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HEADLINE: Getting Ahead on Baby Screening

BODY:

While state and federal officials mull over whether and how to expand infant screening, parents can take some initiative on the matter.

The first step is education. Jeffrey Botkin, chair of the American Academy of Pediatrics's bioethics committee, advises parents to consult their pediatrician about screening procedures before a baby's birth. While chemical disorders in newborns can be very serious, the incidence of these is actually strikingly low. For example, only about 25 babies in Maryland are diagnosed with any of the eight disorders the state tests for each year. **Susan Panny,** head of Maryland's newborn screening program, expects that figure to rise by only another five or six once TMS screening is initiated. That screening is expected to also find disorders that current tests do not identify.

Newborn screening is done using a few drops of blood usually taken from the infant's heel before hospital discharge or during the first pediatric visit. In the District and Maryland, testing requires a parent's informed consent, which may be included on forms you sign when checking in to the hospital, after the baby is born or at the pediatrician's office. In Virginia, testing is done on all infants unless parents sign a waiver citing a religious objection.

Results are generally sent to the pediatrician. Your doctor should be able to tell you how long it takes to get results back. False-positive rates are high; 95 to 99 percent of babies who initially test positive turn out not to have a disorder, according to Jeffrey Botkin, chairman of the American Academy of Pediatrics's bioethics committee and professor of pediatrics at the University of Utah Medical School. If a result is positive, the test is generally repeated while treatment is begun.

Parents can order supplemental tests themselves. Three labs, including those at Baylor School of Medicine and the Mayo Clinic, offer the testing for $25 to $50 per set of tests. But Baylor and Mayo don't test for galactosemia, biotinidase, sickle cell anemia, hypothyroidism or congenital adrenal hyperplasia, so if your state doesn't test for these, you may want to get your supplemental tests from the third lab, Neo Gen Screening of Bridgeville, Pa.

To get a supplemental test, you don't need to take the baby to the lab. Test kits that can be ordered ahead of time include special filter paper used to capture the blood sample. Most labs suggest giving the filter paper to the delivery nurse so she or he can put blood from the baby's heel stick on it. Find out in advance if the hospital will mail it to the lab for you, or if you need to do that on your own. Results from the labs, like the state tests, are generally sent to your pediatrician.

Don Chase, medical director of Neo Gen Screening, says testing is generally done within a day of receiving test samples, and results are generally available within a day after that, especially if an abnormality is found.

* Maryland Newborn Screening Program: http://mdpublichealth.org/genetics/html/nbs_ndx.html.

* Virginia Newborn Screening Program: www.vahealth.org/psgs/datapsgs.htm.

* District of Columbia Newborn Screening Program: 202-645-5618 or 202-645-5658.

* March of Dimes: http://www.modimes.org/HealthLibrary/334_595.htm.

* Baylor Medical Center: www.baylorhealth.com/newbornscreening.

* Mayo Medical Laboratories: www.mayo.edu/bgl/bglsns.html.

* Neo Gen Screening: www.neogenscreening.com.

* General information: Save Babies Through Screening, an advocacy group whose Web address is www.savebabies.org, provides information on infant disorders for which tests exist.