

APHL Actions

- Convene national newborn screening partners from public and private sectors to initiate a review of the laboratory aspects of the newborn screening system.
- Develop and conduct training for hospital staff and nurses in collection, handling and transport of blood samples, including the vital importance of rapid delivery of blood samples to the lab
- Share best practices on state health laboratory tracking and delivery systems
- Survey state health laboratories to assess newborn screening practices, including testing turnaround time and tracking of receipt of samples.

Newborn Screening Process is Dynamic

- Advancing technology has led to expanded screening (e.g., MS/MS, microarray)
- Addition of MS/MS in 2000s dramatically increased number of conditions tested for, thus saving more babies' lives
- Expanded process detects more newborns with treatable disorders

APHL is taking action to improve the newborn screening system to ensure accurate and early testing. Continuous quality improvement is a core value of APHL and public health laboratory culture.

Obstacles to Improving System

- Impact of economic downturn has been severe for PHLs. Lack of funding for newborn screening at federal and state levels
- SCID added to RUSP in 2010 – currently only 16 states are testing for it with 2-3 adding annually. Federal funding needed to expand testing in states when new conditions added to RUSP
- Newborn Screening Saves Lives Reauthorization Act stuck in Congress
- NBS is a system, and system change takes time– programs are state operated and differ from one another

Value of NBS system

- More than 12,000 lives are saved or improved by newborn screening each year in the US.
- Newborn screening is a fast, safe way to protect babies against medical conditions that can cause permanent disability or death.
- Significant cost benefit: Undetected congenital hypothyroidism (CH) causes severe intellectual delays; early detection prevents these disabilities. Cost of individuals living with undetected CH is roughly \$400 million in care and lost productivity. Cost of nationwide newborn screening for CH is \$20 million annually. That's a savings of \$380 million annually.

Family stories:

- Two Siblings Born With Isovaleric Acidemia: One Caught by Newborn Screening, One Wasn't <http://bit.ly/StephenAndCaroline>
- No Story Is the Best Story <http://bit.ly/MarensStory>