

Birth Defects Resources on the Internet - January 2006

Focus on Preconceptional Health*

The information and resources listed here are intended for educational use only and are provided solely as a service. The information provided should not be used for diagnosing or treating a health problem or disease, and 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.

**The Internet resources specific to Preconceptional Health (and related elements, such as family history, folic acid, genetic counseling) are shaded.*

Birth Defects Research and Prevention Information

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

This site is dedicated to sharing data, news and views on the research, monitoring, and prevention of congenital malformations. It provides information about the Clearinghouse, membership directory, publications/papers, and birth defects links for professionals and general audiences.

March of Dimes (MOD) Birth Defects Foundation: <http://www.modimes.org>

This site contains a wealth of information about MOD, birth defects, and infant health statistics. There are also additional links to other sources of birth defects data.

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

NBDPN is a national organization of individuals at the local, state, and national level working in birth defects surveillance, research, and prevention. This site offers organizational information, newsletters, a list-serv, and related links to state birth defects monitoring programs and other national organizations.

Spina Bifida Association of America (SBAA): <http://www.sbaa.org>

The mission of SBAA is to promote the prevention of spina bifida and to enhance the lives of all affected. This site offers downloadable patient education materials and folic acid tutorials for professionals.

Birth Defects Databases

GeneTests: <http://www.geneclinics.org>

GeneTests is a medical knowledge base that relates genetic testing to the diagnosis, management, and genetic counseling of individuals and families with specific inherited disorders. Its website contains a database of genetic diseases with summaries and diagnostic information, clinical descriptions, management details, resources and references.

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

This website contains a surplus of information of many national and international birth defects and genetics/birth defects organizations (including hyperlinks). Additionally, the site also contains referral information for those wishing to seek a health care professional concerning a birth defect or genetic disorder.

Family Support Groups/Information for Families

About Pediatrics: http://pediatrics.about.com/od/parentingtips/a/05_fam_history.htm

This article provides a brief introduction for parents to the risk of disease and family history. The links included in on the website provide visitors with additional information on topics such as: creating a medical family tree to help determine genetic predisposition to certain diseases and genetic traits; prenatal and pediatric genetics screening questionnaires; *My Family Health Portrait* tool as developed by the U.S. Surgeon General's Family History Initiative; and information from the Mayo Clinic on family history and the role it plays in health and disease.

Genetic Alliance: Advocacy, Education & Empowerment: <http://www.geneticalliance.org>

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

Family Village: <http://www.familyvillage.wisc.edu>

This site integrates information and resources on the Internet for people with disabilities and their families. It includes informational resources on specific diagnoses, communication connections, adaptive products, technology, and adaptive recreational activities, education, worship, health issues, and disability-related media and literature.

Internet Resources for Special Children (IRSC): <http://irsc.org>

IRSC is an on-line resource dedicated to children with disabilities and their families. Its website supports a directory of links to a variety of subject areas including cognitive disabilities, diseases, conditions, and support/assistance.

Keep Kids Healthy: http://www.keepkidshealthy.com/inside_pediatrics/family_history.html

This is a parent-focused site that contains a wealth of resources on family history in relation to diseases. It helps increase awareness of the role family history plays in both risk of disease and the promotion of health. The useful links included direct visitors to information on family history as presented by the Centers for Disease Control and Prevention (CDC), the National Society of Genetic Counselors, and the American Medical Association.

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

This website is designed to provide information and support for caregivers and family members with disabled children, as well as others who work with children with special needs. The included sections include organizational information, support staff, and caregiver resources.

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

This link is dedicated to providing support and information to parents and caregivers of children with special needs. This website includes family issues, success stories, and useful information for parents and caregivers, including a section on tips for caregivers.

The Arc of the United States: <http://www.thearc.org/fetalalcohol.html>

This organization works to promote services and supports for people with mental retardation and other developmental disabilities. Its website offers fact sheets and other resources pertaining to disabilities, including FAS and other alcohol-related conditions.

