care for chronically ill, aged, or disabled loved ones.

National Organization for Rare Disorders (NORD)

www.rarediseases.org

NORD is a non-profit organization, which provides information, programs and services for thousands of rare medical conditions, including primary immunodeficiencies.

National Patient Travel Center

www.patienttravel.org

This non-profit organization provides a variety of services to individuals and families seeking ways to travel long-distances for specialized medical evaluation, diagnosis and treatment.

Parent USA (P2PUSA)

www.p2pusa.org

A national non-profit organization committed to promoting access, quality and leadership in parent-to-parent support across the country.

Patient Advocate Foundation

www.patientadvocate.org

The Patient Advocate Foundation is a national non-profit organization that seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability.

Patient Notification System

www.patientnotificationssystem.org

This program, developed by the Plasma Protein Therapeutics Association (PPTA), notifies patients who receive plasma products, such as IVIG, about product recalls.

Patient Services Incorporated (PSI)

www.uneedpsi.org

PSI is a non-profit charitable organization dedicated to subsidizing the high cost of health insurance premiums and co-payments for persons with specific chronic illnesses, including primary immunodeficiencies. PSI also provides Social Security and disability representation to patients.

Technical Assistance ALLIANCE for Parent Centers (the ALLIANCE)

www.taalliance.org

A partnership of one national and six regional parent technical assistance centers, each funded by the U.S. Department of Education's Office of Special Education Programs (OSEP). These seven projects comprise a unified technical assistance system for the purpose of developing, assisting, and coordinating the over 100 Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) under the Individuals with Disabilities Education Act. The national and regional parent technical assistance centers work to strengthen the connections to the larger OSEP Technical Assistance and Dissemination Network and fortify partnerships between Parent Centers and education systems at local, state, and national levels.

Families and Youth

Band-aides and Blackboards

www.lehman.cuny.edu/faculty/ifleitas/bandaides

Band-aides and Blackboards is a Web site about growing up with medical problems. The site helps people understand what it is like, from the perspective of children and teens.

There are separate areas for kids, teens and adults.

KidsHealth

www.kidshealth.org

KidsHealth is a Web site that provides health information to kids, teens and parents. The site contains articles, animations, games and resources.

Immune Deficiency Foundation

Immune Deficiency Foundation. *Patient and Family Handbook for Primary Immunodeficiency Diseases*, 4th edition, 2007. 3rd edition available in Spanish.

Immune Deficiency Foundation. LeBien, Sara. *Our Immune System*. 2008.

Immune Deficiency Foundation. *IDF School Guide*, 2nd edition, 2009.

Immune Deficiency Foundation. *Diagnostic and Clinical Care Guidelines for Primary Immunodeficiency Diseases*, 2nd edition, 2009.

Immune Deficiency Foundation. *IDF Guide for Nurses on Immunoglobulin Therapy for Primary Immunodeficiency Diseases*, 2nd edition, 2007.

Other Publications and Resources General Information on Immunology and Primary Immunodeficiencies

AAAAI. *IVIG Toolkit*. www.aaaai.org/members/resources/initiatives/ivig.stm

National Institutes of Health, National Institute of Allergy and Infectious Diseases. *Primary Immune Deficiency Diseases: Discovering Causes; Improving Lives; Working Toward A Cure*. 1998.

U.S. Department of Health and Human Services. *Understanding the Immune System*. 1990. NIH Publication No. 90-529.

National Institute of Child Health and Human Development. *When the Body's Defenses are Missing: Primary Immunodeficiency*. 1999.

U.S. National Institute of Allergy and Infectious Diseases. *The Immune System: How it Works*. NIH Publication No. 92-3229.

Books for Youth

Balkwill, Frances R. *Amazing Schemes within Your Genes*. Lerner Publishing Group. 1993. (Ages 8–11)

Balkwill, Frances R. *Cell Wars*. Lerner Publishing Group. 1992. (Ages 12 and up)

Balkwill, Frances R. *DNA Is Here to Stay*. Carolrhoda Books. 1994. (Ages 9–12)

Balkwill, Frances R. *Germ Zappers*. Cold Spring Harbor Laboratory Press. 2001. (Age 7)

Berger, Melvin. *Germs Make Me Sick!* Harper Trophy. 1995. (Ages 4–8)

Boudreau, Gloria. *The Immune System*. Cengage Gale. 2004. (Ages 9–12)

Bourgeois. *Franklin Goes to the Hospital*. Scholastic, Inc. 2000. (Ages 4–7)

Bridwell, Norman. *Clifford Visits the Hospital*. Scholastic, Inc. 2000. (Ages 4–8)

Cole, Joanna. *The Magic School Bus: Inside the Human Body*. Scholastic, Inc., New York, NY. 1989. (Ages 6–9)

