

Consumer Genetics Education Network (CGEN) Project

FACT SHEET



Charles B. Wang
Community Health Center



What is CGEN?

The Consumer Genetics Education Network (CGEN) Project is an effort to improve genetic literacy in underserved populations and to increase access to culturally and linguistically appropriate genetics education programs and services. Four community partners are developing and implementing population-specific genetics education programs.

What is the goal of CGEN?

The overall goal of the CGEN Project is to increase the genetic literacy of African Americans, Latinos, Asian Americans and Pacific Islanders, which will lead to:

- informed health decision-making
- consultation with family and primary care physicians
- use of genetic services among high-risk populations
- adoption of lifestyle changes to reduce genetic-based health risks

Best practices and lessons learned will be disseminated through local and national networks of professional and consumer groups interested in genetics.

How does CGEN work?

Using principles of community-based participatory research (CBPR) and evaluation techniques, four organizations are creating culturally appropriate education models and materials for low literate populations of various backgrounds and cultures.

Who are the CGEN partners?

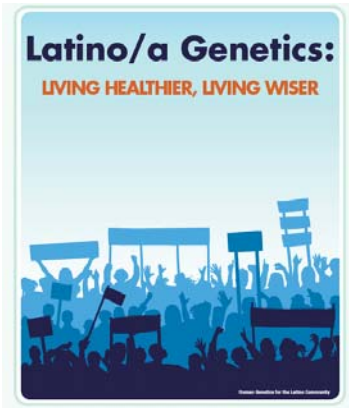
- Dominican Women's Development Center, New York, NY
- Charles B. Wang Community Health Center, New York, NY
- Genetic Science Learning Center at the University of Utah and Utah Department of Health Chronic Disease Genomics Program, Salt Lake City, UT
- National Human Genome Center – GenEthics Unit at Howard University, Washington, DC
- Evaluation: Midwest Latino Health Research, Training and Policy Center at the University of Illinois at Chicago

How do I get more information?

Contact Dr. Diane Ashton, Deputy Medical Director, March of Dimes, 914-997-4265, dashton@marchofdimes.com or Ms. Penny Kyler, Project Officer, Health Resource and Services Administration, 301-443-1080, pk Tyler@hrsa.gov or visit www.marchofdimes.com/genetics or a partner web site (see reverse side).

Midwest Latino
Health Research, Training and Policy Center

Consumer Genetics Education Network (CGEN) Project: Products and Activities



Dominican Women's Development Center www.dwdc.org

- Bilingual (English and Spanish) genetics curriculum for Community Health Workers (CHWs) – Topics include:
 - Where Do We Come From?
 - Understanding Genetics
 - The Developing Baby and the Environment
 - Genetic Diseases
 - Genetic Tools
 - Ethical, Legal, and Social Implications of Genetics
- Genetics education workshops for the community

Charles B. Wang Community Health Center www.cbwchc.org

- Brochures in Chinese, Korean and English
 - Amniocentesis: How It Can Help You & Your Baby
 - The Benefits of Genetic Testing & Counseling For You & Your Family
 - Maternal Serum-Triple Screen: A Test That Lets You Know About the Risks Your Baby May Face
 - Understanding Thalassemia: How It Affects You & Your Baby
- Genetics education workshops for patients and community members



Genetic Science Learning Center at University of Utah and Utah Department of Health

www.learn.genetics.utah.edu and www.health.utah.gov/genomics

- Genetics curriculum and educational material for elementary and high school students and their families in English and Spanish
- Curriculum for fifth grade that focuses on heredity and includes take-home activities:
 - Family Traits Trivia
 - Handy Family Tree
 - Family Traits and Traditions
- High school materials on family health history for Biology or Health classes include a take-home guide “What’s Your Family Health History”
- Genetics education workshops for teachers and family events



National Human Genome Center – GenEthics Unit at Howard University

www.genomecenter.howard.edu

- Community workshops that expand on information provided in two interactive booklets
 - “Race”, Genetics, and Health
 - Planning for a Healthy Future: The Importance of Family Health History
- Public Service Announcement (PSA) on Family Health History
- A toll-free number, 1-866-455-0501 for individuals to request information
- Web site – www.myfamilies.org

