



Adding Conditions to State Newborn Screening Panels: Recommendations for Decision Makers

Newborn screening is the practice of screening every baby prior to hospital discharge for certain harmful or potentially fatal metabolic and genetic conditions that are not otherwise apparent at birth. Newborn screening allows babies to be identified and treated before they get sick, preventing serious health problems or even death. It is the largest and most successful health promotion and disease prevention system in the country, and the fastest, safest way to help protect against certain diseases and medical conditions.

KEY CONSIDERATIONS

Though technology has made it possible to screen for an increasing number of conditions, evidence does not support screening for all detectable disorders. Decision makers should consider multiple factors to assess the value and feasibility of adding a condition/s to the state's newborn screening panel. These include:

- Is there sufficient evidence of the effectiveness of screening for the condition?
- Will the child and family benefit from early detection?
- How would addition of this condition align with other state policies and values?
- Is funding available to support all costs of implementation including parental education, follow-up, diagnosis, treatment and management, and program evaluation?
- Do the responsible state agencies have the staffing and administrative capacity to support implementation of a new condition?

States should evaluate addition of a condition/s to the state's screening panel using established state or federal deliberative processes that apply recommended criteria and obtain input from relevant stakeholders. Where feasible, states should conduct pilot studies on potential conditions and provide a process for parental consent.

SPEAKING WITH STATE DECISION MAKERS

Newborn screening specialists and their supporters can frame discussions with state decision makers using the following recommended criteria for adding conditions:

- Universal screening is critical to identify all babies who may need treatment
- Affected babies will have a significant, life-challenging risk of illness, disability or death if not treated in the newborn period

- Effective treatment is available for the condition/s
- Treatment during the newborn period is more beneficial than later treatment
- Resources for and access to treatment and counseling are universally available
- The health and societal benefits outweigh the risks and burdens of screening and treatment on newborns and relatives.

LIMITING THE UNINTENDED CONSEQUENCES OF LEGISLATION

Sometimes, despite the best efforts of newborn screening specialists and supporters, legislation will advance that is counter to their recommendations. In these instances, newborn screening allies should advocate that the bill include:

- Sufficient funding for time and costs of implementation as well as administration
- Parental consent required for conditions added in the absence of screening recommendations through an established national or state deliberative process
- Rigorous evaluation required at set intervals to measure the effectiveness of population-wide screening for the condition/s
- Strong protection from liability for screening of the condition/s.

ACKNOWLEDGMENTS / SOURCES

APHL Factsheet, Adding New Conditions to State Newborn Screening Panels (August 2015).

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