NEWBORN SCREENING IS MORE THAN A TEST. IT IS A SYSTEM.

Newborn screening (NBS) is a state public health program that identifies heritable conditions that are treatable when detected with early screening. **The roughly four million babies born in the US each year receive NBS.** All screens are performed in a state public health laboratory or in a partner laboratory under state public health laboratory oversight.

For a disorder to be added to a state NBS panel, what should it have?

1. A valid laboratory screening test
2. Availability of an accurate diagnostic test
3. Evidence of potential net benefit of screening
4. The availability of an effective treatment
5. The availability of specialists to provide treatment

Why are only some disorders screened?

The rigorous evaluation process is designed to ensure that a scientifically sound and accurate screening test, confirmatory test and treatment plan is available. Unfortunately many disorders do not have all three components to ensure those who are found to have an abnormal result are provided with an effective plan of care. The lack of an effective treatment or follow-up plan raises ethical issues for the diagnosed community.

Are there companies that test for more disorders?

Yes, there are. However, private laboratories do not have the same responsibility as a public health program to provide:

- Equity of services and resources for all newborns
- Resources for parents
- Follow-up services for every newborn with an abnormal result

Private laboratory involvement in NBS that is independent of the state NBS program is generally not connected to the states' tracking and case management provisions.

NBS is a coordinated system that includes:

Screening
NBS begins with a small heel prick to collect a few drops of blood on filter paper cards within first 24-48 hours of life. Samples are transported to the public health laboratory for screening.

Results

Normal results
Provider is notified and parents are informed of results at baby's first wellness visit; no further action is needed

Abnormal results
Provider is notified and sometimes requests a retest or further testing.

Diagnostic tests must be done immediately to confirm results

Education
Increase understanding of newborn screening process and importance of follow-up when treatment is necessary.

Follow-up
For diagnosed positive newborns, medical specialists and pediatricians develop a treatment plan and guide parents in caring for baby.

Case management
Program staff track and ensure families with diagnosed positive newborns are linked to appropriate providers and health services.

Without a robust & coordinated system, consequences could include:

- False positives and false negatives due to low-quality screening tests
- Lack of a coordinated follow-up system may cause babies with positive screens to be neglected
- Unanswered questions for parents of children found to have positive screens
- Lack of adherence to follow-up and case management
- Delayed diagnostic work-up and treatment causing potentially irreversible harm

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