

# A Guide for School Personnel

PRIMARY IMMUNE DEFICIENCY DISEASES



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# A Guide for School Personnel Primary Immune Deficiency Diseases

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*The Immune Deficiency  
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# A Guide for School Personnel



# Foreword

It is estimated that more than 50,000 individuals in the United States are affected by primary immune deficiency diseases (PIDD). Nearly half of these individuals are children. Fortunately, due to advances in treatment, most children with PIDD are able to attend school, learn and socialize normally.

The Immune Deficiency Foundation developed this booklet to educate school personnel about primary immune deficiency diseases and the children who are affected by them. Each year, meetings held between school personnel and these families may be the most important actions to ensure the health and well being of children with PIDD within the school setting. This booklet provides the reader with key medical points about PIDD and should assist in understanding the nature of these diseases. It also includes valuable resource referrals for more information. Most importantly, the booklet is intended to facilitate effective communication between parents of children with PIDD and the school system personnel, including administrators, teachers, and nurses. It will be a valuable reference for all school personnel throughout the school year. Finally, the booklet includes a personal medical history section where parents can record current treatment, allergies, emergency information and physician contacts.

PIDD's are chronic illnesses and the symptoms and impact of the diseases may vary considerably by the specific disease diagnosis and by individual. Therefore, this booklet should be accompanied by information on the student's specific diagnosis for the most comprehensive information. As with any chronic illness, several steps can be taken to ensure improved disease management and minimize the social stressors associated with PIDD. Education of school administrators, teachers, and nurses is essential to ensure the health and well being of the student in the school setting.

## *The Importance of Communication*

Every child has the right to feel safe and comfortable in the school environment. Communication with parents and students affected by primary immune deficiency diseases is of the utmost importance. Therefore, it is essential for school personnel to initiate meetings and maintain regular communication with the families. Using this book as a basis of discussion with the families will help identify the individual needs of students with PIDD. The overview and background information in this booklet will help you to understand a small portion of what students with PIDD are experiencing in their lives. Meeting with the family affected by PIDD will enable you to discuss the specifics about the individual student and foster an ongoing relationship between the family and school system to ensure that the rights and needs of the student are met. In some cases, it may also be helpful for school personnel to contact the student's physician for more information, provided consent has been obtained from the student's parent or guardian. Forming a school health care team that would include the student affected by PIDD, his/her parents, school personnel and if necessary, the student's physician, would most comprehensively address the issues affecting the student and will ensure the best communication among all participants.

*The World Health Organization recognizes more than 120 primary immune deficiency diseases. Some disorders such as selective IgA Deficiency can be quite common, occurring as often as 1/300 to 1/500 individuals. Others, such as Severe Combined Immune Deficiency, may be as rare as one individual affected per 100,000.*

# Overview of Primary Immune Deficiency Diseases



# Overview of Primary Immune Deficiency Diseases

Primary immune deficiency diseases are disorders in which part of the body's immune system is missing or does not function properly. In contrast to secondary immune deficiency diseases in which the immune system is compromised by factors outside the immune system, such as viruses or chemotherapy, the primary immune deficiency diseases are caused by intrinsic defects in the person's own immune system. The intrinsic defects are usually inherited or genetic defects. Primary immune deficiency diseases are not contagious and have no connection with AIDS (Acquired Immune Deficiency Syndrome/HIV).

The World Health Organization recognizes more than 120 primary immune deficiency diseases. Some disorders such as Selective IgA Deficiency can be quite common, occurring as often as 1/300 to 1/500 individuals. Others, such as Severe Combined Immune Deficiency, may be as rare as one individual affected per 100,000. Untreated PIDDs may be characterized by frequent life threatening infections and debilitating illnesses. Advances in medical understanding and treatment of primary immune deficiency diseases have made it possible for many individuals with PIDD to live nearly normal lives. However, it is important to remember that PIDDs are chronic illnesses and even with therapy, individuals may still experience frequent and recurrent infections that can impact every day life.

