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The Internet offers many resources that may be useful to national, state and local public health professionals interested in learning more about genomics and public health. This chapter provides a selected list of sites that offer starting points; a longer list is available in the online version of this report, available at <http://www.cdc.gov/genomics/activities/ogdp/2003.htm>. Many other online resources are available; this list is only a snapshot of some that may be useful for integrating genomics into health promotion and disease prevention programs. Please refer to the disclaimer at the end of this chapter.

CDC Office Of Genomics And Disease Prevention (OGDP)

<http://www.cdc.gov/genomics/>

This site provides information about ways that human genomic discoveries can be used to improve health and prevent disease. It provides links to activities in public health genomics across the lifespan, including links to programs throughout CDC.

- **Weekly Update:**
<http://www.cdc.gov/genomics/update/current.htm>
A weekly update on the impact of human genetic research on disease prevention and public health. To receive notification of this update by e-mail, please send the following message:
To: listserv@listserv.cdc.gov
Subject: (leave blank)
Message: subscribe genetics
- **Public Health Perspectives Series:**
<http://www.cdc.gov/genomics/info/perspectives/series.htm>
On the Highlights page on the OGDP Web site, each *Public Health Perspective* focuses on a single topic and provides information relevant to public health practice. Past topics include family history, *BRCA1/2* testing, obesity, and others.
- **Genomics and Disease Prevention Information System (GDPInfo):**
<http://www2a.cdc.gov/genomics/GDPQueryTool/default.asp>

The GDPInfo query tool allows you to define your search of the OGDIP Web site with a combination of genes, diseases/conditions, topics and other factors. The search provides a list of all related documents and links to other sites.

Human Genome Project

Human Genome Project Information from the US Department of Energy:

http://www.ornl.gov/sci/techresources/Human_Genome/home.shtml

The U.S. Department of Energy and the National Institutes of Health formally initiated the Human Genome Project in 1990. The project originally was planned to last 15 years, but rapid technological advances allowed it to be completed in 2003. This site provides an overview of the Human Genome Project and links to other sites.

National Human Genome Research Institute (NHGRI):

<http://www.nhgri.nih.gov/>

The NHGRI supports genetic and genomic research, investigation into the ethical, legal and social implications surrounding genetics research, and educational outreach activities in genetics and genomics.

The Human Genome—A Guide to Online Information Resources from the National Library of Medicine:

<http://www.ncbi.nlm.nih.gov/genome/guide/human/>

A comprehensive site that provides information and links to information about specific genes and genetic diseases.

Selected articles:

- **Celebrating the 50th Anniversary of the Double Helix:**
<http://www.annals.org/content/vol138/issue7/>
Articles from Annals of Internal Medicine 1 April 2003 Volume 138 Issue 7
- **Primer on Medical Genomics: History of Genetics and Sequencing of the Human Genome:**
<http://www.mayo.edu/proceedings/2002/aug/7708mgl.pdf>
- **A Vision for the Future of Genomics Research:**
http://www.nature.com/cgi-taf/DynaPage.taf?file=/nature/journal/v422/n6934/full/nature01626_fs.html

- **New England Journal Of Medicine: Genomic Medicine Series (2002-2003):**
<http://content.nejm.org/misc/genmed.shtml>
The full text of all thirteen articles in this series is available free to all users.

Genomic Research

Human Genetics and Medical Research:

<http://history.nih.gov/exhibits/genetics/>

An online exhibit for the public providing information about the use of genetics in medicine sponsored by the National Institute of Health (NIH),

<http://www.nih.gov/>

Genes and Populations:

http://www.nigms.nih.gov/news/science_ed/genepop/

A series of questions and answers for patients considering participation in research studies from the National Institute of General Medical Sciences,

<http://www.nigms.nih.gov/>

August 2003 Issue Brief “Applied Public Health Research in Genomics”:

<http://www.astho.org/pubs/AppliedPHResearchinGeneticsIssueBrief.pdf>

An issue brief released by ASTHO that outlines the importance of applied public health research in genomics and the types of research needed, the ethical, legal, and social issues that accompany this type of research, current public health genomics research activities, and future research directions.

Genetic Testing

GeneTests/GeneClinics:

<http://www.genetests.org/>

A publicly-funded medical genetics information resource developed for physicians, other healthcare providers, researchers, and others needing information about existing genetic tests. This site includes expert-authored reviews, directories of laboratories and clinics offering genetic tests, and educational materials.

National Academy of Sciences: Human Gene Testing:

<http://www.beyonddiscovery.org/content/view.article.asp?a=239>

A summary of human genetic testing that ranges from the unraveling of the nature of the gene to the social dilemmas posed by genetic testing.

