



program to enhance the
Health & Development
OF INFANTS AND CHILDREN

A program of the American Academy of Pediatrics in cooperation with the Centers for Disease Control & Prevention

Newborn Screening Initiatives

Newborn Screening: Evaluate and Improve Your Practice



For more information go to: <http://bit.ly/PQTXMk>

Rapid detection and treatment can mean the difference between life and death, or living with a disability. Identify and close newborn screening practice gaps with the new AAP EQIPP *Newborn Screening Evaluate and Improve Your Practice*. This online quality improvement program delivers information, resources and tools that can help you more rapidly diagnose and treat patients. Learn to better:

- Identify areas of practice improvement
- Create and implement a quality improvement plan
- Document all screening services, results and family services, ensuring compliance with state rules
- Confirm diagnosis and initiate timely intervention
- Address family concerns
- Coordinate long-term follow-up for patients with conditions
- Establish optimum newborn screening office procedures
- Understand NBS and EMDI policies endorsed by the AAP and the state NBS programs, which mutually outline the PCPs' explicit responsibilities for newborn Dried Blood Spot Screening (DBS) and hearing screening.

All EQIPP courses help satisfy Maintenance of Certification Part 4 requirements and can be completed in as little as 120 days. For more information about EQIPP courses visit www.eqipp.org.

Newborn Screening for Critical Congenital Heart Defects (CCHD): a Resource for Primary Care Pediatricians

Approximately 18 out of every 10,000 babies are born with a critical congenital heart defect (CCHD). While these defects are life threatening and require early infancy intervention, signs of CCHD are not always detected prenatally or upon exam in the nursery and some infants with CCHD are released home where they quickly decompensate. As a result, the Secretary of Health and Human Services (HHS) recently recommended that CCHD screening be added to the uniform screening panel for newborns.

To help primary care pediatricians navigate the implementation process and provide effective, long-term medical homes for babies with the condition, the American Academy of Pediatrics (AAP) has developed a new online resource. The site, www.aap.org/pehdc/cchd, provides peer-reviewed answers to many frequently asked questions about the rationale for screening, implementation, data collection and management, and screening in special settings such as home births or high altitudes. There are also links to additional resources and a forum for pediatricians to ask questions not already addressed on the site.

Content for the site was developed by a panel of six physicians with expertise in pediatric cardiology, screening implementation and public health. Members of the panel continue to work with the AAP to prepare responses to questions submitted through the website on an ongoing basis.

PediaLink
Online Center for Lifelong Learning

Coming Soon...

Newborn Screening for CCHD
PediaLink course will be
available in December 2013.

Newborn Screening During Emergencies

The newborn screening during emergencies resource was developed to encourage pediatricians to prepare for times when the normal newborn screening process is interrupted by an emergency or disaster. This Web page provides practical guidance to encourage pediatricians and public health leaders to implement pediatric preparedness strategies and action plans specific to newborn screening.

In the midst of an emergency or disaster, the newborn screening process can quickly become disrupted, and cause issues in detecting and treating these preventable diseases. Pediatricians can and should work with public health and other leaders in their states to prepare for disasters and ensure that newborn screening services are maintained to the extent possible in a disaster situation.

During an emergency, newborn screening can be disrupted if there is a breakdown in communication involving any of the following: hospital, health department, laboratory, pediatrician's office, or the baby's parents. Problems can also occur if there is damage to laboratory equipment, shortage of testing materials, improper storage of specimens, or delays with the mailing or shipping systems.

The Newborn Screening during Emergencies www.aap.org/disasters/screening Web page provides information on the pediatrician's role in creating contingency plans, identifies topics pediatricians can raise with families about newborn screening, and offers resources for pediatricians regarding newborn screening and communication tactics during disasters.

Tools to Improve Outcomes Following Newborn Hearing Screening

The AAP Task Force on Improving Newborn Hearing Screening, Diagnosis and Intervention (EHDI Task Force) has developed five tools/resources for medical home providers to improve care around early hearing detection and intervention:

- Newborn Hearing Screening: Lost to Documented Follow-up Considerations for the Medical Home;
- Glossary of Terms for Newborn Hearing Screening;
- 1-3-6 Newborn Hearing Screening Checklist;
- Guidelines for Rescreening in the Medical Home Following a "Do Not Pass" Newborn Hearing Screening; and
- Reducing Loss to Follow-up/Documentation in Newborn Hearing Screening: Guidelines for Medical Home Providers (Algorithm).



Since 2000, the percentage of newborns screened for hearing loss increased from 52% to 95%. However, almost half of the children who "do not pass" (including infants who "failed," missed the screening or had invalid interpretable result) lack a documented diagnosis.

Unidentified hearing loss at birth can adversely affect speech and language development as well as academic achievement and social-emotional development. The infant's primary care medical home provider plays an important role in ensuring timely follow-up and appropriate documentation. Without assistance of the medical home, the infant may be considered "lost" in the early hearing detection and intervention (EHDI) system.

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