

Genetics & Public Health and Related Resources on the World Wide Web

Fall 2001

Federal Resources

- ***Centers for Disease Control***

Centers for Disease Control (CDC): 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.

The Human Genome Epidemiology Network (HuGE Net):

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.

- ***Maternal and Child Health Bureau/HRSA***

Incorporating Genetic Medicine and Technology into Practice and Service: A Health Resources and Services Administration, Maternal and Child Health Bureau Invitational Meeting, November 1999 Hyatt Arlington at Washington's Key Bridge:

<http://mchneighborhood.ichp.edu/geneticsmeeting1999>

Integration of Science and Technology into Public Health: A Health Resources and Services Administration/Maternal and Child Health Bureau, Genetic Services Branch Invitational Meeting, September 2000:

<http://mchneighborhood.ichp.edu/GeneticsMeeting2000/default.htm>

Maternal and Child Health Bureau of the Health Resources and Services Administration

www.mchb.hrsa.gov

MCHB provides leadership, partnership, and resources to advance the health of all our Nation's mothers, infants, children and adolescents-including families with low-income levels, those with diverse racial and ethnic heritages and those living in rural or isolated areas without access to care.

MCH Neighborhood: 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. The following links to their respective documents, of a select number of sites, are found at the above address.

- Existing Data Sets in MCH
- Genetics & Diversity
- Genetics & Your Practice Curriculum - Third Edition Update
- Genetics & Your Practice National and State Resources
- Washington State Genetics Documents
- Program Genetic Risk Screening Office Guide
- Pacific Northwest Regional Genetics Group (PacNoRGG)

The National Newborn Screening and Genetic Resource Center (NNSGRC):

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.

Title V Information System (Title V IS): <http://www.mchdata.net/>

The Title V Information System (Title V IS) electronically captures data from annual Title V Block Grant applications and reports submitted by all 59 U.S. States, Territories, and Jurisdictions and provides information on key measures of maternal and child health (MCH) in the United States. This site provides information on the status of MCH in the United States.

- *National Institutes of Health*

National Human Genome Research Institute: www.nhgri.nih.gov

Established in 1989, The National Center for Human Genome Research's (NCHGR) mission is to head the Human Genome Project for the National Institutes of Health (NIH).

National Institutes of Health: www.nih.gov

The collective research components of the NIH make up the largest biomedical research facility in the world. NIH is part of the U.S. Department of Health and Human Services.

Office of Rare Diseases: rarediseases.info.nih.gov

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.

Online Mendelian Inheritance in Man: www.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.

Secretary's Advisory Committee on Genetic Testing (SACGT):

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

Former Secretary of the United States Department 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.

- *U.S. Department of Energy*

The Human Genome Program: 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).

Human Genome Project Information: 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.

Joint Genome Institute and Gene Sequencing Facility:

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.

- *Private Organizations*

American Society of Human Genetics: 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.

American College of Medical Genetics: www.acmg.net

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.

Association of State and Territorial Health Officials (ASTHO): www.astho.org

ASTHO is the national non-profit organization representing the state and territorial public health agencies of the United States, the U.S. Territories, and the District of Columbia.

The Council for Responsible Genetics: www.gene-watch.org

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.

Family Voices: www.familyvoices.org

Family Voices is a national, grassroots clearinghouse for information and education concerning the health care of children with special health needs.

Gene Almanac: vector.cshl.org

The Dolan DNA Learning Center (DNALC) is the world's first science center devoted entirely to public genetics education and is an operating unit of Cold Spring Harbor Laboratory, an important center for molecular genetics research. This site serves as a source for timely information about genetics in education.

GeneClinics: www.geneclinics.org

GeneClinics is an expert-authored, peer-reviewed clinical genetic information resource consisting of concise descriptions of specific inherited disorders and authoritative, current information on the role of genetic testing in the diagnosis, management, and genetic counseling of patients with these inherited conditions.

GeneTests: 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).

Genetic Alliance: www.geneticalliance.org

The Genetic Alliance is an international coalition of individuals, professionals and genetic support organizations that are working together to promote healthy lives for everyone impacted by genetics.

The Genome Action Coalition: 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.

Health Privacy Project: www.healthprivacy.org

The Health Privacy Project is dedicated to raising public awareness of the importance of ensuring health privacy in order to improve health care access and quality, both on an individual and a community level. The Project objectives include empowering health care consumers, responding to evolving health care technology, anticipating and filling information gaps and convening diverse stakeholders.

March of Dimes: www.modimes.org

The Resource Center of the March of Dimes 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.

National Coalition for Health Professional Education in Genetics: 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.

National Organization for Rare Disorders: www.rarediseases.org

NORD is the only organization of its kind--a unique federation of more than 140 not-for-profit voluntary health organizations serving people with rare "orphan" disorders and disabilities. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

New York Online Access to Health (NOAH): www.noah-health.org

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.

- **Regional Genetics Networks**

MARHGN: Mid-Atlantic Regional Human Genetics Network, Serving: Delaware, Maryland, New Jersey, Pennsylvania, Virginia, Washington D.C., and West Virginia

www.pitt.edu/~marhgn

MSRGSN: Mountain States Regional Genetic Services Network, Serving: Arizona, Colorado, Montana, New Mexico, Utah and Wyoming

www.mostgene.org

NERGG: New England Regional Genetics Group, Serving: Connecticut, Maine, Vermont, New Hampshire, Massachusetts, Rhode Island

<http://www.acadia.net/nergg/>

PSRGN: Pacific Southwest Regional Genetics Network, Serving: California, Hawaii and Nevada

www.psrgn.org

SERGG: Southeastern Regional Genetics Group, Serving: Alabama, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina and Tennessee

www.cc.emory.edu/PEDIATRICS/sergg

TEXGENE: Texas Genetics Network, Serving: Texas

<http://www.tdh.texas.gov/genetics/home.htm>

Genetics Network of New York State, Serving: Puerto Rico, the Virgin Islands and New York State

www.wadsworth.org/index.htm/

- *University-Based Organizations*

Communities of Color and Genetics Policy Project: 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.

Family Village: www.familyvillage.wisc.edu

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!

The Genetics Resource Center: www.pitt.edu/~edugene

The Genetics Education and Counseling Program, a joint effort of the University of Pittsburgh and UPMC Health System, is dedicated to providing up-to-date information about inherited conditions and related services for individuals, families, and whole communities. For a detailed list of resources, add “/resource” to the end of address.

HuGEM II Project: www.gucdc.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.

Kansas University Medical Center: www.kumc.edu/gec

Genetics Education Center - For educators interested in human genetics and the human genome project.

Kansas University Medical Center: www.kumc.edu/gec/geneinfo.html

Information for genetics professionals - clinical, research, and educational resources for genetic counselors, clinical geneticists, and medical geneticists.

The National Center for Cultural Competence (NCCC):

gucdc.georgetown.edu/nccc/index.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.

National Reference Center for Bioethics Literature:

<http://www.georgetown.edu/research/nrcbl/scopenotes/sn22.htm>

The SCOPE NOTE Series is intended to present a current overview of issues and viewpoints related to specific topics in biomedical ethics. It is not designed as a comprehensive review, but rather offers immediate reference to facts, opinion, and legal precedents (if applicable) for scholars, journalists, medical and legal practitioners, students, and interested laypersons. The above link is Scope Note #22 "Genetic testing and Genetic Screening".

The Sickle Cell Information Center: www.emory.edu/PEDS/SICKLE/

The mission of this site is to provide sickle cell patient and professional education, news, research updates and worldwide 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.