

## INTERNET RESOURCES

The information and resources listed 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.

### GENERAL BIRTH DEFECTS & BIRTH DEFECTS DATA

#### **Centers for Disease Control and Prevention (CDC) Birth Defects** ([www.cdc.gov/ncbddd/birthdefects](http://www.cdc.gov/ncbddd/birthdefects))

This website provides information and on birth defects in general. Sub-pages provide resources documenting the public health burden of birth defects and their complications in the United States. Statistics on the occurrence of some of the more common birth defects and links to additional information and resources can also be found here.

#### **Centers for Disease Control and Prevention (CDC) / National Center on Birth Defects and Developmental Disabilities** ([www.cdc.gov/ncbddd/](http://www.cdc.gov/ncbddd/))

This website provides information on preconception, pregnancy, birth defects, and developmental disabilities as well as CDC's activities related to each of these topics. The site includes relevant publications, health topics A-Z, and links to the CDC home page.

#### **March of Dimes (MOD) Foundation** ([www.marchofdimes.com](http://www.marchofdimes.com))

This site contains a wealth of information about the March of Dimes, birth defects, and infant health statistics. There are also additional links to other sources of birth defects data ([www.marchofdimes.com/baby/birthdefects.html](http://www.marchofdimes.com/baby/birthdefects.html)).

#### **National Institutes of Health - Birth Defects** ([www.health.nih.gov/topic/BirthDefects](http://www.health.nih.gov/topic/BirthDefects))

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. The Birth Defects page ([www.nichd.nih.gov/health/topics/birth\\_defects.cfm](http://www.nichd.nih.gov/health/topics/birth_defects.cfm)) provides links to various related organizations and resources.

#### **Organization for Teratology Information Services (OTIS)** ([www.otispregnancy.org](http://www.otispregnancy.org))

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

#### **Teratology Society** ([www.teratology.org](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.

### ***The Arc of the United States*** ([www.thearc.org](http://www.thearc.org))

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. The Arc was born 60 years ago from a grassroots movement of families working vigilantly to create services for children and adults who were being denied day care, educational opportunities and work programs. They encompass all ages and all spectrums from autism, Down syndrome, Fragile X and various other developmental disabilities.

### ***Family Village*** ([www.familyvillage.wisc.edu](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.

### ***HealthyChildren.Org*** ([www.healthychildren.org](http://www.healthychildren.org))

This is a parenting website backed by 60,000 pediatricians committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults. There is general information related to child health as well as more specific guidance on parenting issues. Information regarding the American Academy of Pediatrics many programs and activities can also be found here. The information from this site comes from the nation's leading child health experts that support the information provided on the website.

### ***Institute for Child Health Policy*** ([www.ichp.ufl.edu/](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 connected 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.

### ***Keep Kids Healthy*** ([www.keepkidshealthy.com/inside\\_pediatrics/family\\_history.html](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 include 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.

### ***National Center for Medical Home Implementation (NCMHI) State Resources*** ([www.medicalhomeinfo.org](http://www.medicalhomeinfo.org))

The overarching goal of the NCMHI is to ensure that all children and youth, including children with special needs, have a medical home where health care services are accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent. The NCMHI State Resources page provides comprehensive information for each state.

### ***Our Kids*** ([www.our-kids.org](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 sections include organizational information, support staff, and caregiver resources.

**Special Child** ([www.specialchild.com](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.

**Surgeon General's Family History Initiative** ([www.hhs.gov/familyhistory](http://www.hhs.gov/familyhistory))

Offers an online family history tool that the user may complete and download to provide to their physician.

## GENETIC COUNSELING RESOURCES

**GeneTests** ([www.geneclinics.org](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. It is a publicly funded medical genetics information resource developed for physicians, other healthcare providers, and researchers, available at no cost to all interested persons.

**Genetic Alliance: Advocacy, Education & Empowerment** ([www.geneticalliance.org](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. This is the nation's clearinghouse for newborn screening information.

**Medical Genetics, University of Kansas Medical Center** ([www.kumc.edu/gec/geneinfo.html](http://www.kumc.edu/gec/geneinfo.html))

This website contains a surplus of information on 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.

**National Society of Genetic Counselors (NSGC)** ([www.nsgc.org](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.

## PRECONCEPTION HEALTH

**CDC Preconception Health** ([www.cdc.gov/preconception/index.html](http://www.cdc.gov/preconception/index.html))

Learn what you need to know now to have a safe pregnancy and healthy baby with CDC's preconception health web portal, available for women who are of reproductive age.

**CDC Folic Acid** ([www.cdc.gov/ncbddd/folicacid](http://www.cdc.gov/ncbddd/folicacid))

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

## HEALTHCARE PROFESSIONALS AND SCIENTIFIC RESEARCHERS

**American Academy of Pediatrics (AAP)** ([www.aap.org](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*** ([www.aafp.org/afp/20020615/2507.html](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.

