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 ability of states to screen for the disorder
5. The availability of an effective 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 each component to ensure those who are found to have a positive screen 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 for which there may not exist a solution or follow-up system.

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 positive screened newborn

Private laboratory involvement in NBS that is independent of the state program is outside of the states’ responsibility for tracking and case management provisions.

Without a robust & coordinated system, consequences could include:

- False positives and false negatives due to low-quality screening tests
- Lack of coordinated follow-up systems that allows 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
- Untimely diagnostic work-up and delayed treatment causing potentially irreversible harm