



Genetic Alliance's Expecting Health Team Awarded Multi-Million Dollar Newborn Screening Family Education Program

Statement from Expecting Health, an initiative of Genetic Alliance

Washington, DC (September 24, 2018) —Expecting Health (www.ExpectingHealth.org), the Genetic Alliance-led maternal and child health initiative behind Baby's First Test (www.BabysFirstTest.org), will continue to evolve information dissemination and shared decision making through the Newborn Screening Family Education Program award. The Health Resources and Services Administration recently awarded \$2 million over 5 years (\$400,000 per year) to increase knowledge, awareness, and participation of parents and families in newborn screening educational efforts.

Newborn screening began in the early 1960s as a screening tool for phenylketonuria, or PKU. More than 50 years later, this public health service is available for all babies born in the U.S., yet full understanding of the routine practice remains low among parents. In addition, some healthcare professionals do not always feel fully equipped to discuss the many stages of newborn screening. Despite the success of newborn screening in reducing morbidity and mortality for numerous screenable conditions, emerging technologies and policies are exacerbating gaps in public knowledge and building a dire need for trusted, readily available information.

Expecting Health's Founder and Genetic Alliance Chief Strategy Officer, Natasha Bonhomme, stated, *"We know that there are proven ways to increase awareness and to empower families to make healthy, informed decisions, and we're thrilled to embark on this project as a means to keep families central to the newborn screening system."*

Over the next five years under this cooperative agreement, the Expecting Health team and its partners will increase newborn screening awareness and understanding through partnerships, training development, and outreach; with a focus on diverse and medically-underserved audiences.

With over a decade's worth of experience in newborn screening knowledge sharing, and lessons learned in disseminating actionable health information aimed at behavior change,

Expecting Health is strategically positioned to educate the public on this critical public health program.

About Expecting Health

Expecting Health was founded by a group of women with a simple idea: families deserve and should expect more—more support, more guidance, better health. We believe that all new and expecting families deserve accessible, timely, and science-based information to make the best decisions for their health and the health of their children. Rooted in 32 years of community programs and representing national voices and family-centered experiences, Expecting Health shares science-based and policy-informed information that reflects the lived experiences of individuals and families. For more information, visit www.ExpectingHealth.org.

About Genetic Alliance

Genetic Alliance engages individuals, families, and communities to transform health. Founded in 1986, it is the world's largest nonprofit health advocacy organization network. Genetic Alliance's network includes more than 1,200 disease-specific advocacy organizations, as well as thousands of universities, private companies, government agencies, and public policy organizations. For more information about Genetic Alliance, visit www.GeneticAlliance.org.