

Birth Defects Resources on the Internet

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.

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.

Centers for Disease Control and Prevention (CDC): <http://www.cdc.gov/nceh/ncehome.htm>

This web site provides information regarding various divisions, branches, and offices working in birth defects, genetics, and developmental disabilities. Other information includes publications, employment, and links to the CDC homepage and health topics A-Z. In addition, a kid's version and a Spanish version are also available.

GeneClinics: 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.

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.

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.

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

This website 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.

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 (AR, CO, FL, HI, IA, NC, NJ, NY, ND, and TX) and national organizations.

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 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.

National Organization for Rare Disorders, Inc. (NORD): <http://www.rarediseases.org/>

NORD is an organization of more than 140 not-for-profit voluntary health organizations serving people with rare disorders and disabilities. The web site contains organizational and services information, a rare disease database, an organizational database, an orphan drug database, newsletters, etc.

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 website 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.

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.

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 web site contains organizational information and activities, facts about spina bifida, clinic directory, educational materials, etc.

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.