Immune Deficiency Foundation Resources

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

Services for Patients and Families

• **Ask IDF:** Contact IDF with questions about living with primary immunodeficiency diseases through the IDF website: www.primaryimmune.org/ask-idf. IDF has a vast reserve of innovative resources and individualized assistance to help with the unique aspects of living with a primary immunodeficiency. From learning more about the diseases, to understanding insurance coverage, to lifestyle issues and more, be sure to Ask IDF.

• **Locate a Physician:** Contact IDF to find a physician in your area who is an expert on primary immunodeficiency diseases.

• **Peer Support:** Connecting people and patients who share similar relationships to primary immunodeficiency diseases.

• **Patient Assistance Resources:** Individualized assistance is available for patients experiencing problems with insurance denials for treatment, reimbursement issues, concerns with Medicare or Medicaid, disability, and accessing copayment and premium assistance. Resources and tools are available to help tackle insurance challenges.

• **Information about Patient Rights:** Patients can contact IDF to learn about their rights concerning product choice and treatment options, employment and school issues, as well as fair treatment, privacy or other rights.

• **IDF eHealthRecord:** An electronic personal health record designed for the primary immunodeficiency community to help organize health information in one place.

Programs for Patients and Families

• **Local Patient Meetings:** Education programs featuring local experts and networking opportunities.

• **Operation Outreach:** Patient education meetings designed to strengthen underserved areas.

• **IDF Retreats:** Weekend events for all ages that feature medical and life management sessions.

• **IDF Youth Programs:** Designed for children diagnosed with a PIDD or have a family member with this condition.

• **IDF Teen Escape:** Weekend program developed to acquaint teens diagnosed with primary immunodeficiency diseases.

• **IDF National Conference:** The world’s largest gathering of families affected by primary immunodeficiency diseases.

• **Volunteer:** Network of volunteers who provide peer support, create awareness, help host educational meetings, advocate for public policy, visit plasma centers and organize fundraising events throughout the country.

• **Scholarship Program:** Awards for students living with primary immunodeficiency diseases who plan on completing their secondary education.

• **Take the Zebra Challenge!** Fundraising campaign that provides the IDF community with multiple resources to create personal fundraisers and teach the world about “zebras.”

• **IDF Plasma Centers Partners Program:** Awareness and fundraising initiatives within plasma centers across the country arranged by IDF that highlights the work of plasma center staff members, plasma donors and IDF volunteers.

Services for Healthcare Professionals

www.primaryimmune.org/healthcare-professionals

• **IDF Medical Advisory Committee:** Comprised of prominent immunologists to support the mission of the IDF. Available as a resource for clinicians diagnosing and treating patients with primary immunodeficiency diseases.

• **IDF Nurse Advisory Committee:** Comprised of exceptional nurses to support the mission of the IDF. Available as a resource for nurses administering immunoglobulin therapy or treating patients with primary immunodeficiency diseases.

• **IDF Online Continuing Education Course for Nurses (English):** Primary Immunodeficiency Diseases and Immunoglobulin Therapy: A free, 5-hour, U.S. accredited course for nurses that provides an update on primary immunodeficiency diseases, immunoglobulin therapies and the nurse’s role with these therapies: www.primaryimmune.org/healthcare-professionals/continuing-education-course-for-nurses.
• **IDF Video Translations for Nurses (French, German, Spanish): Primary Immunodeficiency Diseases and Immunoglobulin Therapy:** A free, non-credit video series translated into French, German and Spanish. The series is based on the IDF Online Continuing Education Course for Nurses, which provides an update on primary immunodeficiency diseases, immunoglobulin therapies and the nurse’s role with these therapies.

• **IDF Consulting Immunologist Program:** A free service for physicians which provides consults with expert clinical immunologists on issues of diagnosis, treatment and disease management.

• **USIDNet:** The United States Immunodeficiency Network (USIDNet), an international consortium established to advance scientific research in the primary immunodeficiency diseases through peer reviewed research grants, education and mentoring programs, DNA and cell repository, and patient registries. Administered by IDF.

