

Genetics Website Links

National Resources

[Centers for Disease Control and Prevention: Pediatric Genetics](http://www.cdc.gov/ncbddd/pediatricgenetics/)

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The Centers for Disease Control (CDC) and Prevention's National Center on Birth Defects and Developmental Disabilities (NCBDD) has developed a new Pediatric Genetics website. This site contains easy-to-read information on genetic disorders, family health history, genetic counseling, and newborn screening, as well as an individualized page for health professionals. Accessing the CDC's homepage will allow you to view more topics, including Pregnancy, Infants, Child Development, and Disabilities.

[Centers for Disease Control and Prevention: Public Health Genomics](http://www.cdc.gov/genomics/)

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This section of CDC's website focuses on Public Health Genomics. Several resources and trainings are available for both the public and healthcare professionals.

[National Human Genome Research Institute](http://www.genome.gov)

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The National Human Genome Research Institute (NHGRI) supports the development of resources and technology that will accelerate genome research and its application to human health. A critical part of the NHGRI mission continues to be the study of the ethical, legal and social implications (ELSI) of genome research. This site contains up-to-date information on research, ethical issues, fact sheets, Genetics 101, resources for health professionals, and quick links for patient care. Information on the Human Genome Project can also be found here.

[National Organization for Rare Disorders, Inc.](http://www.rarediseases.org)

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The National Organization for Rare Disorders, Inc. (NORD) is a 501(c)3 organization committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service. NORD's website contains a Rare Disease Database, Research Information, and Free Booklets for Physicians.

[National Newborn Screening and Genetics Resource Center](http://genes-r-us.uthscsa.edu/index.htm)

(<http://genes-r-us.uthscsa.edu/index.htm>)

This site provides information and resources in the area of newborn screening and genetics to benefit health professionals, the public health community, consumers and government officials. Fact sheets for both families and professionals are available.

[Organization of Teratology Information Specialists](#)

(<http://www.otispregnancy.org/otis-fact-sheets-s13037>)

The Organization of Teratology Information Specialists (OTIS) is a non-profit organization dedicated to providing accurate evidence-based, clinical information to patients and health care professionals about exposures during pregnancy and lactation. This link directs you to OTIS Fact Sheets on a wide range of exposures, including medications, infections, illicit drugs, and maternal health conditions (provided in both English and Spanish).

[National Society of Genetic Counselors](#)

(www.nsgc.org)

The National Society of Genetic Counselors (NSGC) is a professional organization with a mission to advance the various roles of genetic counselors in health care by fostering education, research, and public policy to ensure the availability of quality genetic services. Here is a direct link to [FAQs about Genetic Counselors and the NSGC](#)

(<http://www.nsgc.org/About/FAQsaboutGeneticCounselorsandtheNSGC/tabid/143/Default.aspx>).

The website also includes NSGC Practice Guidelines, Code of Ethics, and a search tool to find local genetic counselors.

[American Society of Human Genetics](#)

(<http://www.ashg.org/press/healthprofessional.shtml>)

The American Society of Human Genetics (ASHG) is the primary professional membership organization for human genetics specialists worldwide. This link directs you to Genetics Resources for Health Providers, including a glossary of genetic terms and “quick reference” resources.

[American College of Medical Genetics](#)

(http://www.acmg.net/AM/Template.cfm?Section=Genetics_Frequently_Asked_Questions_GFAQs_&Template=/CM/HTMLDisplay.cfm&ContentID=5864)

The American College of Medical Genetics (ACMG) is a professional society of genetics professionals with a mission to improve health through medical genetics. This link directs you to ACMG’s Genetics FAQs page. Other resources available on the website include Practice Guidelines, ACT sheets and algorithms for health professionals involved in newborn screening, and information about genetics conferences.

[American Board of Genetic Counseling](#)

(www.abgc.net)

The American Board of Genetic Counseling (ABGC) is the credentialing organization for the genetic counseling profession in the United States and Canada. The Resources and Links section contains a downloadable pdf booklet called [Making Sense of Your Genes: A Guide to Genetic Counseling](#) (*<http://www.abgc.net/docs/gcbrochure%20final.pdf>*).

[American Board of Medical Genetics](#)

(www.abmg.org)

The American Board of Medical Genetics (ABMG) serves the public and the medical profession by promoting and assuring standards of excellence in medical genetics. You can search for a Certified Geneticist and find information about educational meetings.