Government Agencies

CDC, National Center on Birth Defects and Developmental Disabilities: <http://www.cdc.gov/ncbddd/>

This website provides information regarding various divisions, branches, and offices in birth defects and developmental disabilities, as well as publications, health topics A-Z, employment opportunities, and links to the CDC home page.

CDC Pregnancy-planning Education Program: <http://www.cdc.gov/ncbddd/pregnancy/>

Learn what you need to know now to have a safe pregnancy and healthy baby with CDC's online education program, available for women who are planning to become pregnant. By enrolling at www.ihealthrecord.org, an interactive health record, you can receive health information via email every other week for 3 months as you prepare for pregnancy.

CDC Folic Acid Now: <http://www.cdc.gov/ncbddd/folicacid>, <http://www.cdc.gov/ncbddd/folico/default.htm> (Spanish)

This site provides information on the importance of folic acid in the prevention of birth defects. Also featured are an online CDC folic acid publication order form, a FAQ section, a folic acid fact sheets, and a quiz. The Spanish version features questions and publications sections for the Hispanic population.

CDC Science Ambassador Program: <http://www.cdc.gov/ncbddd/folicacid/ScienceAmbassador.htm>

Follow the "Lesson Plans" link to "Standards Aligned Lesson Plans & Activities" to access a collection of health and science lesson plans. The lesson plans have been correlated to state and national standards and were developed to reach middle and high-school audiences. Topics include birth defects, neural tube defects, cystic fibrosis, alcohol and pregnancy, folic acid, cytogenetics and epidemiology.

Education Resource Organization Directory: <http://bcol02.ed.gov/Programs/EROD/>

This site lists the State Directors of Children with Special Health Care Needs under “Organizations by Type”.

National Guideline Clearinghouse (NGC): <http://www.guideline.gov>

NGC is a public resource for evidence-based clinical practice guidelines and an initiative of the Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services. NGC’s mission is to provide physicians, nurses, other health professionals, health care providers, health plans, integrated delivery systems, purchasers and others with an accessible mechanism for obtaining objective, detailed information on clinical practice guidelines and to further their dissemination, implementation and use. Under *preconception health*, the site offers a clinical practice guideline on preconception care of women with diabetes.

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

This website provides updates on the latest health and scientific research conducted by NIH. The “Health Information Index” has a subject-word guide to diseases and conditions under investigation at NIH. This site also provides access to online catalogs, journals, and grant funding information.

Healthcare Professionals and Scientific Researchers

American Academy of Pediatrics (AAP): <http://www.aap.org>

This link provides online access to AAP’s recommendations, research findings, and policy statements, which convey helpful tips and health information for parents and providers on all child health topics.

American Family Physician: <http://www.aafp.org/afp/20020615/2507.html>

This website provides a comprehensive peer-reviewed cover article on preconceptional health care. It includes a patient handout on preconceptional health, a preconceptional health care checklist, and information on various elements of preconceptional health, including promotion of folic acid, assessment of genetic risks, carrier screening by ethnicity, congenital infections, environmental toxins, risk of prescription drug use during pregnancy, management of chronic maternal illnesses during pregnancy, exercise and nutrition, and psychosocial factors.

California Preconception Care Initiative: http://www.marchofdimes.com/california/4949_8258.asp

MOD provides links to a variety of resources that have demonstrated success in increasing the understanding and use of preconceptional care strategies in California. This website includes an executive summary on the importance of seeking preconceptional care, English and Spanish fact sheets on folic acid, diabetes and pregnancy, infections and immunizations, genetic counseling, domestic violence, smoking, and healthy lifestyle choices. There is also a fact sheet on billing codes for preconceptional care that have been used successfully in California.

