



NEWBORN METABOLIC SYSTEM REDESIGN

Quality communication is a critical component in all aspects of public health and clinical care. Consequently, as the Bureau for Public Health implements planned changes in Newborn Metabolic Screening, updates will be placed on the MCFH website.

FREQUENTLY ASKED QUESTIONS

Why is WV just now preparing to expand the newborn metabolic and heritable disease panel?

WV initially waited for federal and nationally recognized medical guidance to identify conditions recommended for screening, reporting, and follow-up. It is important to note that 84 congenital conditions were studied by the Health and Human Services Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases before the recommended 29 screening tests were selected. There were also as many as twenty-nine additional conditions that were rejected for screening because of lack of reliable tests.

The second reason for delay in implementation was money. West Virginia has relied on Public Health Title V resources to finance the entire system. The expansion requires money for reagents, equipment rental, personnel, tracking software, etc.

In Fiscal Year 2007, the State Legislature appropriated monies for equipment rental and personnel to initiate the expansion.

When West Virginia expands to the 29 tests as recommended by the HHS Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases, will that be all the changes?

Twenty-nine is not a magic number. As tests are developed for other conditions the panel may be expanded.

Who has the authority to change the panel of disorders?

The Commissioner of State Public Health has the authority.

Who pays for screening tests?

Historically government paid for screening, spending over one million dollars per year to screen for six disorders. As science has expanded the capability of identifying more problems among newborns, governments across the country, including West Virginia, have started to bill for these services. The Bureau for Public Health will bill birthing facilities \$45.00 for each live birth. It is expected that the birthing facilities will recover costs incurred through appropriate third party payment processes.

Pediatricians are often contacted with the request to have the family bring the child in for a repeat screen. Who pays the \$45.00 charge?

The initial screen is paid for by the birthing facility with the expectation that the facility will recoup the cost from the insurer. The charge of \$45.00 is the inclusive charge even though a repeat screen is often required. There is no charge for the repeat screen.

What additional system components does the fee cover?

The costs associated with distribution of specimen kits, laboratory services, repeat testing, short-term follow-up, and diagnosis.

What happens if an infant/family does not have insurance coverage?

Approximately 93% of the State's children are insured. However, for those without insurance, government will pay the screening cost.

Testing information is confidential...yes?

Absolutely, the information about your newborn is known only to Maternal, Child and Family Health/Bureau for Public Health, the State Lab and your child's doctor.

How are consent, confidentiality and other privacy issues addressed by statute or administrative code/regulation?

All newborns must participate in newborn screening. The person who administers screening must fully inform the parents of the purpose of the test.

Who is responsible for ensuring a newborn screen is performed?

The statute states, "the hospital or birthing center...the parents or legal guardians, the physician attending the newborn, or any person attending a newborn not under a physician's care..."

What happens if my baby has a rare disorder?

The infant's medical practitioner will contact you, so it is important to identify, at time of delivery, the place/name of who will be providing medical care for the infant.

Some treatment will be available in West Virginia; other treatment will be available in surrounding states in the region or even across the country. Some disorders are so rare that only a small number of medical genetics experts may have familiarity with the disease. Staff at MCFH and WVU Department of Pediatrics will identify medical resources and help families to obtain services for their child.

Are newborn screening laboratory services regulated? How?

The statute states, "The Bureau of Public Health shall establish and maintain facilities at its State Hygienic Laboratory for testing specimens. The State Laboratory meets nationally established clinical laboratory guidelines.