Understanding Gene Testing:

<http://press2.nci.nih.gov/sciencebehind/genetesting/genetesting00.htm>

Illustrates what genes are, explains how mutations occur and how they are identified within genes, and discusses the benefits and limitations of gene testing for cancer and other disorders. Provided by the National Cancer Institute.

Family History

Genetics & Your Practice:

<http://www.marchofdimes.com/gyponline/index.bm2>

A resource that provides practical information and resources to assist the busy professional in integrating genetics into their patient care.

- Family Health and Social History: (Link same as above)
A timesaving method of family history taking and sample family history questionnaires.

The Genetic Family History in Practice newsletter for health care professionals from NCHPEG's Family History Working Group:

<http://www.nchpeg.org/newsletter/newsletter.asp>

Your Family History:

<http://genetics.faseb.org/genetics/ashg/educ/007.shtml>

A family history tool developed through the collaboration with the American Society of Human Genetics, the National Society of Genetic Counselors and Genetic Alliance.

Genes and Diseases

Disease InfoSearch™:

<http://www.geneticalliance.org/DIS/index.html>

A tool to assist in finding specific and quality information about genetic conditions, provided by the Genetic Alliance, <http://www.geneticalliance.org>

GeneReviews:

<http://www.geneclinics.org/servlet/access?id=8888891&key=EU5gttBEabgRZ&fcn=y&fw=wIJK&filename=/home/grcover.html>

An online publication of expert authored disease reviews from GeneTests, <http://www.geneclinics.org/>

Genetics Home Reference:

<http://ghr.nlm.nih.gov/ghr/template/Home.vm>

Provides consumer information about genetic conditions and associated genes.

From the National Library of Medicine, <http://www.nlm.nih.gov/nlmhome.html>

Office of Rare Diseases (ORD):

<http://rarediseases.info.nih.gov/>

This Web site provides information about ORD-sponsored scientific activities, an ORD cosponsored genetic and rare diseases information center, and a portal to databases that provide information on major topics of interest in rare diseases research.

Genes and Diseases:

<http://www.ncbi.nlm.nih.gov/books/bv.fcgi?call=bv.View..ShowSection&rid=gnd>

A collection of articles that discuss genes and the diseases that they cause from the National Center for Biotechnology Information (NCBI),

<http://www.ncbi.nlm.nih.gov/>

Online Mendelian Inheritance of Man (OMIM):

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM&cmd=Limits>

A database providing a catalog of human genes and genetic disorders authored by the Johns Hopkins University Medical School and developed by the National Center for Biotechnology Information (NCBI), <http://www.ncbi.nlm.nih.gov/> at the National Library of Medicine, <http://www.nlm.nih.gov/>

Genes and Diseases: Cancer

National Cancer Institute:

<http://www.cancer.gov/>

- Cancer Genetics:

<http://www.cancer.gov/cancerinfo/prevention-genetics-causes/genetics>

A comprehensive list of cancer genetics information ranging from general to specific cancer information, policy, and cancer genetics research and information.

Genes and Diseases: Birth Defects

March of Dimes Birth Defects Foundation:

<http://www.marchofdimes.com/home.asp>

A not-for-profit organization with the mission to improve health of babies by preventing birth defects and infant mortality.

- Birth Defects and Genetic Conditions:

<http://www.marchofdimes.com/pnhec/4439.asp>

National Birth Defects Prevention Network:

<http://www.nbdpn.org/>

A group with the mission to establish and maintain a national network of state and population-based programs for birth defects surveillance and research to assess the impact of birth defects upon children, families, and health care; to identify factors that can be used to develop primary prevention strategies; and to assist families and their providers in secondary disabilities prevention.

Genes and Diseases: Newborn Screening

National Newborn Screening and Genetics Resource Center (NNSGRC):

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

Provides information and resources in the area of newborn screening and genetics

to benefit health professionals, the public health community, consumers, and government officials:

- a report on the characteristics of state NBS programs,
- state newborn screening program resources, and
- resources for state genetics planning.

Association of Public Health Laboratories (APHL) Newborn Screening and Genetics Program:

http://www.aphl.org/Newborn_Screening_Genetics/index.cfm

March of Dimes Newborn Screening Recommendations:

http://www.marchofdimes.com/professionals/580_4043.asp

Public Health Ethical, Legal and Social Issues (PHELSI)

The U.S. Department of Energy Human Genome Project:

http://www.ornl.gov/sci/techresources/Human_Genome/elsi/elsi.shtml

An educational and informational site about the human genome project. This is a publication of the U.S. Department of Energy Human Genome Program.