HuGE Net: The Human Genome Epidemiology Network: <http://www.cdc.gov/genomics/hugenet/default.htm>

The HuGE Net represents a collaboration of individuals and organizations from diverse backgrounds that are committed to the development and dissemination of population-based human genome epidemiologic information. The website 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.ufl.edu/>

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 has focused its attention on children in managed care with special emphasis on children with special health care needs. Issues of access, utilization, cost, quality and family involvement are principal areas of interest for the policy/program development, health services research, and evaluation programs.

MOD: Genetics & Your Practice Curriculum: <http://www.marchofdimes.com/gyponline/index.bm2>

This website includes a curriculum designed for health care professionals and customized for those working with preconception/prenatal, infant/children, and adolescent/adult client types. It provides practical information and resources to assist the busy professional in integrating genetics into their patient care. A comprehensive array of information is

provided under three topic areas: genetic testing and screening; family health and social history; and referral to genetic services.

MOD: Preconception Curriculum: http://www.marchofdimes.com/professionals/14429_1483.asp

This website is designed for physicians providing health care to women who may become pregnant. Its curriculum includes a series of PowerPoint slide sets, a core module (which should be viewed first), and a separate module for each of the following four medical specialties: obstetrics/gynecology, internal medicine, family medicine, and pediatrics. There are also presentation notes included, which also make this an educational tool that may be used as teaching presentations for residents, fellows, nurses and primary care practitioners in clinical conferences, didactic sessions or Grand Rounds.

National Center for Biotechnology Information—Online Mendelian Inheritance in Man (OMIM):

<http://www3.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM>

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

National Council on Folic Acid (NCFA): <http://www.folicacidinfo.org>

NCFA is a partnership of over 80 national organizations and associations, state folic acid councils, and government agencies whose mission is to improve health by promoting the benefits and consumption of folic acid. NCFA is managed by the National Healthy Mothers, Healthy Babies Coalition (www.hmhb.org) through a cooperative agreement with CDC. NCFA's goals are: to reduce folic acid preventable birth defects by recommending that women of childbearing age take 400 micrograms of synthetic folic acid daily, from fortified foods and/or supplements, in addition to consuming food folate from a varied diet; and to communicate and promote emerging and new science on folic acid, especially that relate to maternal and child health.

National Society of Genetic Counselors (NSGC): <http://www.nsgc.org>

NSGC is the leading voice, authority and advocate for the genetic counseling profession. The "Consumer Information" section of their website explains the role of genetic counselors. The site also provides contact information for genetic counselors for those seeking a referral, both nationally and internationally.

State University of New York, Albany, School of Public Health: <http://www.albany.edu/sph/coned/preconcept.htm>

This website offers a free Women's Health Grand Rounds web cast on preconceptional care. The goal of this program is to improve health care providers' knowledge, understanding, and practice of preconceptional care as a means of improving pregnancy outcomes for women and children. The conference builds on a Preconceptional Care Curriculum developed for MOD. Continuing education credits may be obtained after viewing the web cast and completing an evaluation. Other resources available on the site include a preconceptional screening and counseling checklist, as well as a set of PowerPoint slides that accompany the presentation.

Organization for Teratology Information Services (OTIS): <http://www.otispregnancy.org>

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

Surgeon General's Family History Initiative: <http://www.hhs.gov/familyhistory>

Offers an online family history tool that the user may complete and download.

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

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

Wisconsin Association for Perinatal Care: <http://www.perinatalweb.org/association/pcon.html>

This association provides leadership and education for improved perinatal health outcomes of women, infants, and their families. Online resources include *Becoming a Parent* leaflet and parent booklet; a preconception checklist; preconceptional care position paper; information for professionals on screening for prenatal and postpartum depression; and fact sheets on women with asthma, depression, diabetes, and epilepsy. The site also includes a position statement on the importance of folic acid. Additional publications include a *Health Care Provider's Guide to Preconceptional Risk Assessment* and the *Becoming a Parent: Things to Think About* video.