

Resources on the World Wide Web

This resource list was prepared by HRSA with input from CDC and NIH for the “3rd National Conference on Genetics and Public Health: Connecting Research, Education, Practice & Community”, September 19-20, 2000 in Ann Arbor, Michigan. This list was last updated on August 17, 2000.

The GPC group has begun to add web resources to this list as they come to our attention and as we find them useful. We consider this an on-going project and welcome suggestions.

Genetics and Public Health Resources on the World Wide Web

1. **Genetic Alliance** <http://www.geneticalliance.org/>

The Genetic Alliance (formerly The Alliance of Genetic Support Groups, Inc.) is an international coalition of individuals, professionals and genetic support organizations that is working together to enhance the lives of everyone impacted by genetic conditions.

2. **National Human Genome Research Institute** <http://www.nhgri.nih.gov/>

The National Human Genome Research Institute (NHGRI) was originally established in 1989 as The National Center for Human Genome Research (NCHGR). Its mission is to head the Human Genome Project for the National Institutes of Health (NIH). NHGRI is one of 24 institutes, centers, or divisions that make up the NIH, the federal government's primary agency for the support of biomedical research.

3. **National Organization for Rare Disorders** <http://www.rarediseases.org/>

The National Organization for Rare Disorders (NORD) is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

4. **Office of Rare Diseases** <http://rarediseases.info.nih.gov/ord/index.html>

The Office of Rare Diseases (ORD), National Institutes of Health (NIH) provides information on more than 6000 rare diseases, including current research, publications from scientific and medical journals, completed research, ongoing studies, and patient support groups.

5. **Rare Genetic Diseases In Children** <http://mrcr2.med.nyu.edu/murphp01/homenew.htm>

An Internet jump-station to sources of information on rare genetic diseases affecting children. Under the aegis of the NYU Medical Center, this site has provided its services continuously since April 30, 1996.

6. **Online Mendelian Inheritance in Man** <http://www3.ncbi.nlm.nih.gov/Omim/>

This database is a catalog of human genes and genetic disorders authored and edited by Dr. Victor A. McKusick and his colleagues at Johns Hopkins and elsewhere, and developed for the World Wide Web by NCBI, the National Center for Biotechnology Information. The database contains textual information, pictures, and reference information. It also contains copious links to NCBI's Entrez database of MEDLINE articles and sequence information.

7. **Kansas University Medical Center** <http://www.kumc.edu/gec/geneinfo.html>
Information for genetic professionals at the University of Kansas Medical Center is updated regularly with clinical, research, and educational resources for genetic counselors, clinical geneticists, and medical geneticists. This is a useful resource for teachers, as well.
8. **National Institutes of Health** <http://www.nih.gov/>
Web site for the National Institutes of Health (NIH), U.S. Department of Health and Human Services.
9. **National Cancer Institute** http://cancernet.nci.nih.gov/h_genetics.html
CancerNet is the gateway to the most recent and accurate cancer information from the National Cancer Institute, a component of the National Institutes of Health.
10. **Family Village** <http://www.familyvillage.wisc.edu/index.htmlx>
The Family Village is a global community that integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families, and for those that provide them services and support. The community includes informational resources on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, disability-related media and literature, and much, much more!
11. **The Genetics Resource Center** <http://www.pitt.edu/~edugene/resource/>
The Genetics Resource Center is an online resource and starting point for genetic-counseling-related information. The web-site is constructed and maintained by the Genetics Education and Counseling Program at the University of Pittsburgh.
12. **National Coalition for Health Professional Education in Genetics**
<http://www.nchpeg.org>
Started in 1996 by the American Medical Association, the American Nurses Association, and the National Human Genome Research Institute, the National Coalition for Health Professional Education in Genetics (NCHPEG) is a national effort to promote health professional education and access to information about advances in human genetics. NCHPEG members are an interdisciplinary group of leaders from over 100 diverse health professional organizations, consumer and voluntary groups, government agencies, private industry, managed care organizations, and genetics professional societies. By facilitating frequent and open communication between stakeholder groups, NCHPEG seeks to capitalize on the collective expertise and experience of members and to reduce duplication of effort.
13. **The Genome Action Coalition** <http://www.tgac.org>
The Genome Action Coalition, begun in 1995, is comprised of patient advocacy organizations, professional organizations in the field of genetics and genomics, consumer organizations, university-based research facilities, pharmaceutical research companies and biotechnology companies. The Coalition exists to promote an environment in government and in the private sector in which genome research can continue to flourish.