• **IDF & USIDNet LeBien Visiting Professor Program:** Promote improved knowledge by providing faculty at teaching hospitals with a Visiting Professor with expertise in primary immunodeficiency disease. Offers Grand Rounds and clinical presentations at medical institutions throughout North America.

**Publications**

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

**For patients and families:**

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

**For healthcare providers:**

- **IDF Diagnostic & Clinical Care Guidelines for Primary Immunodeficiency Diseases 2nd Edition**
- **IDF Guide for Nurses on Immunoglobulin Therapy for Primary Immunodeficiency Diseases 3rd Edition**
- **Clinical Focus on Primary Immunodeficiencies:**
  - “Clinical Update in Immunoglobulin Therapy for Primary Immunodeficiency Diseases”
  - “Subcutaneous IgG Therapy in Immune Deficiency Diseases”
  - “Primary Humoral Immunodeficiency Optimizing IgG Replacement Therapy”
  - “The Clinical Presentation of Primary Immunodeficiency Diseases”
  - “Treatment and Prevention of Viral Infections in Patients with Primary Immunodeficiency Diseases”
  - “IgG Subclass Deficiency”
  - “Immunization Of The Immunocompromised Host”

**Communications**

- **IDF Advocate:** Newsletter, published three times per year.
- **Primary Immune Tribune:** E-newsletter, published monthly.
- **IDF Friends, [www.idffriends.org](http://www.idffriends.org):** A social network exclusively for the primary immunodeficiency community.
- **IDF Common Ground, [www.idfcommonground.org](http://www.idfcommonground.org):** An online community for teens with primary immunodeficiency diseases.
- **IDF TV, [www.primaryimmune.org/idf-tv](http://www.primaryimmune.org/idf-tv):** A web-based TV channel that that brings issues that affect the primary immunodeficiency community to life.
- **IDF Arcade, [www.primaryimmune.org/idf-arcade](http://www.primaryimmune.org/idf-arcade):** Games designed for children ages 4 to 12 that are a great way to have fun, while learning about the immune system.
Resources

(IDF Resources continued)

- **IDF Reel Stories**, [www.primaryimmune.org/idf-reel-stories](http://www.primaryimmune.org/idf-reel-stories): IDF Reel Stories is a patient-generated video community designed to encourage and empower fellow patients and their loved ones.

- **IDF Blog**, [www.primaryimmune.org/blog](http://www.primaryimmune.org/blog): Includes updates on IDF programs and services as well as important issues. Users can comment, submit news, and share posts about awareness activities, advocacy initiatives, fundraising events and more.

- **IDF SCID Newborn Screening Blog**, [www.idfscidnewbornscreening.org](http://www.idfscidnewbornscreening.org): Documents the fight to establish Severe Combined Immunodeficiency (SCID) newborn screening programs in all 50 states. Babies with SCID appear healthy at birth, but without early treatment, most often by bone marrow transplant from a healthy donor, these infants cannot survive. Testing for SCID is not currently included in the newborn screening panels of all states.

**Public Policy Initiatives**

- Advocacy efforts monitor public policy issues that are critical to patients at national and state levels, including Medicare Patient IVIG Access Act, SCID Newborn Screening, Health Insurance Ig Guidelines and more.

- Grassroots advocacy program mobilizes members of the PIDD community to contact their government representatives to promote healthcare legislation that will positively affect the community.

- IDF Advocacy Center features Action Alerts, enabling users to easily voice their concerns to decision makers, and the IDF Advocacy Channel, featuring patient and caregiver stories: [www.primaryimmune.org/idf-advocacy-center](http://www.primaryimmune.org/idf-advocacy-center).

