
Genetics Education Needs Evaluation (GENE) Project Fact Sheet

The Genetics Education Needs Evaluation (GENE) Project is a 5-year project to investigate and improve consumer access to genetics information. Launched in June 2000, it is managed by the March of Dimes under a cooperative agreement with the Maternal and Child Health Bureau of the Health Resources and Services Administration. Two other partners are: Family Voices, a national, grassroots network of families speaking on behalf of children with special health needs; and the Genetic Alliance, a coalition of consumers and professionals that promote the interests of children, adults and families living with genetic conditions.

The central mission of the project is to develop community-based, participatory strategies to improve access to culturally and linguistically appropriate genetics information, resources and services to assist underserved populations in making informed choices about their health.

Goals:

The goals of the GENE project are to:

- Strengthen and expand existing partnerships between the Health Resources and Services Administration, March of Dimes, Family Voices and the Genetic Alliance to develop, sustain and replicate a model of genetics education with and for populations who are underserved and under-represented.
- Develop a model of community-based participatory consumer genetics education that includes: partnering with two communities; developing local coalitions; identifying community needs and strengths; developing educational messages and strategies; and evaluating and synthesizing the experiences.
- Build on the community involvement and disseminate and replicate the model of community-based participatory consumer genetics education.
- Increase participation of community members on public health policy initiatives regarding genetics.

Activities:

Activities to achieve these goals include:

- Literature reviews and other needs assessment activities.
- Community-based projects that engage local partners to address genetics information needs in their communities.
- A dissemination of the results of these community projects for replication by other organizations.

The long-range vision of the GENE Project is to create a collaborative network for the development and dissemination of culturally appropriate human genetic information that will assist individuals and groups in making inquiries and informed choices about health.

Contact information:

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Web sites:



www.mchb.hrsa.gov



www.marchofdimes.com/geneproject



www.familyvoices.org



www.geneticalliance.org



http://groups.yahoo.com/group/gene_coalition



www.migeneproject.msu.edu