14. **The Council for Responsible Genetics** <http://www.gene-watch.org/org.html>
The Council for Responsible Genetics (CRG), founded in 1983, is a national nonprofit organization of scientists, environmentalists, public health advocates, physicians, lawyers and other concerned citizens. CRG encourages informed public debate about the social, ethical, and environmental implications of new genetic technologies, and advocates for socially responsible use of these technologies. CRG monitors the development of new genetic technologies in two broad program areas: human genetics, and commercial biotechnology and the environment.

15. American regional networks which provide genetic services to patients and professionals:

GLaRGG: Great Lakes Regional Genetics Group

<http://www.waisman.wisc.edu/glargg/index.html> Serving: Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin

MARHGN: Mid-Atlantic Regional Human Genetics Network

<http://www.pitt.edu/~marhgn/> Serving: Delaware, Maryland, New Jersey, Pennsylvania, Virginia, Washington D.C., and West Virginia

MSRGSN: Mountain States Regional Genetic Services Network

<http://www.mostgene.org> Serving: Montana, Wyoming, Utah, Colorado, Arizona, New Mexico

NERGG: New England Regional Genetics Group

<http://www.acadia.net/nergg/index.html> Serving: Maine, Vermont, New Hampshire, Massachusetts, Rhode Island, Connecticut

Pacific Southwest Regional Genetics Network <http://www.psrgn.org/> Serving: California, Hawaii and Nevada

SERGG: Southeastern Regional Genetics Group

<http://www.cc.emory.edu/PEDIATRICS/sergg/> Serving: Alabama, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina and Tennessee

TEXGENE: Texas Genetics Network <http://www.tdh.texas.gov/texgene/texgene.htm>
Serving: Texas

Genetics Network of New York State <http://www.wadsworth.org/index.htm> Serving: Puerto Rico, the Virgin Islands and New York State

16. **HuGEM II Project** <http://www.dml.georgetown.edu/hugem>

The purpose of the HuGEM II Project is to provide educational training and resources to increase the knowledge of and sensitivity to human genetics, the Human Genome Project, and the ethical, legal, and psychosocial issues of genetic testing and research for members of seven collaborating professional organizations.

17. **March of Dimes - Resource Center** <http://www.modimes.org>

The Resource Center provides accurate, timely information and referral services to the public. The staff of the Resource Center includes trained professionals who help people, one on one, to address personal and complex problems. They answer questions from parents, health care providers, students, librarians, government agencies, health departments, social workers--people from all walks of life and from around the world.

18. **New York Online Access to Health (NOAH)** <http://www.noah.cuny.edu/>

NOAH: New York Online Access to Health seeks to provide high quality full-text health information for an underserved population of health consumers that is accurate, timely, relevant and unbiased. NOAH supports English and Spanish. Originally funded by the U.S. Department of Commerce's National Telecommunications and Information Administration (NTIA) and matching grants, NOAH currently has numerous sponsors including the March of Dimes.

19. **Human Genome Project Information** <http://www.ornl.gov/hgmis/>

Learn the basics about the Human Genome Project: what it is; its progress, history, and goals; frequently asked questions; and other information for people new to the project. Funded by the U.S. Department of Energy.

20. **Secretary's Advisory Committee on Genetic Testing (SACGT)**

<http://www4.od.nih.gov/oba/sacgt.htm>

Secretary of Health and Human Services Donna Shalala chartered the Secretary's Advisory Committee on Genetic Testing (SACGT) in June 1998 in response to recommendations of two working groups commissioned jointly by the National Institutes of Health (NIH) and the Department of Energy (DOE) for the Human Genome Project.