**Information about Primary Immunodeficiencies**

**Immune Deficiency Foundation**
[www.primaryimmune.org](http://www.primaryimmune.org)
800-296-4433

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

**International Patient Organization for Primary Immunodeficiencies**
[www.ipopi.org](http://www.ipopi.org)

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

**The Jeffrey Modell Foundation**
[www.jmfworld.org](http://www.jmfworld.org)
866-INFO-4-PI (866-463-6474)

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

**Disease Specific Patient Groups and Organizations**

**A-T Children’s Project**
[www.atcp.org](http://www.atcp.org)

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

**Chronic Granulomatous Disease Association**
www.cgdassociation.org

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

**Hereditary Angioedema Association, Inc.**
www.haea.org

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

**Severe Combined Immune Deficiency**
www.scid.net

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

**SCID Angels for Life**
www.scidangelsforlife.com

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

**Understanding XLP**
www.xlp.ca

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

**Wiskott-Aldrich Foundation**
www.wiskott.org

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

**XLP Research Trust**
www.xlpresearchtrust.org

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

### National Organizations

**American Academy of Allergy, Asthma, and Immunology**
www.aaaai.org
313-371-8600
Physician Referral Service: 800-822-2762

The American Academy of Allergy, Asthma, and Immunology (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**
www.aap.org
847-434-4000

The American Academy of Pediatrics (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.
(National Organizations continued)

Clinical Immunology Society
www.clinimm soc.org
414-224-8095
The mission of the Clinical Immunology Society (CIS) 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.

Federation of Clinical Immunology Societies
www.focisnet.org
The Federation of Clinical Immunology Societies (FOCIS) exists to improve human health through immunology by fostering interdisciplinary approaches to both understand and treat immune-based diseases.

Immunoglobulin Nursing Society
www.ig-ns.org
Immunoglobulin Nursing Society (IgNS) is a professional organization dedicated to nursing professionals in education, management, practice and research in the field of immunoglobulin (Ig) therapy.

Infusion Nurses Society
www.ins1.org
The Infusion Nurses Society (INS) is dedicated to exceeding the public’s expectations of excellence by setting the standard for infusion care.

National Marrow Donor Program
www.marrow.org
800-627-7692
The National Marrow Donor Program (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.

International Organizations

European Society for Immunodeficiencies (ESID)
www.esid.org
The European Society for Immunodeficiencies (ESID) is a non-profit medical organization. The purpose of ESID is to foster excellence in research and medical practice and to promote interaction with nurses and patient associations, so as to increase exchange of information among patients, parents of patients, nurses, doctors and researchers.

International Nursing Group for Immunodeficiencies (INGID)
www.ingid.org
The purpose of the International Nursing Group for Immunodeficiencies (INGID) is to improve and extend the quality of nursing care of patients with primary immunodeficiencies, and to increase the awareness and understanding of primary immunodeficiencies amongst nurses.

International Patient Organization for Primary Immunodeficiencies (IPOPI)
www.ipopi.org
The International Patient Organization for Primary Immunodeficiencies (IPOPI) is an international organization whose members are national patient organizations for primary immunodeficiencies. The site provides general information on primary immunodeficiency and resource contacts for patients and professionals worldwide. The following is a list of Member Organizations and International Support Groups:

Argentina: www.aapidp.com.ar
Australia: www.idfaustralia.org
Austria: www.oespid.at
Belarus: Andron116@yandex.ru
Canada: www.cipo.ca
(International Organizations continued)

Chile: vidaportalavida@gmail.com
Colombia: www.fundacionfip.org.co
Cyprus: Maria.g.charalambous@cyta.com.cy
Denmark: www.idf.dk
Estonia: janne.rimmel@mail.ee
Finland: anna-riitta.satama@luukku.com
France: www.associationiris.org
Germany: www.idf.de
Greece: www.paed-anosia.gr
Hungary: hzsu86@gmail.com
Iceland: onaemisgalli@onaemisgallar.is
India: www.ipspiindia.org
Iran: www.ipidr.tums.ac.ir
Ireland: ipiasecretary@gmail.com
Italy: www.aip-it.org
Japan: www.npo-pidtsubasa.org
Mexico: www.fumenip.org.mx
Morocco: www.hajar.org.ma
The Netherlands:
  www.stichtingvoorafweerstoornissen.nl
New Zealand: www.idfnz.org.nz
Norway: evabrox@online.no
Poland: www.immunoprotect.pl
Portugal: mjmousinho@gmail.com