Genetics Education and Counseling Program:

<http://www.pitt.edu/~edugene/resource>

A public health initiative for community and professional education and awareness on genetics. This Web site is sponsored by the University of Pittsburgh.

Public Health Genetics from University of Sheffield-School of Health and Related Research (Scharf):

<http://www.shf.ac.uk/~scharf/public/research/genetics/index.html>

A catalogued series of articles on various topics including technical issues, genetic testing in the workplace, and experiences of individuals affected by genetic diseases from the U.K.

Michigan Centers for Genomics and Public Health:

<http://www.sph.umich.edu/genomics/index.html>

The Michigan Center for Genomics & Public Health seeks to integrate genomic discoveries into public health practice, with consideration of the ethical, legal, and social issues associated with the application of these discoveries, as well as the involvement of the community at large.

Genetics and Ethics Page:

<http://genethics.ca/index.html>

A clearinghouse for information on the social, ethical and policy issues associated with genetic and genomic knowledge and technology.

Policy

National Conference of State Legislatures (NCSL) Genetic Technologies Project Web Site:

<http://www.ncsl.org/programs/health/genetics.htm>

A group commissioned to provide state legislators and other policymakers with objective, comprehensive, and scholarly information from a non-partisan source to facilitate the drafting of sound genetics-related legislation.

Secretary's Advisory Committee on Genetics, Health and Society:

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

“A forum for expert discussion and deliberation and the formulation of advice and recommendations on the range of complex and sensitive medical, ethical, legal and social issues raised by new technological developments in human genetics.”

Genetics and Public Policy Center:

<http://www.dnapolicy.org/index.jhtml>

Information on genetic technologies and genetic policies for the public, media and policymakers. The Genetics and Public Policy Center is funded through a grant from The Pew Charitable Trusts.

Public Health Resources

Genomics: A Guide for Public Health:

<http://www.genomicstoolkit.org/index.shtml>

A guide to help state public health agencies integrate genetics into their programs. This guide provides integration strategies, tools for needs assessment, priority setting guides, snapshots of current integrated programs, many resources, and much more.

Coalition of State Genetic Coordinators:

<http://www.stategeneticscoordinators.org/index.html>

An organization of state and territorial genetics coordinators and others who support the mission to promote core public health functions as they apply to genetics.

Genomics and Chronic Disease Summit Report, 2002:

http://www.chronicdisease.org/Genomics_Summit_Report.pdf

A report from the Association of State and Territorial Chronic Disease Directors.

Harnessing Genetics to Prevent Disease & Improve Health:

<http://www.prevent.org/publications/GeneticsReport.pdf>

A guide to help states shape genetics policies for the purpose of advancing individual and collective health. The report highlights recommendations for

policymakers to address the social, legal and ethical implications of genetics in their states.

Centers for Genomics and Public Health:

<http://www.cdc.gov/genomics/activities/fund2001.htm>

- University of Washington Center for Genomics and Public Health:
<http://depts.washington.edu/cgph/>
- University of Michigan Center for Genomics and Public Health:
<http://www.sph.umich.edu/genomics/>
- University of North Carolina Center for Genomics and Public Health, the Genomics Revolution and Public Health:
<http://www.sph.unc.edu/nciph/phgenetics/index.htm>

The WHO Genetics Programme:

<http://www.who.int/genomics/en/>

Information about activities undertaken by the WHO Human Genetics Program to help control the “most common hereditary diseases and those having a genetic predisposition.”

Educational Resources

National Coalition for Health Professional Education in Genetics (NCHPEG):

<http://www.nchpeg.org/>

A national effort to promote health professional education and access to information about advances in human genetics:

- Genetic Resources on the Web (GROW),
- Genetic Family History Resources, and
- Educational Resources.

Genetic Educational Materials Database (GEMS):

<http://www.gemdatabase.org/GEMDatabase/index.asp>

Searchable listing of public health genetics policy documents and clinical genetics educational materials from the National Newborn Screening and Genetics Resource Center (NNSGRC).

OGDP List of Training Tools:

<http://www.cdc.gov/genomics/training/tools.htm>

A list of available training tools, courses, and multi-media educational materials designed to assist public health professionals and educators integrate genomics into public health practice.

Disclaimer: The CDC Office of Genomics and Disease Prevention makes this information available as a public service only. Providing these links does not constitute an endorsement of these organizations or their programs by CDC or the federal government, and none should be inferred. Exclusion of information does not mean there are no other useful resources available. The CDC is not responsible for the content of the individual organization Web pages found at these links. Note that some links may become invalid over time.