
RESOURCES

INFORMATION ABOUT IMMUNE DEFICIENCIES

Immune Deficiency Foundation: www.primaryimmune.org

Telephone: (800) 296-4433

The national non-profit organization dedicated to improving the lives of individuals affected by primary immunodeficiency disease through research and education.

Immunodeficiency Resource: www.uta.fi/imt/bioinfo/idr/index2.html

This web site was developed in Finland and contains links to numerous web sites on various aspects of primary immune deficiencies.

Links Related to Immunodeficiencies: www.uta.fi/laitokset/imt/bioinfo/B-Kbase/links.html

This web site provides numerous links to websites that provide information on specific immunodeficiency disorders, professional societies, scientific research and support organizations.

The Jeffrey Modell Foundation: www.jmfworld.org

Telephone: (800) JEFF-844

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

Severe Combined Immunodeficiency (SCID) Homepage: www.scid.net

This web site provides excellent information and resources for the immune deficiency, SCID.

FEDERAL ORGANIZATIONS AND ASSISTANCE PROGRAMS

Centers for Disease Control and Prevention, National Immunization Program:

www.cdc.gov/nip/

Telephone: (888) CDC-FAXX

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

Center for Biologics Evaluation and Research, FDA: www.fda.gov/cber/index.html

Telephone: (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.

National Institutes of Health (NIH): www.nih.gov/health

The national organization that provides information on the advances in health, science and medical issues.

NIH Clinical Trials: www.clinicaltrials.gov

Clinical Trials Telephone: (800) 411-1222

The web site contains current information on clinical trials being conducted, some of which may be pertinent to primary immune deficiencies.

National Institute of Allergy and Infectious Diseases (NIAID): www.niaid.nih.gov

Office of Communications Telephone: (301) 496-5717

A division of NIH that provides information on allergy and infectious diseases, but also primary immune deficiencies.

National Institute of Child Health and Human Development (NICHD): www.nichd.nih.gov

Telephone: (301) 496-5133

A division of the NIH that provides general information on children's health issues, including an in-depth booklet on primary immune deficiencies.

U.S. Department of Health and Human Services (HHS): www.dhhs.gov

Telephone: (877) 696-6775

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.

Health Care Financing Administration (HCFA): www.hcfa.gov

The federal agency that administers Medicare, Medicaid and the State Children's Health Insurance Program (SCHIP). The web site provides information on these programs and contains the initiatives put out by 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.

U.S. Department of Justice Civil Rights Division, Office of ADA: www.usdoj.gov

Telephone: (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. Equal Employment Opportunity Commission (EEOC): www.eeoc.gov

Telephone: (800) 669-4000

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", which protects civil rights in the areas of employment, public accommodation, transportation and telecommunications for people with disabilities, including developmental disabilities.

NATIONAL ORGANIZATIONS

American Academy of Allergy, Asthma, and Immunology: www.aaaai.org

Telephone: (313) 371-8600

Physician Referral Service: (800) 822-2762

A professional organization for physicians who treat patients with allergies, asthma and immunologic disorders. Provides a worldwide referral system for physicians in various geographical regions.

National Marrow Donor Program (NMDP): www.marrow.org

Telephone: (888) 999-6743

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

International Patient Organization for Primary Immunodeficiencies (IPOPI): www.ipopi.org
An international organization whose members are national patient organizations for the primary immune deficiencies. The web site provides general information on PID and resource contacts for patients and professionals worldwide.

Primary Immunodeficiency Association, United Kingdom: www.pia.org.uk
A patient organization that provides services for individuals affected by primary immune deficiencies in the United Kingdom. The web site contains a wealth of information of primary immune deficiencies.

LAGID: Latin American Group for Primary Immunodeficiencies: www.boletin-lagid.lsumc.edu
A professional organization comprised of physicians from various Latino countries who are dedicated to promoting the awareness, diagnosis and treatment of primary immune deficiency diseases in these countries.

EDUCATION ISSUES

HEATH Resource Center: www.heath-resource-center.org
Telephone: (800) 544-3284
This organization 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
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.

PATIENT ADVOCACY AND SUPPORT ORGANIZATIONS

A.C.C.E.S.S: www.gentiva.com/access/
Telephone: (888) 700-7010
"Advocating for Chronic Conditions, Entitlements and Social Services": A program developed by Gentiva Health Services to assist families with social and economic problems that can develop when treating a chronic medical condition, such as a primary immune deficiency.

Center for Patient Advocacy: www.patientadvocacy.org
Telephone: (800) 846-4066
A non-profit organization whose mission is to work for quality health care in America. The web site contains general information on the health care debate in America and provides contact information for those needing advice and assistance in dealing with health insurance issues.