Romania: www.arpid.ro
Russia: anton_emelin@hotmail.com
Serbia: www.pospid.org
South Africa: www.pinsula.org.za
Spain: www.aedip.com
Sweden: www.pio.nu
Switzerland: www.svai.ch
Turkey: www.imyed.org.tr
United Kingdom: david@ipopi.org
United States www.primaryimmune.org,
  www.info4pi.org
Venezuela: idpvenezuela@gmail.com

Latin American Society for Primary Immunodeficiencies (LASID)
www.lasid.org

The Latin American Society for Primary Immunodeficiencies (LASID) is a professional organization comprised of physicians from various Latino countries who are dedicated to promoting the awareness, diagnosis and treatment of primary immunodeficiency diseases in these countries.

Federal Organizations

Centers for Disease Control and Prevention, National Immunization Program
www.cdc.gov/vaccines
800-CDC-INFO (800-232-4636)

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

Center for Biologics Evaluation and Research, FDA
www.fda.gov/BiologicsBloodVaccines
800-835-4709

A division of the Food and Drug Administration (FDA) whose mission is to protect and enhance public health through regulation of biological products to ensure their safety, effectiveness and timely delivery to patients. This agency provides information on biological products, such as blood and plasma, including new product approvals, adverse events, product recalls and withdrawals.
Centers for Medicare and Medicaid Services
www.cms.gov
800-633-4227
The Centers for Medicare and Medicaid Services (CMS) provides information for individuals receiving services from Medicare, Medicaid or SCHIP.

National Institutes of Health
U.S. Department of Health And Human Services:
National Institutes of Health
www.nih.gov
301-496-4000
The National Institutes of Health (NIH) provides information on advances in health, science and medical issues. The following are divisions of NIH:

National Cancer Institute
www.cancer.gov
800-422-6237
National Cancer Institute (NCI) provides the following information about cancer: topics, trials, statistics and research.

National Heart, Lung and Blood Institute
www.nhlbi.nih.gov
301-592-8573
The National Heart, Lung and Blood Institute (NHLBI) provides leadership for a national program in diseases of the heart, blood vessels, lung, and blood; blood resources; and sleep disorders.

National Human Genome Research Institute
www.genome.gov
301-402-0911
The National Human Genome Research Institute (NHGRI) applies genome technologies to the study of specific diseases and the genetic components of complex disorders.

National Institute of Allergy and Infectious Diseases
www.niaid.nih.gov
Office of Communications: 301-496-5717
The National Institute of Allergy and Infectious Diseases (NIAID) is provides information on allergy and infectious diseases, as well as primary immunodeficiencies.

National Institute of Child Health and Human Development
www.nichd.nih.gov
800-370-2943
The National Institute of Child Health and Human Development (NICHD) provides general information on children’s health issues, including an in-depth booklet on primary immunodeficiencies.

NIH Clinical Trials
www.clinicaltrials.gov
800-411-1222
The NIH Clinical Trials site contains current information on clinical trials being conducted, some of which may be pertinent to primary immunodeficiencies.

NIH Health Information
www.health.nih.gov
This is an A-Z index of NIH health resources, clinical trials, MedlinePlus and health hotlines.

NIH Office of Rare Diseases
www.rarediseases.info.nih.gov
301-402-4336
The NIH Office of Rare Diseases (ORD) coordinates research on rare diseases and supports research to respond to the needs of patients who have any one of the more than 6,000 rare diseases known today.