21. **The National Center for Cultural Competence (NCCC)**

<http://www.dml.georgetown.edu/depts/pediatrics/gucdc/cultural.html>

The National Center for Cultural Competence (NCCC) is a component of the Georgetown University Child Development Center, Center for Child Health and Mental Health Policy, and is housed within the Department of Pediatrics of the Georgetown University Medical Center. The mission of the NCCC is to increase the capacity of health care programs to design, implement and evaluate culturally competent service delivery systems.

22. **The National Heart, Lung, and Blood Institute (NHLBI)** <http://www.nhlbi.nih.gov/>

The National Heart, Lung, and Blood Institute (NHLBI), National Institutes of Health (NIH) provides leadership for a national program in diseases of the heart, blood vessels, lungs, and blood; sleep disorders; and blood resources.

23. **Centers for Disease Control (CDC)** <http://www.cdc.gov/genetics>

Office of Genetics and Disease Prevention, Centers for Disease Control and Prevention. The site provides current information on the impact of human genetic research and gene discoveries on disease prevention and health promotion. The site includes a weekly update of news stories, scientific literature, announcements, events, and public health perspectives on advances in human genetics.

24. **The Human Genome Epidemiology Network (HuGE Net)**

<http://www.cdc.gov/genetics/hugenet/default.htm>

A global collaboration of individuals and organizations committed to the development and dissemination of population-based epidemiologic information on the human genome. The site features information on: population-specific prevalence data on human gene variants, epidemiologic data on the association between genetic variation and diseases in different populations; quantitative population-based data on gene-environment interaction; and population impact on the use of genetic tests and services in improving health and preventing disease.

25. **U.S. Department of Energy (DOE)**

The Human Genome Program <http://www.er.doe.gov/production/ober/genome.html>

The Human Genome Program was initiated by DOE in 1986 to map and determine the complete DNA sequence of the human genome. The principal goal of this international program is to determine a representative human DNA sequence of all 3 billion base pairs in the human genome. The U.S. Human Genome Project is jointly managed by DOE and the National Institutes of Health (NIH).

Joint Genome Institute and Gene Sequencing Facility

<http://www.er.doe.gov/production/ober/jgipsf.html>

The DOE Joint Genome Institute (JGI) is the product of a managerial strategy to use the complementing strengths of DOE labs involved in human genome research and avoid duplication of effort. Formed in 1997, the JGI is a virtual laboratory whose work will be conducted in a number of labs allowing more efficient and effective use of expertise and resources across labs.

26. **American College of Medical Genetics**

<http://www.faseb.org/genetics/acmg/acmgmenu.htm>

The American College of Medical Genetics (ACMG) is an organization composed of biochemical, clinical, cytogenetic, medical and molecular geneticists, genetic counselors and other health care professionals committed to the practice of medical genetics.

27. **American Society of Human Genetics**

<http://www.faseb.org/genetics/ashg/ashgmenu.htm>

The American Society of Human Genetics (ASHG) was established in 1948 to provide leadership in research, education and service in human genetics. Accordingly it elected to publish The American Journal of Human Genetics and sponsor an annual research meeting. The human genetics community grew and spawned a new field of endeavor, genetic counseling, to support delivery of clinical genetics services. Over 5,000 members include researchers, academicians, clinicians, laboratory practice professionals, genetic counselors, nurses and others involved in human genetics.

28. **Communities of Color and Genetics Policy Project**

<http://www.sph.umich.edu/genpolicy/>

Michigan State University Center for Ethics and Humanities in the Life Sciences and Tuskegee University National Center for Bioethics in Research and Health Care have combined projects to form a five year project designed to provide policy recommendations based on public perceptions and responses to the explosion of genetic information and technology. The project

also tests the process of community dialogue as an effective means to engage citizens in thoughtful and productive discussions about policy needs regarding genetic information and technology and other value-laden issues.

29. **The Sickle Cell Information Center** <http://www.emory.edu/PEDS/SICKLE/>

The mission of this site is to provide sickle cell patient and professional education, news, research updates and world wide sickle cell resources. It is the mission of our organizations to provide world class compassionate care, education, counseling, and research for patients with sickle cell disease. It is our mission to help break the sickle cycle.