***HuGE Net: The Human Genome Epidemiology Network*** ([www.cdc.gov/genomics/hugenet/default.htm](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 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.

***International Clearinghouse for Birth Defects Surveillance and Research*** ([www.icbdsr.org](http://www.icbdsr.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.

***MMWR article, April 21, 2006-55(RR06) 1-23*** ([www.cdc.gov/mmwr/preview/mmwrhtml/rr5506a1.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5506a1.htm))

This MMWR article offers 10 recommendations made by the CDC/ATSDR Preconception Care Group and Select Panel to improve preconceptional health and preconceptional health care in the United States. These recommendations include preconceptional doctor visits and providing additional care and interventions to those women who have been affected by adverse pregnancies and have identified health risks such as heart disease and diabetes.

***National Birth Defects Prevention Network (NBDPN)*** ([www.nbdpn.org](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 listserv, and related links to state birth defects monitoring programs and other national organizations.

***National Center for Biotechnology Information*** ([www.ncbi.nlm.nih.gov](http://www.ncbi.nlm.nih.gov))

The National Center for Biotechnology Information advances science and health by providing access to biomedical and genomic information.

***National Survey of Children with Special Health Care Needs (NS-CSHCN)***

([www.childhealthdata.org/learn/NS-CSHCN](http://www.childhealthdata.org/learn/NS-CSHCN))

This is a subset of the National Survey of Children's Health, a telephone survey of US households sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration. The purpose of the survey is to assess the prevalence and impact of special health care needs among children. Data are collected on indicators such as condition, impact on activity and schooling, health insurance coverage, and access. Find national and state profiles by factors such as sex, race and health condition.

***Pregnancy Risk Assessment Monitoring System (PRAMS)*** ([www.cdc.gov/prams/](http://www.cdc.gov/prams/))

PRAMS is a surveillance project of the CDC and state health departments. PRAMS collects state-specific, population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy. A web-based query system (CPONDER) can be used to access national and state-level PRAMS data. Data sets are available for analysis. There is some variation from state to state. Some states do not participate. For more detailed data requests, also contact your state program. PRAMS data is a potential source for evaluating pregnancy experience regarding maternal risk factors that contribute to birth defects.

## HEALTH EDUCATION FOR PHYSICIANS AND NURSES

### **March of Dimes : Preconception Curriculum** ([www.marchofdimes.com/professionals/19640\\_30351.asp](http://www.marchofdimes.com/professionals/19640_30351.asp))

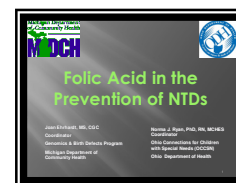
This website is designed for physicians providing health care to women who may become pregnant. Its curriculum includes a series of PowerPoint slide sets, a core module (which should be viewed first), and a separate module for each of the following four medical specialties: obstetrics/gynecology, internal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

### **Preconception Self-Study Courses** (<https://oh.train.org/DesktopShell.aspx>)

The Michigan Department of Community Health's Bureau of Epidemiology and Ohio Department of Health's Bureau for Children with Special Needs are offering free educational self-study trainings for nursing and other health care providers interested in improving the preconception and interconception health of women of childbearing age (18-44 years). These self-studies provide information and resources addressing some common risk factors for poor reproductive outcomes, with a particular emphasis on recognizing and decreasing the risk for birth defects.

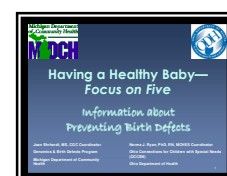
#### **Folic Acid in the prevention of NTDs**

This course contains information about the importance of folic acid in the prevention of neural tube defects; key strategies for helping women of childbearing age get the recommended amount of folic acid; trends among females of childbearing age in regard to folic acid knowledge, information about awareness and consumption that support the need for continued focus on client folic acid education, and professional resources and client education materials to increase folic acid knowledge and awareness. Nurses will receive 1.2 contact hours of continuing nursing education credits (CN#1028507) through the Ohio Department of Health for the course "Folic Acid and the Prevention of NTDS".



#### **Having a Healthy Baby—Focus on Five**

This course describes the public health impact of birth defects and the importance of focusing on preventable risk factors; identification of risk factors and prevention strategies that improve reproductive outcomes (this includes reducing the occurrence of birth defects); provider practices that can be implemented to recognize individual risks and support women of childbearing age in making healthy choices prior to conception; and resources for professional information and client support. Nurses will receive 1.60 nursing continuing education credits (CNE) of continuing nursing education credits [CN#1028474] through the Ohio Department of Health for the course "Having a Healthy Baby—Focus on Five".



### **MOD: Genetics & Your Practice Curriculum** ([www.marchofdimes.com/gyponline/index.bm2](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.