NIH Research Training and Scientific References
www.nih.gov/science
This site contains information about intramural research, Human Embryonic Stem Cell Registry, scientific interest groups, library catalogs, journals, training, labs, scientific computing and more.

National Library of Medicine
www.nlm.nih.gov
888-346-3656
The National Library of Medicine (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.
(Federal Organizations continued)

National Office of Public Health Genomics
www.cdc.gov/genomics
770-488-8510
This site provides updated information on how human genomic discoveries can be used to improve health and prevent disease. It also provides links to Centers for Disease Control and Prevention (CDC) activities in public health genomics.

U.S. Department of Education
www.ed.gov/parents/landing.html
This site contains information for parents about education for children of all ages and abilities.

U.S. Department of Health and Human Services
www.hhs.gov
877-696-6775
The U.S. Department of Health and Human Services (HHS) is the U.S. government’s principal agency for protecting the health of all Americans and providing essential human services. The site contains information on the department’s numerous federal programs.

U.S. Department of Labor: Continuation of Health Coverage (COBRA)
www.dol.gov/dol/topic/health-plans/cobra.htm
COBRA gives workers and their families who lose their health benefits the right to choose to continue group health benefits provided by their group health plan for limited periods of time under certain circumstances such as voluntary or involuntary job loss, reduction in the hours worked, transition between jobs, death, divorce and other life events.

U.S. Department of Labor, Employment Standards Administration, Wage and Hour Division
www.dol.gov
866-4USA-DOL (866-487-2365)
Administers and enforces the Family and Medical Leave Act (FMLA) for all private, state and local government employees, and some federal employees. FMLA entitles eligible employees to take up to 12 weeks of unpaid, job-protected leave in a 12-month period for specified family and medical reasons.

U.S. Equal Employment Opportunity Commission
www.eeoc.gov
800-669-4000
Individuals can find information about the Equal Employment Opportunity Commission (EEOC), its current activities and legislative documents such as The Americans with Disabilities Act (ADA), which protects civil rights in the areas of employment, public accommodation, transportation and telecommunications for people with disabilities, including developmental disabilities.

U.S. Social Security Administration
www.ssa.gov
This website contains complete information about Social Security.

Government Support and Assistance Programs

GovBenefits.gov
www.benefits.gov
This site includes program descriptions and contact information about federal and state assistance programs.

Healthfinder
www.healthfinder.gov
Healthfinder.gov is a Federal website 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.
Resources

(Government Support and Assistance Programs continued)

**Health References and Services Administration**
www.findahealthcenter.hrsa.gov

The Health References and Services Administration (HRSA) provides information about federally funded healthcare centers that provide free or low cost care.

**Hill-Burton Free and Reduced Cost Health Care**
www.hrsa.gov/gethealthcare/affordable/hillburton

In 1946, Congress passed a law that gave hospitals, nursing homes and other health facilities grants and loans for construction and modernization. In return, they agreed to provide a reasonable volume of services to persons unable to pay and to make their services available to all persons residing in the facility's area. The program stopped providing funds in 1997, but about 300 healthcare facilities nationwide are still obligated to provide free or reduced-cost care.

**State Health Insurance Assistance Program**
www.seniorsresourceguide.com/directories/National/SHIP/index.html
www.medicare.gov/contacts/organization-search-criteria.asp

State Health Insurance Assistance Program (SHIP) provides counseling services to Medicare beneficiaries. They help assist patients in making educated, informed decisions on their healthcare benefits.

**State Programs for Children with Special Needs**
http://wdcrobcollp01.ed.gov/Programs/EROD/org_list.cfm?category_ID=SCH

States offer individual programs which provide medical assistance for children with special needs. These may offer assistance in covering medical expenses, help with finding a diagnosis, and other services depending on the state.

**Patient Advocacy and Support Organizations**

**Angel Flight**
www.angelflightatnih.org

Angel Flight at NIH provides air transportation for patients who are in financial need and cannot afford the cost of air travel.

