

NATIONAL STANDARDS FOR NEWBORN SCREENING

AWHONN supports national minimum standards for newborn screening requirements. Certain conditions have been identified as critical for routine screening because they can enable timely intervention for affected infants and therefore assure a significant reduction of morbidity, mortality and disabilities. Federal oversight is necessary in order for all newborns to have equal access to identification and interventions for these disorders. In addition, a combination of adequate federal and state funding should be allocated to initiate and sustain statewide programs to limit the long-term effects of these disorders.

Key elements to a successful newborn screening program include parent and health care provider education. In addition, programs should include:

- Parental notification and consent, even if tests are mandatory
- Timely screening/testing prior to hospital or birthing facility discharge when appropriate
- Post discharge follow-up for necessary testing or other services
- Resources for appropriate referrals
- Accurate systems for data collection
- Policies to ensure patient confidentiality of genetic information (See AWHONN Policy Position Statement on *Privacy and Confidentiality of Genetic Information*, November 2000)
- Access to interventions and treatments indicated by the diagnosis

In the event that state or federal policies mandate some degree of mandatory testing, these requirements should not interfere with parents' rights to be informed of any and all procedures involving their newborns. There should be mechanisms in place that appropriately address a parent's option to decline testing.

Background: Every state does newborn screening, making it one of the largest prevention programs in the country. Current practices for newborn testing are determined at the state level, creating a flawed system where, for example, a newborn that lives in one state is tested for eleven conditions, while an infant born in another is checked for only three. Such disparities result in unfair and incomplete screening and treatment.

The March of Dimes (MOD) and the American Academy of Pediatrics (AAP) support national minimum standards, and MOD identifies nine newborn screening tests that should be included in the minimum standards. These are:

- Phenylketonuria (PKU)
- Congenital hypothyroidism
- Congenital adrenal hyperplasia (CAH)
- Biotinidase deficiency
- Maple syrup urine disease
- Galactosemia
- Homocystinuria
- Sickle cell anemia
- Newborn hearing

State and federal policy makers are currently considering legislative action to unify the varying state laws; and, to ensure that there are adequate resources for testing and treatments. Many of these diseases, even with early identification and intervention, involve life-long treatment and care.

National minimum standards will not solve all of the ethical dilemmas or cost concerns surrounding the current patchwork system where each state has different requirements for newborn testing; however, creating national, minimum uniform standards using evidence-based practice will ensure that all infants have early access to screening and treatment.

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Approved by the AWHONN Board of Directors, June 2002