Children's Defense Fund: www.childrensdefense.org

A non-profit organization devoted to children's issues, including the Children's Health Insurance Program. The web site provides information on these topics.

Families USA: www.familiesusa.org

Telephone: (202) 628-3030

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

Telephone: (505) 867-2368

A national organization that provides information and education concerning the health care of children with special health needs.

National Family Caregivers Association (NCFA): www.nfcacares.org

Telephone: (800) 896-3650

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

Telephone: (800) 999-NORD

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

National Patient Travel Center: www.patienttravel.org

Telephone: (800) 296-3797

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

Patient Advocate Foundation: www.patientadvocate.org

Telephone: (800) 532-5274

A national non-profit organization that serves as an active liaison between the patient and their insurer, employer, and/or creditors to resolve insurance, job discrimination and/or debt crisis matters relative to their diagnosis through case managers, doctors and attorneys.

Patient Notification System: www.patientnotificationsystem.org

Telephone: (888) UPDATE.U

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

Patient Services Incorporated: www.uneedpsi.org

Telephone: (804) 744-3813

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 immune deficiencies.

MANUFACTURING COMPANIES AND PRODUCT RELATED ORGANIZATIONS

ABRA: www.plasmainfo.org

Telephone: (410) 263-8296

This organization is the "International Authority for the Source Plasma Collection

Industry". Its membership is comprised of companies who collect or purchase plasma for further manufacturing purposes. The organization develops standards and training programs for its members and provides forums for debate on emerging issues such as new technologies and public policy. The web site provides information on plasma collection and national locations of plasma donor sites.

Alpha Therapeutics: www.alphather.com

Telephone: (323) 225-2221

The company responsible for production of Venoglobulin S, Immune Globulin Intravenous. The website provides information on the company and this product.

American Red Cross: www.redcross.org/services/biomed/

The national non-profit organization that provides various programs concerning blood and plasma products. It is the distributor of Polygam S/D, Immune Globulin Intravenous and Panglobulin, Immune Globulin Intravenous. The web site provides information about the products as well as plasma safety issues.

Aventis Behring: www.aventisbehring.com/na/Med/Medc.asp

Reimbursement Services Hotline: (800) 676-4266

The company responsible for manufacturing of Gammar-P I.V.. The web site contains information on the company, this product and general immunology and the immune system. The company also has a reimbursement services program to assist patients with health insurance problems.

Baxter Healthcare Corporation: www.baxter.com/ and www.immunedisease.com

The company responsible for production of Gammagard S/D, Immune Globulin Intravenous, Iveegam and Iveegam EN, Immune Globulin Intravenous. Provides information about this product and information about immune diseases. Includes links to other relevant web sites.

Bayer Corporation: www.bayerdirect.com

Telephone: (800) 468-0894

The company responsible for production of Gamimune N, 10%, Immune Globulin Intravenous. Provides information about this product and related links pertinent to primary immune deficiencies.

InterMune Pharmaceuticals, Inc.: www.intermune.com

Telephone hotline: (800) 577-9112

The biotechnology company responsible for the production of ACTIMMUNE (interferon gamma-1b) Injection for the treatment of chronic granulomatous disease (CGD). The company has a reimbursement hotline and patient assistance program to help patients with insurance and reimbursement issues.

Plasma Protein Therapeutics Association (PPTA): www.plasmatherapeutics.org

Telephone: (202) 789-3100

This organization is the primary advocate for the leading producers of plasma-based and related recombinant biological therapeutics. The web site provides specific information on the quality, safety and efficacy of plasma products.

GENERAL HEALTH ISSUES

American Dietetic Association: www.eatright.org

USDA Food and Nutrition Information Center: www.nal.usda.gov

Provides general information and tips on maintaining a healthy lifestyle through good nutritional habits.

MayoClinic.com: www.mayoclinic.com

The web site is a service of the renowned Mayo Clinic health care system and provides a wealth of information on health and medical topics. New material is added every workday and is reviewed by Mayo Clinic experts.

WebMD: www.webmd.com

A commercial web site containing information on general health, medical and fitness issues.

GENETIC ISSUES

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 web site contains information on genetic testing with regard to privacy and legislation, gene patenting, gene therapy and genetics used in the courtroom.

Genetic Alliance: www.geneticalliance.org

Telephone: (800) 336-GENE

"An international coalition of families, health professionals, and genetic support organizations" that provides information, support and advocacy to those affected by genetic conditions, including primary immune deficiencies.

DNA Sciences, Inc.: www.dna.com

A "genetics discovery company" that provides general information on DNA and genetic aspects of diseases such as inheritance and testing options.