FOR IMMEDIATE RELEASE
October 6, 2009

Contact: Tiphané Turpin
202-966-5557 x212
tturpin@geneticalliance.org

Patient and Provider Education at the Heart of New Prenatal and Early Childhood Diagnosis Program

Genetic Alliance and Partners Awarded HHS HRSA Congenital Conditions Program

WASHINGTON – October 6, 2009 – The U.S. Health and Human Services, Health Resources and Services Administration (HRSA), Genetic Services Branch, awarded Genetic Alliance, in partnership with the National Coalition for Health Professional Education in Genetics and other partners, a four year $3.28 million cooperative agreement for the implementation of the Prenatally and Postnatally Diagnosed Conditions Awareness Act (PPDCAA). PPDCAA is dedicated to improving the system of information and support for prenatal and early childhood diagnosis. The partners will develop models for diagnosing congenital conditions, beginning with: Down syndrome, spina bifida and dwarfism. The program will create replicable, sustainable mechanisms for patient and provider education.

"Receiving prenatal or early childhood diagnosis is a life-changing event with countless challenges," explained Sharon Terry, president and chief executive officer of nonprofit health advocacy organization Genetic Alliance. "Families have to navigate a fractured healthcare system to attain the services and care their children deserve. The Congenital Conditions Program will provide individuals, families and providers with access to accurate, evidence-based, timely, unbiased, quality information to foster informed decision making that will impact all aspects of a child's life."

The goal of the Congenital Conditions Program is to collect and disseminate evidence-based information, while coordinating the availability of supportive services for parents whose child receives a diagnosis prenatally, at birth, or up to one year after birth. Program partners will work with HRSA to expand and improve:

- Awareness of national and local peer-support programs
- Creation of awareness and educational programs for healthcare providers who provide, interpret and inform parents of confirmatory diagnosis results
- Public use of the Genetics and Rare Diseases Information Center
- Integration of the Quality Assessment Toolbox, as developed through a Centers for Disease Control and Prevention cooperative agreement for the Access to Credible Genetics Resources Network

"This initiative provides an opportunity for family-centered groups to work with health professionals, regional and state programs, federal agencies, and other stakeholders in a cohesive program that increases awareness, educates families and providers, and delivers information during a critical time in a child's development," said Joseph D. McInerney, executive director of the National Coalition for Health Professional Education in Genetics.

PPDCAA paved the way for funding supporting the diagnosis of conditions that impact many individuals throughout their lifespan. Down syndrome, the most commonly occurring chromosomal condition in the U.S., occurs in one in every 733 babies annually. Today there are more than 400,000 people living with Down syndrome. The National Center for Health Statistics indicates that spina bifida, a condition that affects the neural tube, is found in one newborn in 2,500. Types of dwarfism occur in one in every 95,000 newborns. Although the program will focus on these three conditions initially, it will create and solidify a model that can be applied to other conditions.

"I look forward to building on the work of organizations committed to Down syndrome, spina bifida, dwarfism, and other congenital conditions. This project will be fueled by collaboration," said Natasha Bonhomme, project director of the Congenital Conditions Program and the vice president of strategic development at Genetic Alliance.

###

About Genetic Alliance

Genetic Alliance transforms health through genetics, promoting an environment of openness centered on the health of individuals, families, and communities. Genetic Alliance brings together diverse stakeholders that create novel partnerships in advocacy; integrates individual, family, and community perspectives to improve health systems; and revolutionizes access to information to enable translation of research into services and individualized decision making. For more information about Genetic Alliance, visit http://www.geneticalliance.org.