

Genetic Services Branch

Programs of the Genetic Services Branch provide early identification of heritable conditions; the development of comprehensive, culturally competent, and family-centered newborn screening and genetic services; and an understanding of how newborn screening and genetic services affect the maternal and child health (MCH) population's health.

MCH genetic services include a broad range of clinical and public health activities, such as individual and community health assessment, genetic screening and counseling for inherited conditions, measuring susceptibility and prevalence of gene-related conditions that result from specific environmental exposures, and helping the MCH population with genetic conditions manage their health. Currently, these and other services are provided in a variety of settings such as community health clinics, academic health centers, public health departments, public and private laboratories, and private health care providers.

Activities

The Branch has implemented projects in the following program areas:

- Public health infrastructure for the incorporation of new technology into newborn screening programs
- Emerging issues and technologies in newborn screening
- Training and education in newborn screening and MCH genetics for MCH health professionals
- Consumer initiatives and genetic education for the MCH populations
- Community genetics and newborn screening services, such as the National Hemophilia Program and Sickle Cell Disease programs

These programs encourage the integration of various types of Federal, State, and community funded newborn screening and genetics services into systems of care that are responsive to the individual needs of the people being served. The Branch works toward several goals that are part of this overarching purpose. These goals are:

- Expand newborn screening programs, and nurture partnerships among them and existing State and community systems of care for children with special health care needs
- Examine emerging issues and technologies in the field of MCH genetics and newborn screening and identify their financial, ethical, legal, and social implications for the MCH population
- Improve the MCH population's understanding of genetics and newborn screening. This understanding includes knowing about benefits, risks, and limitations of genetic and newborn screening and testing, as well as the implications of genetic information
- Help MCH health care providers, social service professionals, and public health officials serving the MCH population accurately communicate benefits, risks, and limitations of genetic and newborn screening and testing, as well as help them accurately interpret and properly use this information in their practices
- Support the National Hemophilia Program and showcase it as a model for health care providers serving populations of all ages with special health care needs

- Provide national leadership on expanding and enhancing newborn screening and genetic services for the United States by building on the collective experience of the MCH community

Overall, grants through the Genetics Services Branch are expected to:

- Improve follow-up rates and treatment for newborns with genetic conditions such as sickle cell disease that are identified by States' newborn screening programs
- Develop formal partnerships between MCH public health and health care providers and statewide systems of care
- Improve long-term outcomes for children with medically complex genetic disorders, such as cystic fibrosis and sickle cell disease, by ensuring each child has a medical home
- Develop care protocols for children with metabolic and other genetically based conditions
- Expand screening resources for, and increase the MCH population's awareness of, genetic and newborn screening
- Establish training programs for MCH health care and other types of service providers serving the MCH population
- Develop a standardized outcome database on morbidity and mortality in infants with genetic conditions detected by State newborn screening programs

In addition, the Branch develops programs that assure genetic and newborn screening will be done with appropriate counseling, and that such screening is accompanied with proper and timely interventions. For instance, the National Hemophilia Program has helped families and individuals with hemophilia and other bleeding disorders for more than 23 years. The program supports comprehensive health care services and has helped develop a national base of expertise regarding diagnosis and specialty care for the condition. About \$5.3 million annually in grants has been administered through this program, which supports a network of 145 hemophilia treatment centers across the country.

Resources

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.

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.

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 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 to access instructions and other pertinent information.

The Genetic Services Branch is in the Division of Services for Children with Special Health Needs, which is part of the Maternal and Child Health Bureau. For more information, call (301) 443-2170, or visit www.mchb.hrsa.gov.