This Sickle Cell Information Web Site is Sponsored by the following partners: The Georgia Comprehensive Sickle Cell Center at Grady Health System, Atlanta, Georgia; Emory University School of Medicine, Department of Pediatrics, and Department of Medicine, Division of Hematology - Oncology; The Sickle Cell Foundation of Georgia Inc.; Morehouse School of Medicine.

30. **National Immunization Program** <http://www.cdc.gov/nip/>

The National Immunization Program (NIP) is a part of the Centers for Disease Control and Prevention, located in Atlanta, Georgia. This site provides recent and accurate immunization information from the NIP, the Federal Government's principal agency for immunization policy and recommendations. You will find a wide range of immunization information including information about vaccine preventable diseases, the benefits of immunization, and the risks of immunization vs. the risk of disease. In addition, you will find a wide range of educational materials and resources.

31. **National Immunization Program Immunization Registry Clearinghouse - Activities and Updates** <http://www.cdc.gov/nip/registry/articupd.html>

The National Immunization Program (NIP) of the Centers for Disease Control (CDC), is committed to promoting the development and maintenance of state- and community-based computerized registries which capture immunization information on all children. To aid in the development of these systems, NIP has developed an Immunization Registry Clearinghouse.

MCHB/HRSA Grantees

1. **GeneTests** <http://www.genetests.org>

Funded by the National Library of Medicine of the NIH and Maternal & Child Health Bureau of HRSA, GeneTests™ is a genetic testing resource that includes: A Genetics Laboratory Directory, a Genetics Clinic Directory, an introduction to genetic counseling and testing concepts (in About Genetic Services), and a Powerpoint slideshow presentation for genetics professionals (in Teaching Tools).

2. **GeneClinics** <http://www.geneclinics.org>

A clinical information resource relating genetic testing to the diagnosis, management, and genetic counseling of individuals and families with specific inherited disorders.

3. **The National Newborn Screening and Genetic Resource Center (NNSGRC)**
<http://GENES-R-US.uthscsa.edu>

A cooperative agreement between the Maternal and Child Health Bureau, Genetic Services Branch, HRSA and the University of Texas Health Science Center at San Antonio, Department of Pediatrics. The mission of the NNSGRC is to provide a forum for interaction between consumers, health care professionals, researchers, organizations, and policy makers in refining and developing public health newborn screening and genetics programs and to serve as a national resource center for information and education in the areas of newborn screening and genetics.

4. **The MCH Neighborhood** <http://mchneighborhood.ichp.edu/>

Support and training for the development of web-sites for projects funded by the Maternal and Child Health Bureau. MCH Neighborhood will host your site free of charge and will provide you with exclusive password-protected remote access privileges so that you may keep your site up-to-date and dynamic -- from wherever you may be located.

5. **Family Voices** <http://www.familyvoices.org/>

Families and friends speaking of behalf of children with special health care needs.

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Genetics in Primary Care

Additional Resources on the World Wide Web

- **GROW (Genetics Resources on the Web) Search Tool:** <http://search.info.nih.gov/grow/>

GROW is a search tool for genetics resources that is in the early stages of development. Using search terms, you are provided with a ranked listing of useful web resources for your query. 15,000 references are currently archived.

- **Image Archive on the American Eugenics Movement:** <http://vector.cshl.org/eugenics/>

In this Archive, you can search the original materials from the Eugenics Record Office at Cold Spring Harbor. The Cold Spring Harbor Laboratory was the center of American eugenics research from 1910-1940. In the Archive you will see numerous reports, articles, charts, and pedigrees that were considered scientific "facts" in their day.

- **CDC Prevention Guidelines:**
<http://aepo-xdv-www.epo.cdc.gov/wonder/prevguid/prevguid.htm>

The Prevention Guidelines Database is a comprehensive compendium of all of the official guidelines and recommendations published by the US Centers for Disease Control and Prevention (CDC) for the prevention of diseases, injuries, and disabilities. This compendium was developed to allow public health practitioners and others to quickly access the full set of CDC's guidelines from a single point, regardless of where they were originally published.