**Table 1**

Examples of Primary Immune Deficiency Diseases

DISEASE	IMMUNE DEFECT	PRIMARY TREATMENT
X-Linked Agammaglobulinemia (XLA or Bruton's Disease)	B-Cell Defect/Antibody Deficiency	Immune Globulin Infusions
Common Variable Immune Deficiency (CVID)	B-Cell Defect/Antibody Deficiency	Immune Globulin Infusions
Hyper IgM Syndrome	B-Cell Defect/Antibody Deficiency	Immune Globulin Infusions
IgG Subclass Deficiency	B-Cell Defect/Antibody Deficiency	Antibiotic Therapy; 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	Adult Bone Marrow or Cord Blood Stem Cell Transplants; Immune Globulin Infusions
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
Complement Component Deficiencies	Complement Defect (Over 30 different complement components)	Antibiotic Therapy
Chronic Granulomatous Disease (CGD)	Phagocyte Function Defect	Gamma Interferon Injections
DiGeorge Syndrome	T-Cell Defect/Thymic Aplasia	Thymic Transplant; Immune Globulin Infusions

**Table 2**

Examples of infections and other clinical symptoms experienced with Primary Immune Deficiency Diseases\*

IMMUNE DEFECT	CLINICAL SYMPTOMS
B-Cell Defects/Antibody Deficiencies	Sinusitis, Pulmonary infections, Gastrointestinal infections/complications, Autoimmune Diseases
T-Cell Defect	Pneumonia due to both bacteria and viruses, Gastrointestinal infections due to viruses, Skin and mucous membrane infections due to fungi
Combined B- and T-Cell Defects	Pneumonia due to both bacteria and viruses, Gastrointestinal infections due to viruses, Skin and mucous membrane infections due to fungi
Phagocytic Defects	Infections and abscesses of the skin and reticuloendothelial system due to fungi, mycobacteria, staphylococci and enteric bacteria
Complement Component Defects	Sepsis and other blood-borne infections due to streptococci, pneumococci, and neisseria; Autoimmune diseases

\*Excerpted from "IDF Clinical Focus: Clinical Presentation of Primary Immunodeficiency Diseases", March, 2002, Table 5, p.3

*There are a number of specific medical therapies available to individuals with primary immune deficiency diseases. The type of therapy received by an individual depends on the type and severity of the primary immune deficiency disease.*

# Medical Therapy for Primary Immune Deficiency Diseases

# Specific Medical Therapies

## *Therapies for B-Cell Defects and Antibody Deficiencies*

Antibody deficiencies are some of the most common PIDDs. Antibodies are produced by B-cells. In diseases with B-cell defects, antibody replacement therapy is initiated via human immune globulin infusions. Immune globulin refers to the fraction of blood plasma that contains immunoglobulins or antibodies. It is typically infused intravenously and known as immune globulin intravenous therapy, or IGIV. Individuals who are unable to produce adequate amounts of immunoglobulins or antibodies may benefit from replacement therapy with immune globulin. The immune globulin temporarily replaces the missing antibodies and helps prevent infections. Patients must be infused on average every 3-4 weeks in order to maintain adequate levels. IGIV infusions usually take several hours. Subcutaneous administration of immune globulin is increasingly becoming an option for individuals affected by antibody deficiencies. Subcutaneous immune globulin, Subq IG, is typically administered through a small needle under the skin for several hours two to four times per month.

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

**Stem cell transplantation** is a form of treatment for individuals with T- cell defects. Stem cells from a normal adult's blood or bone marrow or from the cord blood of a normal newborn are transplanted to an immune deficient recipient. It is a highly specialized treatment that can be used to treat some PIDDs. Another method to obtain stem cells is from bone marrow. Bone marrow is removed from the pelvic bones of a healthy donor and transplanted through a needle into a vein of the immune deficient individual.

**Enzyme replacement therapy** may be used for individuals who have Severe Combined Immune Deficiency due to adenosine deaminase (ADA) deficiency. Intramuscular injection of polyethylene glycol or PEG-ADA twice a week maintains enough ADA activity in the bloodstream of patients to effectively eliminate the toxic effects of deoxyadenosine that cause the immune deficiency.