**BenefitsCheckUp**
www.benefitscheckup.org

Many older people need help paying for prescription drugs, healthcare, utilities and other basic needs. Ironically, millions of older Americans—especially those with limited incomes—are eligible for but not receiving benefits from existing federal, state and local programs. Ranging from heating and energy assistance to prescription savings programs to income supplements, there are many public programs available to seniors in need if they only knew about them and how to apply for them.

**Caregiver Action Network**
www.nfcares.org
800-896-3650

The Caregiver Action Network (CAN) is a family caregiver organization working to improve the quality of life for those who care for loved ones with chronic conditions, disabilities, disease or the frailties of old age.

**Children’s Defense Fund**
www.childrensdefense.org
800-233-1200

The Children’s Defense Fund is a non-profit organization devoted to children's issues, including the Children’s Health Insurance Program.
Resources

(Patient Advocacy and Support Organizations continued)

Families USA
www.familiesusa.org
202-628-3030
Families USA is a non-profit organization dedicated to the achievement of high-quality, affordable health and long-term care for all Americans. The website contains state and national resources.

Family Voices
www.familyvoices.org
888-835-5669
Family Voices is a national organization that provides information and education concerning the healthcare of children with special health needs.

Health Insurance Resource Center
www.healthinsurance.org
A resource for families, individuals and the self-employed, the Health Insurance Resource Center provides the tools to become a better-informed health insurance consumer.

Insure Kids Now
www.insurekidsnow.gov
This site provides links to state child and adolescent health insurance programs.

Invisible Disabilities Association
www.invisibledisabilities.com
The Invisible Disabilities Association (IDA) helps those living with various conditions, as well as their loved ones, through their website, articles, literature, projects and seminars.

The Medicine Program
www.themedicineprogram.com
The Medicine Program is a patient advocacy organization helping individuals and families all across America get access to up to 2,500 prescription medications available today for free or nearly free of charge through Patient Assistance Programs.

National Committee for Quality Assurance
www.ncqa.org
The National Committee for Quality Assurance (NCQA) is a private, not-for-profit organization dedicated to assessing and reporting on the quality of managed care plans.

National Disabilities Rights Network
www.ndrn.org
The National Disabilities Rights Network (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
www.nfcacares.org
800-896-3650
The National Family Caregivers Association (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
www.rarediseases.org
800-999-NORD
The National Organization for Rare Disorders (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
800-296-3797
The National Patient Travel Center is a non-profit organization that provides a variety of services to individuals and families seeking ways to travel long-distances for specialized medical evaluation, diagnosis and treatment.

NeedyMeds
www.needymeds.org
NeedyMeds provides information on programs that help people facing problems paying for medications and healthcare; assists those in need in applying to programs; and provides health-related education using innovative methods.
(Patient Advocacy and Support Organizations continued)

**Partnership for Prescription Assistance**  
www.pparx.org  
888-4PPA-NOW (888-477-2669)  
The Partnership for Prescription Assistance brings together America’s pharmaceutical companies, doctors, other healthcare providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that’s right for them.

**Patient Advocate Foundation**  
www.patientadvocate.org  
800-846-4066  
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.patientnotificationsystem.org  
888-UPDATE-U (888-873-2838)  
The Patient Notification System is a program developed by the Plasma Protein Therapeutics Association (PPTA) to notify patients who receive plasma products, such as intravenous immunoglobulin (IVIG), about product recalls.

**Patient Services Incorporated (PSI)**  
www.patientservicesinc.org  
800-366-7741  
Patient Services Incorporated (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.

**RxAssist**  
www.rxassist.org  
Patient assistance programs are run by pharmaceutical companies to provide free medications to people who cannot afford to buy their medicine. RxAssist offers a comprehensive database of these patient assistance programs, as well as practical tools, news, and articles so that healthcare professionals and patients can find the information they need.

**Save Babies Through Screening Foundation**  
www.savebabies.org  
888-454-3383  
Save Babies Through Screening Foundation educates parents, pediatric healthcare providers, and policy makers about available comprehensive newborn screening.

