

# Genetics Education Project

**The Genetics Education Project** works to increase the maternal and child health (MCH) population's understanding of the benefits, risks, and limitations of genetic and newborn screening and testing.

The use of genetic and newborn screening and testing as a way to diagnose disease or identify health risks is growing. However, as the use of such technologies increases, the potential risk of abuse also grows. One of the best societal protections from possible misuses of genetic information is knowledge about newborn screening and genetics and how genetic information can and should be used. Additionally, a better understanding of newborn screening and genetics leads to a better appreciation of the genetic similarities and differences among people, enhances cultural understanding, offers hope for improved treatments, and provides insights into health promotion.

## Activities

To support the development of the Genetics Education Needs Evaluation (GENE) Project, the Maternal and Child Health Bureau formed a 5-year cooperative agreement with the March of Dimes Birth Defects Foundation to support the development of a network for newborn screening genetic resources and service information for the maternal and child health (MCH) population.

The project includes established partners, such as the Genetic Alliance and Family Voices, which serve as representatives of children, adults, and families living with genetic conditions. GENE brings these groups together with State MCH program officials and professionals, along with ethicists, educators, information technologists, and MCH health care providers.

## Resources

The **National Newborn Screening and Genetics Resource Center** offers newborn screening and genetics resources for MCH health professionals, the public health community, families, and government policymakers. To see a complete set of offerings, visit <http://genes-r-us.uthscsa.edu> or call (512) 454-6419.

**GeneTests-GeneClinics** is a publicly funded medical genetics information resource developed for health care providers and researchers. To learn more, visit [www.geneclinics.org](http://www.geneclinics.org).

The **National Coalition for Health Professional Education in Genetics** is a coalition of more than 100 health organizations. To learn more, visit [www.nchpeg.org](http://www.nchpeg.org).

The **HRSA Information Center** offers a wealth of maternal and child health publications and resources. To see a complete list of offerings, visit [www.ask.hrsa.gov](http://www.ask.hrsa.gov) or call toll-free (888) ASK-HRSA (275-4772).

**MCHB Program Grants Guidance and Application Materials** are available online. Those interested in applying for MCHB grants should visit [www.mchb.hrsa.gov/html/grantsguidance](http://www.mchb.hrsa.gov/html/grantsguidance) to access instructions and other pertinent information.

*The Genetics Education Project, which is administered by the Genetic Services Branch of the Division of Services for Children with Special Health Needs (DSCHSN), is a joint effort of the Genetic Services Branch and the March of Dimes Birth Defects Foundation. DSCHSN is part of the Maternal and Child Health Bureau. For more information, call (301) 443-2170, or visit [www.mchb.hrsa.gov](http://www.mchb.hrsa.gov).*