### *Therapies for Phagocytic Defects*

Individuals with Chronic Granulomatous Disease (CGD), a type of phagocytic defect, often receive subcutaneous gamma interferon injections three times weekly. 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.



## **Other Therapies**

### *Antibiotic and Antifungal Therapy*

While many of the primary immune deficiency diseases are well-controlled by replacement therapies or transplantation of stem cells, individuals can still experience recurrent bouts of infections, especially during the winter months of the year. For this reason, many individuals affected by PIDD are on numerous courses of antibiotics or antifungal medications throughout the year, depending on the types of infections experienced.

### *Gene Therapy*

In the United States and in Europe, gene therapy is being researched as a potential treatment for primary immune deficiencies in which the defective gene has been identified. It is likely that one day gene therapy will be the procedure of choice for many primary immune deficiency diseases.

# Possible Side Effects of Medical Therapies

While the majority of individuals with PIDD do not experience serious side effects from the aforementioned medical therapies, side effects can occur. Therefore, it is important to discuss with the family the possible side effects that can be associated with the specific medical therapy and the impact on the student's attendance and function in the school setting. It is also important to understand the appropriate protocol to follow in the event that a student is experiencing a side effect following an immune globulin infusion or other medical therapy.

## *IGIV Therapy*

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

It is not uncommon for mild side effects to persist for 2 - 3 days following the IGIV treatment. Understandably, these side effects can cause some students to be absent from school.

## *Gamma Interferon Therapy*

Common side effects of gamma interferon therapy include fever, muscle aches, headaches, and occasionally chills.

## *PEG-ADA*

Aside from the discomfort of an intramuscular injection, PEG-ADA has had no side effects.

*Children with primary  
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infections.*

# Susceptibility to Infections

Children with primary immune deficiency diseases may be more susceptible to infections. Even with regular medical treatment, it is important to be aware that frequent infection is still a possibility. 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, glandular fever, meningitis, hepatitis and measles if these occur either in the child's classroom or in the entire school.
- ❁ 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.

*Parents should be notified  
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# Vaccinations

Live vaccines can harm individuals who have impaired immune systems. In fact, administering a live vaccine to persons with primary immune deficiency diseases could cause them to contract the illness. Therefore, *under no circumstances should a student be administered a vaccination without written parental permission.*

Additionally, parents should be notified of any vaccination program within the school system.

Children with PIDD may be at risk of contracting infection from another individual who has received a live vaccination such as Varivax, the oral polio vaccine, or FluMist, the nasal form of the influenza vaccine. Parents of children with PIDD 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 discuss a plan of the student's temporary removal from the school with the parents and student's physician.

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

*Meeting with the family at the beginning of each year to review the special needs of the child with a primary immune deficiency disease will allow for a safe and smooth transition throughout the school experience.*

# Special Needs

Meeting with the family at the beginning of each year to review the special needs of the child with a primary immune deficiency disease will allow for a safe and smooth transition throughout the school experience. Additionally, it may be necessary to discuss a student's special needs with his/her physician. This should first be discussed with the student's parent and if necessary permission may be given to the school personnel to contact the physician directly. Examples of special needs are listed below:

- ❁ 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 PIDD have chronic ear infections which may limit them from participating in swimming class as part of a physical education program.
- ❁ Hall passes or scheduled nursing visits may be needed for medication administration during school hours.
- ❁ Nutrition and diet may play an important part in the management of some individuals with PIDD. Frequent meals or special nutritional needs due to intestinal malabsorption or other associated nutritional disorders may be required for some students.
- ❁ Special restroom privileges due to gastrointestinal complications associated with the PIDD may be required for some students.

This list is not exhaustive and is dependent on each student's specific diagnosis. Depending on the individual child's needs, it may be necessary to establish a Section 504 Plan or an Individualized Education Plan (IEP) for a student with PIDD that would include his/her specific special needs and accommodations to ensure the greatest access to his/her education. Please see the *Educational Rights under Federal Law* section of this Guide for more information on Section 504 Plans and IEPs.



