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**Internet Resources on Primary Immunodeficiency Diseases**

*International Organizations/Projects*

**The European Society for Immunodeficiencies (ESID)**

The European Society for Immunodeficiencies (ESID) is a non-profit organization having multiple aims. The main objectives are to facilitate the exchange of ideas and information among doctors, nurses, biomedical investigators, patients and their families concerned with primary immunodeficiency diseases and also to promote research on causes, mechanisms and treatment of these disorders. Recently ESID has initiated an educational program. ESID Database includes Statistical graphs and information on total number of patients, diagnosis and documenting centers.  
**URL: <http://www.esid.org/home.php>**

**INFO4PI**

INFO4PI is the official webpage of the Jeffrey Modell Foundation and an online resource center for Primary Immunodeficiency. INFO4PI was designed for scientists, patients and their families, physicians, government, industry partners and the general public to be able to quickly and seamlessly access information on Primary Immunodeficiency Diseases; earliest precise diagnoses, appropriate treatments and sometimes cures of the more than 200 different PI diseases affecting over 10,000,000 children and adults worldwide.  
**URL: <http://www.info4pi.org/index.cfm?CFID=3169571&CFTOKEN=28540>**

*National organizations*

**ASCIA PID Register Australia and New Zealand**

In 1994 an Australian register of patients was first established by means of a questionnaire issued to Clinical Immunologists across the country. The results were published and have been of great assistance in defining the extent of disease, and in the planning of medical services. The ASCIA (Australian Society of Clinical Immunology and Allergy) PID Register Australia and New Zealand combines these data with extensive new information from the Australian Pediatric Surveillance Unit (APSU).

**URL: <http://www.immunodeficiency.org.au/index.html>**

### **Italian Primary immunodeficiency network** (in English and in Italian)

The web-site includes recommendations on diagnosis and treatment.

**URL:** [http://www.aieop.org/area3/ris\\_soci\\_prot\\_immuno\\_en.htm](http://www.aieop.org/area3/ris_soci_prot_immuno_en.htm)

### **United Kingdom Primary Immunodeficiency Network**

The UK Primary Immunodeficiency Network (UKPIN) is a multidisciplinary organisation of those caring for patients with primary immunodeficiencies. UKPIN aims to share methods of best practice, and to accredit immunology centres which practice in this way. The web-site includes reports, guidelines and other information.

**URL:** <http://www.ukpin.org.uk/>

### **Immune Deficiency Foundation (US)**

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 was founded in 1980 by parents of primary immune deficient children and their physicians. IDF is helping the patient and medical community gain a broader understanding of primary immune deficiency diseases through our education and outreach efforts; promoting, participating, and funding research that has helped characterize primary immune deficiency diseases and given patients and physicians substantially improved treatment options; addressing patient needs through its public policy programs on a national level by focusing on issues such as insurance reimbursement, patient confidentiality, preventing genetic discrimination, ensuring the safety and availability of IGIV, and maintaining and enhancing patient access to treatment options.

**URL:** <http://www.primaryimmune.org>

### *Articles*

**M.N. Yartsev, K.P. Yakovleva, M.V. Plakhtienko. Primary Immunodeficiency by Data of the Primary Immunodeficiency's Register at the Immunology Institute of the Russian Federal Medical-Biological Agency.** *Consilium-Medicum, Pediatrics, Volume 08/N 1/2006(In Russian)*

**URL:** [http://www.consilium-medicum.com/media/pediatr/06\\_01/4.shtml](http://www.consilium-medicum.com/media/pediatr/06_01/4.shtml)

*(Thanks to Irina Shumilova)*

**T.G. Kosacheva, A.P. Prodeus, A.Yu. Shcerbina, A.G. Romyantsev. Therapy and Management of Patients with Primary Immunodeficiency Diseases.** *The Difficult Patient, No.2-2007 (In Russian)*

**URL:** [http://www.t-patient.ru/archive/tp2-2007/tp2-2007\\_272.html](http://www.t-patient.ru/archive/tp2-2007/tp2-2007_272.html)

**The European internet-based patient and research database for primary immunodeficiencies: results 2004-06.** *Clin Exp Immunol. 2007 Feb;147(2):306-12.*

“Because primary immunodeficiencies (PID) are rare diseases, transnational studies are essential to maximize the scientific outcome and lead to improved diagnosis and therapy. Immunologists in Europe have united to determine the prevalence of PID in Europe and to establish and evaluate harmonized guidelines for the diagnosis and treatment of PID as well as to improve the awareness of PID in Europe. In order to achieve this aim we have developed an internet-based database for

clinical and research data on patients with PID. This database forms the platform for studies of demographics, the development of new diagnostic and therapeutic strategies and the identification of novel disease-associated genes. The database is completely secure, while providing access to researchers via a standard browser using password and encrypted log-in sessions and conforms to all European and national ethics and data protection guidelines. So far 2386 patients have been documented by 35 documenting centres in 20 countries. Common variable immunodeficiency (CVID) is the most common entity, accounting for almost 30% of all entries. First statistical analyses on the quality of life of patients show the advantages of immunoglobulin replacement therapy, at the same time revealing a mean diagnostic delay of over 4 years. First studies on specific questions on selected PID are now under way. The platform of this database can be used for any type of medical condition.”

