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Contact: Natasha Bonhomme  
202-966-5557 x211  
[nbonhomme@geneticalliance.org](mailto:nbonhomme@geneticalliance.org)

## **Future of Newborn Screening Envisioned: Proceedings Now Viewable Online**

WASHINGTON – January 7, 2010 – More than 200 health professionals, family members, and others participated in the recent *Newborn Screening Summit: Envisioning a Future for Newborn Screening* to discuss how long-standing state public health programs can evolve to keep up with new technology, societal and governmental trends, and medical advances. “This meeting provided a wonderful opportunity to visualize the newborn screening system from the point of view of many stakeholders. Working together we can provide the support the entire system needs,” said Sharon Terry, President and CEO of [Genetic Alliance](http://www.geneticalliance.org), which hosted the event in Bethesda, Maryland, December 7-8, 2009.

Families, healthcare providers, researchers, state programs facilitators, and laboratory professionals all participated in the Summit both in-person and virtually. The meeting was webcast live, and the videotaped proceedings can now be accessed at: [http://www.geneticalliance.org/ws\\_display.asp?filter=nbs.summit](http://www.geneticalliance.org/ws_display.asp?filter=nbs.summit).

States screen newborns for at least 29 conditions. Over the past 10 years, newborn screening programs have kept pace with emerging science and expanded accordingly. More than 4 million babies are screened annually, which allows for the rapid identification of infants with diseases requiring early intervention. For example, as a result of this screening and intervention, children with the inborn enzyme deficiency phenylketonuria (PKU) can be spared serious disability and death.

The system faces many challenges, however. Procedures are not standardized across states, and testing for some diseases is complex and requires follow-up to reach a definitive diagnosis – a process that can cause parents anxiety. The rapid advances in genetic screening technology and increasing state resource deficits are also impacting the system, making this a critical time for newborn screening.

As a public health initiative, newborn screening impacts us all. Transparency is a guiding principle in Genetic Alliance’s work, and a priority of this meeting was to engage individuals with as many perspectives as possible. “Attendees had open, frank conversations that are often not possible at meetings,” said Natasha Bonhomme, director of Genetic Alliance newborn screening projects. “Each participant contributed immensely through presentations, comments, questions, and suggestions. People specifically said

that they felt valued.” The Summit promoted dialogue among all stakeholders in newborn screening and identified actionable steps for the improvement of the system.

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***About Genetic Alliance***

Founded in 1986 as the Alliance for Genetic Support Groups, Genetic Alliance is now the world's leading nonprofit health advocacy organization committed to transforming health through genetics. Our open network connects members of parent and family groups, community organizations, disease-specific advocacy organizations, professional societies, educational institutions, corporations, and government agencies to create novel partnerships. We improve access to information for individuals, families and communities, and support the translation of research into services.