# Special Needs

## *Emotional/Social Issues*

The challenge of living with a chronic illness such as primary immune deficiency disease 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 PIDD. It is, therefore, important for all school personnel associated with a student affected by a PIDD 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/her family seek appropriate interventions in a timely manner.

*Students with primary  
immune deficiency diseases  
often miss more school than  
their classmates.*

# Absenteeism



# Absenteeism

Students with primary immune deficiency diseases often miss more school than their classmates because of regularly scheduled treatments, doctor's visits, and infections that may develop. Often, a student looks healthy to others, but the student's parents are aware that a simple cold can lead to other complications. Because of their keen awareness of their child's history, many times these parents are in the physician's office with their children before symptoms have time to present themselves. A parent knows their child best of all and will often pick up the early signs of potential trouble. Consequently, children with primary immune deficiency diseases often have an increased number of absences from school.

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 Section 504 Plan or an Individual Education Plan (IEP) may be helpful in this case. Permission for absences, without penalty, due to illness, doctor's visits, and/or regularly scheduled treatments can be included as part of the student's special needs in a Section 504 Plan or IEP. Please see the *Educational Rights under Federal Law* section of this Guide for more information on Section 504 Plans and IEPs.

*While it is essential that students with primary immune deficiency diseases be allowed to maintain as normal a school life as possible, some students may have special needs in the school setting.*

# Educational Rights under Federal Law



# Educational Rights under Federal Law

While it is essential that students with primary immune deficiency diseases be allowed to maintain as normal a school life as possible, some students may have special needs in the school setting as described in the sections on *Special Needs* and *Absenteeism*. Federal laws have been developed to help protect individuals with disabilities from discrimination. Specific federal education laws help protect children with disabilities from discrimination in the school setting and allow them to achieve the best possible education. The provisions outlined in these laws may not be necessary for all students with primary immune deficiency diseases. It will depend on each student's diagnosis and individual case as to whether or not they would need to discuss the implementation of a special plan as outlined below to ensure that their special needs are met in the school setting. Below is a summary of the federal laws that have been enacted to protect students with disabilities.

## ***Section 504 of the Rehabilitation Act of 1973***

Section 504 of the Rehabilitation Act of 1973 is a civil rights law which protects the rights of individuals with disabilities in programs and activities that receive federal funds from the U.S. Department of Education. "Section 504" requires school districts to provide a "free appropriate public education (FAPE)" to each qualified individual with a disability. To be protected under Section 504, a student must be determined to: 1) have a physical or mental impairment that substantially limits one or more major life activities; 2) have a record of such an impairment, or 3) be regarded as having such an impairment.

- ***Section 504 Plan*** - A Section 504 Plan is a written education plan that outlines specific medical accommodations, educational aids and services that a student with a disability may need to function appropriately in the school setting. Specific examples of items for inclusion in a Section 504 Plan for a student with PIDD are listed in the *Special Needs* section of this Guide.

## ***Individuals with Disabilities Education Act (IDEA) of 1990***

The Individuals with Disabilities Education Act (IDEA) of 1990 is a civil rights law that provides a “free appropriate public education” to individuals with disabilities between the ages of 3 and 21 years in the “least restrictive environment”. This law protects individuals whose disability adversely affects their educational performance and provides special education services for eligible students.

- ***Individualized Education Plan (IEP)*** - A student with special educational needs is entitled to an Individualized Education Plan (IEP) which identifies and outlines the special services needed in a written format.

## ***Americans with Disabilities Act (ADA) of 1990***

The Americans with Disabilities Act (ADA) of 1990 is a civil rights law that guarantees equal opportunity to individuals with disabilities in employment, public accommodations, transportation, state and local government services, and telecommunications. Students with PIDD may qualify as having a disability under the ADA, depending on their particular diagnosis and clinical symptoms. The ADA defines a disability as a physical or mental impairment that substantially limits one or more “major life activities”. “Major life activities” are defined as functions such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working. The ADA mandates that “reasonable accommodations” be made for individuals with disabilities in the above mentioned settings. Students with primary immune deficiency diseases usually fall under the “Other Health Disabled” category if they are deemed disabled because of their medical condition. “Other Health Disabled” is defined as having limited strength, vitality, or alertness.

