

## **Selected Resources on Genetics/Genomics**

**American Nurses Association** published guidelines from a consensus panel **Essential Nursing Competencies and Curricula Guidelines for Genetic and Genomics**. Outlines essential competencies, practice and curriculum implementation strategies, and resources to support the competencies:

<http://www.genome.gov/Pages/Careers/HealthProfessionalEducation/geneticscompetency.pdf> .

### **International Society of Nurses in Genetics (ISONG)**

A global nursing specialty organization dedicated to fostering the scientific and professional growth of nurses in human genetics and genomics worldwide through fostering the scientific, professional, and personal development of members in the management of genomic information

<http://isong.org/index.cfm>

### **National Coalition for Health Professional Education in Genetics (NCHPEG)**

<http://www.nchpeg.org/> Several educational resources are available through this site.

### **National Human Genome Research Institute (NHGRI)**

Resource for genetic, research, policy, and education information – provides information to address the ethical, legal and social implications of human genetics research and multiple other topics at [www.nhgri.nih.gov](http://www.nhgri.nih.gov) and is also a good site for educational materials for DNA Day, April 25th. <http://www.genome.gov/DNADay/>

### **Topics in the NHGRI website include the following:**

**Genetics and Genomics for Health Professionals** - Genetics and Genomics for Health Professionals provides reliable, up-to-date genetics and genomics information related to patient management, curricular resources, new National Institutes of Health and NHGRI research activities, and ethical, legal, and social issues. [www.genome.gov/27527599](http://www.genome.gov/27527599)

**Genetics 101 for Health Professionals**, National Institutes of Health - The resources in this section provide basic information about genetics and genomics in clear language and provide links to online resources. [www.genome.gov/27527637](http://www.genome.gov/27527637)

**Talking Glossary of Genetic Terms**, National Human Genome Research Institute - Simply click on the term of interest to open a page with a wealth of information, including the term's pronunciation, audio information, images, and additional links to related terms. Students, teachers, and parents will find the glossary an easy-to-use, always available learning source on genetics. [www.genome.gov/page.cfm?pageID=10002096](http://www.genome.gov/page.cfm?pageID=10002096)

**From the Blueprint to You**, National Human Genome Research Institute –explores the world of genetics, DNA, the Human Genome Project, the ethical, legal and social implications of genetic research, and the future of genomics.

[www.genome.gov/Pages/Education/Modules/BluePrintToYou/Blueprint3to4.pdf](http://www.genome.gov/Pages/Education/Modules/BluePrintToYou/Blueprint3to4.pdf)

### **National Newborn Screening & Genetics Resource Center, Genetics in Primary Care (GPC) Training Program Curriculum Materials**

The modules provide a series of teaching cases, developed to be representative of patients seen in primary care, while also allowing for the demonstration of genetics issues and principles. Each module cites web-sites for additional background information and articles from the medical literature, including relevant consensus and policy statements where applicable. [http://genes-r-us.uthscsa.edu/resources/genetics/primary\\_care.htm](http://genes-r-us.uthscsa.edu/resources/genetics/primary_care.htm)

**Genetic Tools: Genetics Through a Primary Lens:** 41 teaching cases indexed by age, purpose, and mode of inheritance; and ethical, legal, and social issues in genetics. A PRACTICE MODEL for cultural competency in primary care genetics is presented. This HRSA funded project

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was headed by the University of Washington, with broad developmental support. The URL is <http://www.genetests.org/servlet/access?id=8888892&key=w0-zk3pa2LTLe&fcn=y&fw=mzCI&filename=/tools/index.html>.

The **American Society of Human Genetics** supports an informative website of Health Provider Genetics Resources which can be integrated into practice. You can find this material at <http://www.ashg.org/press/healthprofessional.shtml>.

**Genetics Education Program for Nurses (GEPN)** provides several web-based educational offerings: <http://www.cincinnatichildrens.org/ed/clinical/gpnf/ce>

For those who want more in-depth instruction about pharmacogenetics than the GEPN module on this same topic, consider the **American College of Clinical Pharmacology's free online course** containing 13 different modules on the topic. For more information, please click on <http://www.accp1.org/~user/index.html>.

Telling Stories: Understanding Real Life Genetics is an online resource that can be used by nurses for their own education by the **National Genetics Education and Development Centre of the NHS**. <http://www.geneticseducation.nhs.uk/tellingstories/index.asp>

**Centers for Disease Control – Office of Genetics and Disease Prevention**. This resource provides public health professionals with current information on human genetic research and gene discoveries. Lots of good links, including links to family history tools. <http://www.cdc.gov/genomics/>

**Handbook: Help Me Understand Genetics**, Genetics Home Reference, National Library of Medicine - Presents basic information about genetics in clear language and provides links to online resources. <http://ghr.nlm.nih.gov/handbook>

**Learn.Genetics**, Genetic Science Learning Center, University of Utah - Learn.Genetics delivers educational materials on genetics, bioscience, and health topics. They are designed to be used by students, teachers, and members of the public. <http://learn.genetics.utah.edu/>

**DNA from the Beginning** – Provides an animated primer on the basics of DNA, genes, and heredity. [www.dnaftb.org/dnaftb/](http://www.dnaftb.org/dnaftb/)

**Gene Reviews** – Features expert-authored, peer-reviewed, current disease descriptions that apply genetic testing to the diagnosis, management, and genetic counseling of patients and families with specific inherited conditions. [www.genetests.org/servlet/access?id=8888891&key=etn1HekazydBi&fcn=y&fw=8PQs&filename=/about/content/reviews.html](http://www.genetests.org/servlet/access?id=8888891&key=etn1HekazydBi&fcn=y&fw=8PQs&filename=/about/content/reviews.html)

**Office of Rare Diseases Research (ORDR)** – ORDR coordinates research and information on rare diseases at the NIH and for the rare diseases community. The ORDR Web site provides information for patients and their families with rare diseases and about NIH- and ORDR-sponsored biomedical research and scientific conferences. <http://rarediseases.info.nih.gov/>

**U.S. Surgeon General's Family History Initiative, Family History Tool** - This web-based tool helps users organize family history information and then print it out for presentation to the family doctor. In addition, the tool helps users save their family history information to their own computer and even share family history information with other family members. [www.hhs.gov/familyhistory](http://www.hhs.gov/familyhistory) The tool can be accessed at <https://familyhistory.hhs.gov/>.

**Online Mendelian Inheritance in Man (OMIM):** [www.ncbi.nlm.nih.gov/sites/entrez?db=OMIM](http://www.ncbi.nlm.nih.gov/sites/entrez?db=OMIM). Catalogue of genes and genetic disorders.