

Central message: Newborn screening saves lives; every baby should be screened.

NBS process is vital to children's wellness.

- Expanded process detects more children with treatable disorders.
- Continued research to improve the quality of NBS is critical,
- Research on new disorders saves children from death, disability, e.g., SIDS, CFS, exposure to environmental toxicants, etc.

Policies governing NBS and retention of specimens are evolving in response to advancing technology.

- Health policymakers aim to balance privacy concerns with public health benefits.
- PHLs are awaiting the release of ACHDNC* paper outlining recommended guidelines on retention of newborn specimens. Release is expected soon.
- States will review recommendations of the ACHDNC paper and begin to implement them as appropriate.
- APHL has gone on record stating the importance of greater consistency in state policies re. specimen storage, accession.
- But continuity in NBS is critical: don't want to disrupt the current system which protects virtually all newborns in the US.

Education helps families be comfortable with decisions about retention of NBS specimens.

- All families receiving prenatal care should have the opportunity to learn about newborn screening.
- Parents should be informed about the potential uses of dried blood spots.
- When asked, most people will permit use of residual NBS blood spots.**

Protections are in place to safeguard families' rights.

- All states have an advisory committee to guide NBS policy in their state.
- Americans now have legal protection against discrimination based on genetic discrimination: Genetic Information Non-discrimination Act (GINA) protects against discrimination in health insurance and employment. Many Americans are unaware of this law; full provisions went into effect in November 2009.
- Research on NBS specimens must be approved by the state's IRB and overseen by an independent ethics review panel.
- *Add your state's policy here. Describe clearly and be prepared to provide the details and rationale in writing.*

PHLs are conscientious stewards whose sole mission it is to protect the public health

- PHLs conduct 97% of testing of the 4 million babies born in US each year.
- PHLs use NBS specimens for defined purposes only:
 - Proof of testing
 - Quality control—retesting a specimen
 - Quality assurance—refinements to tests
 - Evaluation of new testing technologies
 - Method development for new disorder

**HHS Secretary's Advisory Committee on Heritable Disorders in Newborns and Children*

***University of Michigan survey of a national, random sample of nearly 4,000 adults, found that 26% are "very" or "somewhat" willing to permit use of residual NBS specimens. With permission; that number jumps to 76%.*