It is important to form a school health care team to work with the parents of a student with PIDD and even the student’s physician, if necessary, on developing a Section 504 Plan or an Individualized Education Plan (IEP). The *Special Needs* section of this Guide lists examples of the types of special needs that are specific to students with PIDD and would be important to include in a Section 504 Plan or an IEP. <sup>1</sup>

<sup>1</sup> *Protecting Students with Disabilities: Frequently Asked Questions about Section 504 and the Education of Children with Disabilities.* <http://www.ed.gov/about/offices/list/ocr/504faq.html> Viewed July 25, 2005.

*Transition between high school and college or entering the work force can be a difficult time for individuals affected by chronic illnesses such as primary immune deficiency.*

# Considerations for Post-Secondary Education and Employment

The period of transition between high school and college or entering the work force can be a difficult time for individuals affected by chronic illnesses such as primary immune deficiency diseases. Academic and social stressors are major concern for high school students with PIDD thinking about going to college. Practical considerations about choosing a career and maintaining good health insurance after young adults transition from their parents' policies are also major concerns. Anticipating these concerns and working together with the student and established school health care team can help ease this transition period. Below is a summary of considerations for post-secondary education and employment for students with PIDD who have special needs. As discussed in the previous sections on *Educational Rights Under Federal Law*, the following provisions may not apply to all students with PIDD. It will again depend on each individual's diagnosis and health concerns.

### ***Post-Secondary Education***

More and more high school students with primary immune deficiency diseases are planning to continue their education in post-secondary schools, including vocational and career schools, two- and four- year colleges and universities. It is important for the student and school health care team to be well informed about the student's rights and responsibilities as well as the responsibilities that post-secondary schools have to the student. Being well informed will help ensure that the student will have a full opportunity to enjoy the benefits of the post-secondary education experience without confusion or delay.

### ***Section 504 of the Rehabilitation Act of 1973***

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. It is possible to establish a Section 504 Plan for a student in a post-secondary institution. 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 Plan in a post-secondary school. For more information and to request a copy of this guide, please go to the OCR's website: <http://www.ed.gov/about/offices/list/ocr/transition.html> or call the OCR office at (800) 421-3481.

# Employment

## *Vocational Rehabilitation Programs*

Under Title I of the Rehabilitation Act of 1973, states receive federal grants to operate a comprehensive Vocational Rehabilitation (VR) Program. These funds are awarded to designated state VR agencies within each state. This state-operated program is designed to assess, plan, develop and provide VR services to eligible individuals with disabilities, consistent with their strengths, resources, priorities, concerns, abilities, capabilities, interests and informed choice. By providing services in this way, the VR program enables individuals with disabilities to prepare for and engage in employment.

Depending on the specific diagnosis and level of disability, a student with PIDD may be eligible to participate in their state VR program. For more information, please refer to the following websites:

- [www.ed.gov/about/offices/list/osers/rsa/index.html](http://www.ed.gov/about/offices/list/osers/rsa/index.html) for general information;
- [www.ed.gov/about/offices/list/osers/rsa/faq.html](http://www.ed.gov/about/offices/list/osers/rsa/faq.html) for frequently asked questions about VR programs;
- [www.jan.wvu.edu/SBSES/VOCREHAB.HTM](http://www.jan.wvu.edu/SBSES/VOCREHAB.HTM) for a list of state Vocational Rehabilitation agencies.

