

# *Birth Defects Resources on the Internet*

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The information and resources listed here are intended for educational use only and are provided solely as a service. The information provided through this section should not be used for diagnosing or treating a health problem or disease. It is not a substitute for professional care. These links do not constitute an endorsement of these organizations or their programs by the National Birth Defects Prevention Network (NBDPN) and none should be inferred. The NBDPN is not responsible for the content of the individual organization web pages found at these links.

## **Birth Defects Research and Prevention Information**

**International Clearinghouse for Birth Defects Monitoring Systems:** <http://www.icbd.org/>

Dedicated to the sharing of data, news and views on congenital malformations monitoring, research and prevention. Provides information about the Clearinghouse, membership directory, publications/papers, and birth defects links for professionals and general audience.

**March of Dimes Birth Defect Foundation:** <http://www.modimes.org>

This site contains a wealth of information about its organization, birth defects information, and infant health statistics in addition to numerous links to other birth defects data sources.

**National Birth Defects Prevention Network (NBDPN):** <http://www.nbdpn.org/NBDPN>

A national organization of individuals working at the local, state, and national level working in birth defects surveillance, research, and prevention. Site offers organizational information, newsletter, and related links to state birth defects monitoring programs and national organizations.

## **Birth Defects Databases**

**GeneClinics:** [www.geneclinics.org](http://www.geneclinics.org)

GeneClinics is a medical knowledge base relating genetic testing to the diagnosis, management, and genetic counseling of individuals and families with specific inherited disorders. The web site contains a database of genetic diseases with summary and diagnostic information, clinical description, management, resources, and references.

**Medical Genetics, University of Kansas Medical Center:** <http://www.kumc.edu/gec/geneinfo.html>

This web site is jam-packed with information and hyperlinks; it is a resource for many birth defects and genetics/birth defects organizations, nationally and internationally. In addition, the site contains referral information for those wishing to see a health care professional about a birth defect or genetic disorder.

**Pediatric Database:** <http://www.icondata.com/health/pedbase/pedlynx.htm>

The Pediatric Database contains descriptions and general information on an alphabetized list of over 550 childhood disorders, including a large number of genetic diseases and congenital anomalies. The information provided is useful as a quick reference, with descriptions of each condition obtained from the *Nelson Textbook of Pediatrics*, the *Birth Defects Encyclopedia*, and from at least one other published source. The entire database may be downloaded as Shareware. Links to numerous other sites are also provided.

## **Family Support Groups**

### **Alliance of Genetic Support Groups:** <http://www.geneticalliance.org/>

A national coalition of consumers, professionals and genetic support groups to voice the common concerns of children, adults and families living with, and at risk for, genetic conditions. This web site contains membership information and a searchable member directory, useful resources, newsletters and other publications.

### **Children with Spina Bifida: A resource for parents:**

<http://www.waisman.wisc.edu/~rowley/sb-kids/index.htmlx>

This site provides users with links to various subjects including spina bifida organizations, learning issues, family support, and medical information.

### **Our Kids:** <http://www.our-kids.org/>

This web site is designed to provide information and support for caregivers and family members and others who work with special needs children. Sections include organizational information, support staff, and caregiver resources.

### **Rare Genetic Diseases In Children: an Internet Resource Gateway:**

<http://mcrcr2.med.nyu.edu/murphp01/frame.htm>

This site is an Internet jump-station to resource directories for birth defects and rare genetic diseases in children. The site provides resources and links for disabilities, advocacy, support groups, education, financial information, medical information, a reference library and disease web site links.

### **Special Child:** <http://www.specialchild.com/>

This link is dedicated to providing support and information to parents and caregivers of special needs children. This site includes family issues, success stories, information and a caregiver tips section.

### **Spina Bifida Association of America:** <http://www.sbaa.org/>

The mission of the Spina Bifida Association of America is to promote the prevention of spina bifida and to enhance the lives of all affected. The site contains organizational information and activities, spina bifida fact sheets, clinic and chapter directories, resources for the media, and research and educational updates.

## **Government Agencies**

### **Centers for Disease Control and Prevention (CDC):** <http://www.cdc.gov/ncbddd/>

This site provides information regarding various divisions, branches, and offices working in birth defects and developmental disabilities. Other information includes publications, employment, and links to the CDC home page and health topics A-Z.

### **CDC Folic Acid Now:** <http://www.cdc.gov/ncbddd/folicacid/>

This web site provides information on the importance of folic acid in the prevention of birth defects. This web site features a frequently asked questions section and a quiz.

### **CDC Acido Folico Ahora:** <http://www.cdc.gov/ncbddd/folico/default.htm>

This is the Spanish version of the CDC Folic Acid Now web site. This web site features a questions section and a publications section for the Hispanic population.

**Education Resource Organization Directory (EROD):** <http://www.ed.gov/Programs/EROD>

The State Directors of Children with Special Health Care Needs are listed at this site under "types of organizations."

**National Institutes of Health:** <http://www.nih.gov>

Provides updates on the latest health and science research conducted by NIH researchers. The NIH Information Index has a subject-word guide to diseases and conditions under investigation at NIH. Also provides access to online catalogs, journals, and grant funding information.

**Healthcare professionals and scientific researchers**

**American Academy of Pediatrics:** <http://www.aap.org>

Provides online access to AAP's recommendations, research findings, and policy statements. Provides helpful tips and health information for parents and providers on all child health topics.

**HuGE Net:** <http://www.cdc.gov/genetics/hugenet/>

HuGE Net represents the collaboration of individuals and organizations from diverse backgrounds who are committed to the development and dissemination of population-based human genome epidemiologic information. The web site provides information about the HuGE Net and peer-reviewed synopses of epidemiologic aspects of human genes, prevalence of allelic variants in different populations, population-based disease risk information, gene-environment interaction, and quantitative data on genetic tests and services.

**Institute for Child Health Policy:** <http://www.ichp.edu/institute/Default.htm>

The Institute for Child Health Policy, a statewide Institution of Florida's State University System, was established in October 1986. Given the substantial changes in both the financing and organization attendant to the growth of managed health care, the Institute for Child Health Policy has focused its attention on children in managed care with special a emphasis on children with special health care needs. Issues of access, utilization, cost, quality and family involvement are principal areas of interest for our policy/program development, health services research and evaluation programs.

**National Center for Biotechnology Information - Online Mendelian Inheritance in Man (OMIM):**  
<http://www3.ncbi.nlm.nih.gov/Omim/>

This database is a catalog of human genes and genetic and contains textual information, pictures, and reference information. It also contains copious links to NCBI's Entrez database of MEDLINE articles and sequence information.

**National Society of Genetic Counselors:** <http://www.nsgc.org>

The National Society of Genetic Counselors (NSGC) is the leading voice, authority and advocate for the genetic counseling profession. The "What is?" section of their web site explains the role of genetic counselors and the "resource link" lists genetic counselors nationwide and internationally, for those needing a referral.

**Organization for Teratology Information Services (OTIS):** <http://orpheus.ucsd.edu/otis/>

Information about exposures to possible harmful substances during pregnancy. Contains a list of state contacts for teratology information, fact sheets, special projects, and links.

**Teratology Society:** <http://www.teratology.org/>

The Teratology Society web site provides information on teratology, membership information, and links to numerous birth defects sites. Also has a teratology discussion forum.