Collins, Ross. *Germs*. Bloomsbury, USA. 2004. (Ages 4–8)

Donovan Reh, Beth. *Germs*. Cengage Gale. 2005. (Young Adult)

- Duncan, Debbie. *When Molly Was in the Hospital: A Book for Brothers and Sisters of Hospitalized Children*. Rayne Productions, Inc. 1995. (Ages 4–7)
- Gelman, Rita Golden. *Body Battles*. Scholastic, Inc. 1992. (Ages 8–12)
- Garvey, Helen. *The Immune System: Your Magic Doctor*. Shire Press. 1992. (Age 9)
- Hickman Brynie, Faith. *101 Questions about Your Immune System You Felt Defenseless to Answer until Now*. Lerner Publishing Group. 2000. (Young Adult)
- Huegel, Kelly. *Young People and Chronic Illness*. Free Spirit Publishing, Inc. 1998. (Young Adult)
- Kaufman, Miriam. *Easy for You to Say: Q & A's for Teens Living with Chronic Illness or Disabilities*. Firefly Books, Limited. 2005. (Young Adult)
- Kornberg, Arthur. *Germ Stories*. University Science Books. 2007. (Ages 8 – 12)
- Libal, Autumn. *Chained: Youth with Chronic Illness*. Mason Crest Publishers. 2004. (Ages 9–12)
- McGrath, Tom. *When You're Sick or in the Hospital: Healing Help for Kids*. Abbey Press. 2002. (Ages 3–11)
- Mills, Joyce C. *Little Tree: A Story for Children with Serious Medical Problems*. American Psychological Associates. 2003. (Ages 5–8)
- Nadler, Beth. *The Magic School Bus: Inside Ralphie: A Book About Germs*. Scholastic, Inc. 1995. (Ages 6–9)
- Nye, Bill, Weidner Zoehfeld, Kathleen. *Bill Nye the Science Guy's Great Big Book of Tiny Germs*. Hyperion Books for Children. 2005. (Ages 7 – 10)
- Parker, Steve. *Defend Yourself: The Immune System*. Raintree Publishers. 2006. (Ages 12 & up)
- Romanek, Trudee. *Achoo!: The Most Interesting Book You'll Ever Read About Germs*. Kids Can Press, Ltd. 2003. (Ages 12 and up)
- Thames, Susan. *Our Immune System*. Rourke Publishing. 2008. (Ages 4 – 8)
- Thomas, Pat. *Do I Have to Go to the Hospital?: A First Look at Going to the Hospital*. Barron's Educational Series, Inc. 2006. (Ages 5 – 8)
- Trumbauer, Lisa. *Body Warriors*. Raintree Publishers. 2006. (Ages 8 – 12)
- Verdick, Elizabeth. *Germs Are Not for Sharing*. Free Spirit Publishing, Inc. 2006. (Infants – Preschool)
- Zoehfeld, Kathleen Weidner. *Pooh Plays Doctor*. Disney Press. 1999. (Preschool)

Books for Parents

- Barrett-Singer, Alesia T. *Coping with Your Child's Chronic Illness*. Robert D. Reed Publishers. 2004.
- Berends, Polly Berrien, Peck, M. Scott. *Whole Child/Whole Parent*. Harper Collins. 1997.
- Bluebond-Langner, Myra. *In the Shadow of Illness: Parents and Siblings of the Chronically Ill Child*. Princeton University Press. 2000.
- Evelof, Scott. *Both Sides of the White Coat*. iUniverse, Inc. 2000.
- Leff, Patricia Taner, Walizer, Elaine H. *Building the Healing Partnership: Parents, Professionals and Children with Chronic Illness and Disabilities*. Brookline Books. 1992.
- McCollum, Audrey. *The Chronically Ill Child: A Guide for Parents and Professionals*. Yale University Press. 2001.

Medical Textbook and Articles

- Buckley, R. *Primary Immunodeficiency Diseases Due to Defects in Lymphocytes*. New England Journal of Medicine, Nov. 2, 2000, Vol. 343, No. 18, pp. 1313-1324.
- Kirkwood, Evelyn and Lewis, Catriona. *Understanding Medical Immunology*. 2nd ed., John Wiley and Sons. 1991.
- Ochs HD., Smith CI, Puck JM. *Primary Immunodeficiency Diseases: A Molecular and Genetic Approach*. Oxford University Press. 2006.
- Stiehm ER, Ochs HD, Winkelstein JA. *Immunologic Disorders in Infants and Children*. W.B. Saunders, 2004.

Sample Forms

IHP – 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 need for an IHP is based upon a student's need for nursing care while he or she is 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.