*Information about primary  
immune deficiency diseases,  
federal organizations,  
education issues, personal  
medical history & medication  
update.*

# Resources for Educators

## INFORMATION ABOUT PRIMARY IMMUNE DEFICIENCY DISEASES

### [Immune Deficiency Foundation](#)

[www.primaryimmune.org](http://www.primaryimmune.org)

Telephone: (800) 296-4433

*The national non-profit organization dedicated to improving the diagnosis and treatment of primary immune deficiency diseases through research, education and advocacy.*

### [A-T Children's Project](#)

[www.atcp.org](http://www.atcp.org)

Telephone: (954) 481-6611

*A non-profit organization dedicated to raising funds that will help accelerate scientific research into finding a cure for Ataxia Telangiectasia (A-T). The website provides general information on A-T and resources for patients and professionals.*

### [The Chronic Granulomatous Disease Association](#)

[www.home.socal.rr.com/cgda](http://www.home.socal.rr.com/cgda)

*An organization that provides support to individuals and family members affected by Chronic Granulomatous Disease (CGD).*

### [International Patient Organization for Primary Immunodeficiencies \(IPOPI\)](#)

[www.ipopi.org](http://www.ipopi.org)

*IPOPI is an international organization for primary immune deficiency diseases. The web site provides general information on PID and resource contacts for patients and professionals worldwide.*

### [Hereditary Angioedema Association](#)

[www.hereditaryangioedema.com](http://www.hereditaryangioedema.com)

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

### [The Jeffrey Modell Foundation](#)

[www.jmfworld.org](http://www.jmfworld.org)

Telephone: (800) 1-866-INFO-4-P1

*A non-profit research foundation devoted to primary immune deficiency diseases.*

### [Severe Combined Immunodeficiency \(SCID\) Homepage](#)

[www.scid.net](http://www.scid.net)

*This web site provides excellent information and resources on Severe Combined Immune Deficiency.*

### [Velo-Cardio-Facial Syndrome Educational Foundation, Inc.](#)

[www.vcfsef.org](http://www.vcfsef.org)

*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.*

## FEDERAL ORGANIZATIONS

### [Centers for Disease Control and Prevention, National Immunization Program](http://www.cdc.gov/nip) [www.cdc.gov/nip](http://www.cdc.gov/nip)

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Telephone: (888) CDC-FAXX

*This division of the CDC provides information on general vaccinations and specific precautions for individuals with primary immune deficiencies.*

### [Centers for Medicare and Medicaid](http://www.cms.hhs.gov) [www.cms.hhs.gov](http://www.cms.hhs.gov)

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*The federal agency that administers Medicare, Medicaid and the State Children's Health Insurance Program (CHIP). The web site provides information on these programs and other the initiatives of the Department of Health and Human Services such as the "Health Insurance Portability and Accountability Act." It also lists the state health insurance commissioners, which can be helpful in seeking health insurance assistance.*

### [National Institute of Allergy and Infectious Diseases \(NIAID\)](http://www.niaid.nih.gov) [www.niaid.nih.gov](http://www.niaid.nih.gov)

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Office of Communications Telephone: (301) 496-5717

*This organization is a division of the National Institutes of Health that provides information about allergy and infectious diseases, and primary immune deficiency diseases to the public.*

### [National Institute of Child Health and Human Development \(NICHD\)](http://www.nichd.nih.org) [www.nichd.nih.org](http://www.nichd.nih.org)

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Telephone: (877) 696-6775

*A division of the National Institutes of Health that provides general information on children's health issues, including an in-depth booklet on primary immune deficiency diseases.*

### [U.S. Department of Education](http://www.ed.gov/index.jhtml) [www.ed.gov/index.jhtml](http://www.ed.gov/index.jhtml)

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Telephone: (800) 872-5327

*The U.S. Government agency responsible for ensuring equal access to education and for promoting educational excellence throughout the nation.*

[Office for Civil Rights \(OCR\)](http://www.ed.gov/ocr) [www.ed.gov/ocr](http://www.ed.gov/ocr)

Telephone: (800) 421-3481

[Office for Special Education Programs \(OSEP\)](http://www.ed.gov/offices/OSERS/OSEP) [www.ed.gov/offices/OSERS/OSEP](http://www.ed.gov/offices/OSERS/OSEP)

Telephone: (202) 205-5507

### [U.S. Department of Health and Human Services \(HHS\)](http://www.dhhs.gov) [www.dhhs.gov](http://www.dhhs.gov)

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Telephone: (877) 696-6775

*This organization 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 departments numerous federal programs.*

### [U.S. Department of Justice Civil Rights Division, Office of ADA](http://www.usdoj.gov) [www.usdoj.gov](http://www.usdoj.gov)