[Genetics Society of America](http://www.genetics-gsa.org)

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The Genetics Society of America (GSA) seeks to foster a unified science of genetics and to maximize its intellectual and practical impact. This site is developed mainly for genetics professionals, but there are some useful Teaching Resources under the Education tab for individuals interested in exploring more in-depth information about genetics.

[Online Mendelian Inheritance in Man](http://www.ncbi.nlm.nih.gov/omim)

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Online Mendelian Inheritance in Man (OMIM) is an online database that contains information on all known mendelian disorders and over 12,000 genes. OMIM focuses on the relationship between phenotype and genotype. It is updated daily, and the entries contain copious links to other genetics resources. This site is highly technical and geared towards physicians and geneticists.

[GeneTests](http://www.genetests.org)

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Gene Tests is a publicly funded medical genetics information resource developed for physicians, other healthcare providers, and researchers, available at no cost to all interested persons. Searching for a specific genetic condition through the GeneReviews tab will bring you to a comprehensive report, including information about natural history, symptoms, diagnosis, treatment, support, research and testing.

[ClinicalTrials.gov](http://www.clinicaltrials.gov)

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Clinical Trials.gov is a registry of federally and privately supported clinical trials conducted in the United States and around the world. ClinicalTrials.gov gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details.

[Genetics Home Reference](http://ghr.nlm.nih.gov/)

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Genetics Home Reference is the National Library of Medicine's web site for consumer information about genetic conditions and the genes or chromosomes related to those conditions. This website contains a genetics glossary, information about genetic conditions, newborn screening, genes, chromosomes, inheritance patterns and more.

[Genetic Alliance](http://www.geneticalliance.org)

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Genetic Alliance is a nonprofit health advocacy organization committed to transforming health through genetics and promoting an environment of openness centered on the health of individuals, families, and communities. Their website contains publications for both health professionals and the public on topics such as genetics, family history, newborn screening, and genetic conditions. It also includes a Disease InfoSearch option, which will connect you to a variety of disease-specific support groups and foundations.

[March of Dimes](http://www.marchofdimes.com/baby/birthdefects.html)

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The March of Dimes (MOD) is a foundation dedicated to helping moms have healthy pregnancies and babies. This link directs you to MOD Fact Sheets on a variety of birth defects, ranging from spina bifida and club foot to genetic conditions such as Fragile X syndrome and Down syndrome. The website also contains a Pregnancy section with information on prenatal care and common complications, as well as a section specifically for Professionals [Genetics & Your Practice: Professional Genetics Education](http://www.marchofdimes.com/gyponline/index.bm2). (*<http://www.marchofdimes.com/gyponline/index.bm2>*)

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

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This site was developed for educators interested in human genetics and the human genome project. It contains links to several other resources, including booklets, networking, programs, activities and more.

[Your Genes, Your Health](http://www.ygyh.org/)

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Your Genes, Your Health is part of the Dolan DNA Learning Center. The website contains modules on several common genetic conditions with animations and explanations. This is a very easy to use website with information presented in a concise and clear format.

[YourGenome.org](http://www.yourgenome.org)

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This is a website intended to help people understand genetics and genomic science and the implications for us all. It includes very clear explanations and animations of DNA, genes, and genomes. A glossary and resources for teachers are also available.

[The Family Village](http://www.familyvillage.wisc.edu/)

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The Family Village is a global community of disability-related resources. The Library connects you to information on hundreds of different conditions. Information on support groups, organizations, websites, chat groups, fact sheets and more are available for each condition. There are also links to information on several general topics, such as Bereavement Support and Disability Awareness.

[Unique - The Rare Chromosome Disorder Support Group](http://www.rarechromo.org)

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Unique is a source of information and support to families and individuals affected by any rare chromosome disorder and to the professionals who work with them. Parents can enter their child's chromosome condition into a registry and be connected with others with the same or a similar rare chromosome change. Leaflets on several rare chromosome changes are available for families.

[Chromosome Disorder Outreach](http://www.chromodisorder.org)

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Chromosome Disorder Outreach, Inc. is a non-profit organization, founded, supported, and run by parents. These parents have children affected by a wide range of chromosome disorders, including deletions, duplications, trisomies, inversions, translocations, and rings. Their mission is to provide support to parents of children born with rare chromosome disorders, gather together and share information, and to promote research and a positive community understanding of these disorders. The website also has a section titled "Introduction to Chromosomes", which provides a simplified explanation of chromosomes and chromosome abnormalities to parents.