504 Accommodation Plan

A student does not need to receive special education services to be eligible for services under Section 504. Administering medication, allowing the student to carry a water bottle, make frequent phone calls to parents, or developing a procedure that allows the student to keep up with assignments due to absenteeism are examples of related aids or services (accommodations) that may be provided to a student with a primary immunodeficiency disease. To keep everyone informed, a written document should be developed that lists a student's accommodations and modifications. This document may be a Section 504 Plan or 504 Plan.

A 504 Plan is developed by the educational team, which includes the parents and student (if appropriate) and relevant school personnel. The plan should include any accommodations that may not be readily available to students without disabilities.

The types of accommodations offered by a 504 Plan are often informal agreements between parents and school personnel developed sometime during the child's educational experience. Although outlining accommodations and modifications may not seem necessary, it is always best to put things in writing to ensure consistency among all interested parties.

Confidential Personal Medical Information

SAMPLE

Individualized Healthcare Plan - IHP

School Year _____ to _____

Student _____ School _____

Birthdate _____ Age _____ Grade _____ Teacher _____

Mother _____ Home _____ Cell _____

Address _____

Father _____ Home _____ Cell _____

Address _____

Physician _____ Phone _____

Address _____

Hospital Emergency Room _____ Phone _____

Address _____

Ambulance Service _____ Phone _____

School Nurse _____ Phone _____

Medical Overview

Medical Condition _____

Symptoms Student May Report _____

Medications _____

Allergies to medications _____

Necessary Healthcare Procedures at School _____



Background Information/Nursing 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 & Interventions

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

Medications

Name _____	Frequency _____	Side Effect(s) _____
Start date _____	Stop date _____	
Name _____	Frequency _____	Side Effect(s) _____
Start date _____	Stop date _____	
Name _____	Frequency _____	Side Effect(s) _____
Start date _____	Stop date _____	

Check if additional medication information is attached. _____

Healthcare Action Plan
(Continued)

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. _____

Check if no equipment is required. _____

Safety Measures _____

_____ Check if additional information is attached. _____

Emergency Plan _____ Attached Training Plan _____ Attached

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

Possible Problems to be Expected _____

Training _____

Healthcare Plan Review

Next review date of Individualized Healthcare Plan _____

Healthcare Team Members

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

Signature

Date

_____ Administrator or Designee

_____ Teacher

_____ School Nurse

Parent Authorization for Special Health Services

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

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

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

_____ No equipment required. _____

Parent Signature

Parent Signature

Date

Date

SAMPLE

504 Accommodation Plan

Student _____ Birthdate _____ 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 (self-care, 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 and emergency evacuation plan)

Behavioral/Social Accommodations

Accommodations to Maintain Classroom Behavior

Accommodations to Participate in Desired Extra Curricular Activities

Accommodations to Participate in State/District-wide Testing

Medications

Name _____ Frequency _____ Side Effect(s) _____
 Start date _____ Stop date _____

Name _____ Frequency _____ Side Effect(s) _____
 Start date _____ Stop date _____

Name _____ Frequency _____ Side Effect(s) _____
 Start date _____ Stop date _____

Physician _____ Phone _____

Emergency Information _____

Special Recommendations

Next Review Date _____

Team Members

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

CONFIDENTIAL PERSONAL MEDICAL HISTORY

Name: _____ DOB: _____

Diagnosis: _____

Treatment: _____

MEDICATIONS:

Name: _____ Frequency: _____

Start date: _____ Stop date: _____ Side Effect(s): _____

Name: _____ Frequency: _____

Start date: _____ Stop date: _____ Side Effect(s): _____

Name: _____ Frequency: _____

Start date: _____ Stop date: _____ Side Effect(s): _____

Name: _____ Frequency: _____

Start date: _____ Stop date: _____ Side Effect(s): _____

Check if additional medication information is attached. _____

SPECIAL CONCERNS:

Allergies to medications: _____

Special dietary needs: _____

Other needs: _____



CONFIDENTIAL PERSONAL MEDICAL HISTORY

PHYSICIAN CONTACT INFORMATION:

Pediatrician

Name: _____ Phone: _____

Address: _____

E-mail: _____ FAX: _____

Immunologist

Name: _____ Phone: _____

Address: _____

E-mail: _____ FAX: _____

Other Provider (please specify specialty):

Name: _____ Phone: _____

Address: _____

E-mail: _____ FAX: _____

EMERGENCY ROOM INFORMATION:

Preferred emergency room: _____

Address: _____

HEALTH INSURANCE INFORMATION:

Plan Name: _____

Identification Number: _____

Policy Holder: _____

Plan Name: _____

Identification Number: _____

Policy Holder: _____

Plan Name: _____

Identification Number: _____

Policy Holder: _____

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