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Telephone: (800) 514-0301

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

## EDUCATION ISSUES

### HEATH Resource Center

[www.HEATH.gwu.edu](http://www.HEATH.gwu.edu)

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Telephone: (800) 544-3284

*This organization is the national clearinghouse on post-secondary education for individuals with disabilities. It provides information about educational support services, policies, procedures, adaptations and opportunities at American campuses, vocational-technical schools and other post secondary training sites.*

### National Information Center for Handicapped Children and Youth

[www.nichcy.org](http://www.nichcy.org)

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Telephone: (800) 695-0285

*This organization 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.*

### Wrightslaw

[www.wrightslaw.com](http://www.wrightslaw.com)

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

# PERSONAL MEDICAL HISTORY

Name: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

Treatment: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## MEDICATIONS:

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_

Start date \_\_\_\_\_ Stop date \_\_\_\_\_

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_

Start date \_\_\_\_\_ Stop date \_\_\_\_\_

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_

Start date \_\_\_\_\_ Stop date \_\_\_\_\_

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_

Start date \_\_\_\_\_ Stop date \_\_\_\_\_

## SPECIAL CONCERNS:

Allergies to medications: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Special dietary needs: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Other needs: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## 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: \_\_\_\_\_

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## EMERGENCY CONTACT INFORMATION

Name: \_\_\_\_\_

Telephone: (work) \_\_\_\_\_ (home) \_\_\_\_\_

(cell) \_\_\_\_\_

Relationship to student: \_\_\_\_\_

Name: \_\_\_\_\_

Telephone: (work) \_\_\_\_\_ (home) \_\_\_\_\_

(cell) \_\_\_\_\_

Relationship to student: \_\_\_\_\_

### 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: \_\_\_\_\_

Plan Name: \_\_\_\_\_

Identification Number: \_\_\_\_\_

Policy Holder: \_\_\_\_\_

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# MEDICATION UPDATE

Name of Student: \_\_\_\_\_

## MEDICATIONS:

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Start date \_\_\_\_\_ Stop date \_\_\_\_\_

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Start date \_\_\_\_\_ Stop date \_\_\_\_\_

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Start date \_\_\_\_\_ Stop date \_\_\_\_\_

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Start date \_\_\_\_\_ Stop date \_\_\_\_\_

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Start date \_\_\_\_\_ Stop date \_\_\_\_\_

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Start date \_\_\_\_\_ Stop date \_\_\_\_\_

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Start date \_\_\_\_\_ Stop date \_\_\_\_\_

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Start date \_\_\_\_\_ Stop date \_\_\_\_\_

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Start date \_\_\_\_\_ Stop date \_\_\_\_\_

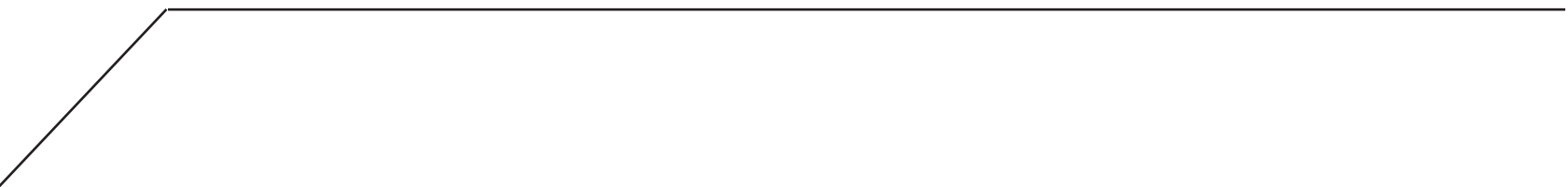
Name: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Start date \_\_\_\_\_ Stop date \_\_\_\_\_

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Start date \_\_\_\_\_ Stop date \_\_\_\_\_

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Start date \_\_\_\_\_ Stop date \_\_\_\_\_

Name: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Start date \_\_\_\_\_ Stop date \_\_\_\_\_

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Inside Back Pocket

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through a generous grant from the



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