



GETTING THE WORD OUT: NEW WEBSITE EDUCATES ABOUT NEWBORN SCREENING

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In September, Baby's First Test (www.babysfirsttest.org), a new resource about newborn screening, launched. A national clearinghouse of newborn screening information, this web tool will increase awareness and knowledge of newborn screening and better inform the decision-making process for stakeholders, including new parents and healthcare providers. Condition-specific information, materials for healthcare providers, detailed education on the newborn screening process, and family stories are just some of the highlights of the new website.

In 2008, Congress passed the Newborn Screening Saves Lives Act to expand support, research, and education opportunities for newborn screening. Because of this legislation, the HHS Health Resources and Services Administration's Genetic Services Branch awarded a cooperative agreement to Genetic Alliance and partners to establish an online newborn screening information resource center specifically for parents and the public. The goal is to connect parents and healthcare providers with resources and information relevant to the more than four million newborns screened annually. Over the past two years, Genetic Alliance and partners mapped out a vision of this resource based on this legislation. The process included engagement with state and regional newborn screening programs, input from prenatal care providers, and feedback from consumer advocacy groups.

One of these collaborative efforts is with APHL. Through a challenge award funded by Genetic Alliance, APHL has worked extensively to discuss newborn screening through social media channels and has hosted Twitter chats to answer common questions about newborn screening. Baby's First Test and APHL will continue their partnership efforts in the upcoming year to ensure state labs have ample opportunities to use and comment on the new tool.

Baby's First Test will serve as a comprehensive guide for many aspects of newborn screening, including conditions covered and what to do in case of a screen positive test result. The site aims to support families by providing early education about newborn screening and highlighting the many partners that make screening work.

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