**SKIP: Sick Kids Need Involved People**  
www.skipofny.org  
212-268-5999  
This is an advocacy group which helps families in the state of New York receive financial aid, nursing services and government medical services that they may be entitled to for their chronically ill child.
Education Resources

HEATH Resource Center
www.heath.gwu.edu
800-544-3284

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 Information Center for Handicapped Children and Youth
www.nichcy.org
800-695-0285

National Information Center for Handicapped Children and Youth (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.

Manufacturing Companies and Product Related Organizations

Manufacturing companies’ websites offer a wealth of valuable information and may provide information about the companies, their products, general information about primary immunodeficiency diseases and reimbursement assistance.

Baxter Healthcare Corporation
www.baxter.com


Bio Products Laboratory
www.bpl.co.uk
+44 (0) 20 8957 2342

Bio Products Laboratory manufactures Gammaplex.

Biotest Pharmaceuticals Corporation
www.biotestpharma.com
800-458-4244
Bivigam Cares Program: 855-248-4426 (BIVIGAM)

Biotest Pharmaceuticals manufacturers Bivigam.

CSL Behring
www.cslbehring.com
Care Coordination Center: 800-676-4266, option 5
IgIQ Resource Hotline: 877-355-IgIQ (877-355-4447)

CSL Behring manufactures Hizentra, Carimune andPrivigen.

Grifols
www.grifols.com
Grifols USA Customer Service: 800-243-4153 and 888-325-8579, option 3
Patient Assistance for Flebogamma: 888.GRIFOLS (888-474-3657)

Grifols manufactures Flebogamma DIF and Gamunex-C.

Kedrion
www.kedrionusa.com
Medical Inquiries, Reimbursement & Customer Service: 855-353-7466

Kedrion manufactures Gammaked.
Resources

(Manufacturing Companies and Product Related Organizations continued)

Octapharma
www.octapharma.com
Customer Service: 866-766-4860
Reimbursement: 800-554-4440
Octapharma manufactures Octagam.

Plasma Protein Therapeutics Association
www.plasmatherapeutics.org
410-263-8296
The Plasma Protein Therapeutics Association (PPTA) is the primary advocate for the leading producers of plasma-based and related recombinant biological therapeutics. The website provides specific information on the quality, safety and efficacy of plasma products.

Sigma Tau Pharmaceuticals
www.sigmatau.com
Product Information: 866-634-2765
Coverage Assistance and Patient Access Program:
877-534-9627
Sigma-Tau Pharmaceuticals manufactures Adagen.

Vidara Therapeutics
www.vidararx.com
Comprehensive Personalized Patient Prescription Advocacy and Support Services (COMPASS) Program:
877-305-7704
Vidara Therapeutics manufactures Actimmune.

Genetic Issues

DNA from the Beginning
www.dnaftb.org
DNA from the Beginning is an animated primer on the basics of DNA, genes and heredity, organized around key concepts. The science behind each concept is explained by: animation, image gallery, video interviews, problem, biographies and links.

Genetic Alliance
www.geneticalliance.org
800-336-GENE
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
At this site one can enter a diagnosis and pull up scholarly articles about many primary immunodeficiency diseases.

Human Genome Project: Ethical, Legal, and Social Issues (ELSI)
www.ornl.gov/hgmis/elsi/elsi.html
The ELSI division of the Human Genome Project is the world’s largest bioethics program devoted to studying these issues related to the availability of genetic information. The website contains information on genetic testing with regard to privacy and legislation, gene patenting, gene therapy and genetics used in the courtroom.

Immunodeficiency Resource
http://bioinf.uta.fi/idr/index.shtml
Immunodeficiency Resource (IDR) is a compendium of information on the immunodeficiencies available online, including data for clinical, biochemical, genetic, structural and computational analyses. IDR includes also articles, instructional resources, analysis and visualization tools as well as advanced search routines.