**URL:**

**<http://www.pubmedcentral.nih.gov/articlerender.fcgi?tool=pubmed&pubmedid=17223972>**

**Applying Public Health Strategies to Primary Immunodeficiency Diseases: A Potential Approach to Genetic Disorders. *MMWR Recomm Rep. 2004 Jan 16;53(RR-1):1-29.***

„In November 2001, a workshop was convened by CDC in Atlanta, Georgia, to discuss ways to improve health outcomes among persons with PI disease... A systematic assessment based on the established public health framework was applied to the growing group of PI diseases, whose diverse genetic mutations span multiple components of the immune system but all lead to increased incidence and severity of infections. During the meeting, specialists in clinical immunology, public health, genetics, pediatrics, health communication, and ethics from state and federal agencies, academic centers, professional organizations, and advocacy foundations discussed the four components of the public health framework as they relate to PI diseases. These four components include 1) public health assessment (application of traditional public health methods to assess the occurrence and impact of PI diseases on communities); 2) population-based interventions (development, implementation, and evaluation of screening tests administered to newborns and clinical algorithms for early recognition of symptomatic persons to facilitate the earliest possible diagnosis and treatment for PI diseases); 3) evaluation of screening and diagnostic tools (to ensure their quality and appropriateness for identification of patients with PI diseases); and 4) communication (communication with and information dissemination to health-care providers and the public to facilitate prompt and appropriate diagnosis and intervention). The working *group's* deliberations focused on *challenges and opportunities*, priority research questions, and recommendations for future action for these four components. These recommendations, developed by workshop participants, will be useful to medical and public health professionals who are evaluating methods to increase recognition of PI diseases and other genetic disorders.“

**URL: <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5301a1.htm>**

**García JM, Español T, Gurbindo MD, Casas C C. Update on the treatment of primary immunodeficiencies. *Allergol Immunopathol (Madr). 2007 Sep-Oct;35(5):184-92.***

A general review of advances in the treatment of Primary Immunodeficiencies (PID).

**URL: [http://db.doyma.es/cgi-](http://db.doyma.es/cgi-bin/wdbcgi.exe/doyma/mrevista.pubmed_full?inctrl=05ZI0102&rev=105&vol=35&num=5&pag=184)**

**[bin/wdbcgi.exe/doyma/mrevista.pubmed\\_full?inctrl=05ZI0102&rev=105&vol=35&num=5&pag=184](http://db.doyma.es/cgi-bin/wdbcgi.exe/doyma/mrevista.pubmed_full?inctrl=05ZI0102&rev=105&vol=35&num=5&pag=184)**

*Patient education materials*

**Primary Immunodeficiency**

From National Institute of Child Health and Human Development. The NICHD was initially established to investigate the broad aspects of human development as a means of understanding developmental disabilities, including mental retardation, and the events that occur during pregnancy. Today, the Institute conducts and supports research on all stages of human development, from preconception to adulthood, to better understand the health of children, adults, families, and communities.

**URL:** [http://www.nichd.nih.gov/health/topics/Primary\\_Immunodeficiency.cfm](http://www.nichd.nih.gov/health/topics/Primary_Immunodeficiency.cfm)

**IDF Patient & Family Handbook For Primary Immunodeficiency Diseases, 4th Edition**

This book contains general medical information. Medical knowledge and practice can change rapidly. Therefore, this book should not be used as a substitute for professional medical advice.

[http://www.primaryimmune.org/pubs/book\\_pats/book\\_pats.htm](http://www.primaryimmune.org/pubs/book_pats/book_pats.htm)

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**Health Resources Digest Forthcoming Topics**

[Provisional]

Medical Calculators; Statistical Methods in Clinical Research; Handheld Computers in Healthcare

If you have a suggestion for a Digest topic, or would like to contribute information about Internet resources, then please contact [ibra@zadar.net](mailto:ibra@zadar.net)

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Compiled by Irina Ibraghimova,  
Coordinator, Medical and Information Resources  
American International Health Alliance  
[ibra@zadar.net](mailto:ibra@zadar.net)

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