

Dispelling Myths:—what Newborn Screening IS and ISN'T

Important points to remember about Newborn Screening

Bloodspot specimens and information might be kept long-term and used without my consent—In Arizona specimens are destroyed after 90 days and are **NOT** used for outside research. They are never sold to outside companies. Demographic information is **NEVER** used to determine immigration status.

DNA might be extracted from the sample and used in police or other investigations—the bloodspots are **ONLY** analyzed to determine the likelihood of 28 genetic and metabolic newborn conditions. We do not test for drug use or sexually transmitted diseases. The testing is metabolic screening analysis, not genetic profiling.

I refuse all interventions for my newborn because they might harm the infant—a small heel stick is used to collect a few drops of blood. **NO** medication is introduced.

Two screens are not really needed; one should be enough—there is an **IDEAL WINDOW** for each newborn disorder and while some are most easily detected before the baby is well fed, other conditions take a little longer to be discovered. Both screens ensure the best chance for detection. In 2009, 10 babies with normal first screens were diagnosed with Congenital Hypothyroidism, Homocystinuria, and Cobalamin Defect. For NICU babies, a third screen is sometimes recommended.

These conditions are so rare that I will never see one in my practice—some conditions screened for are quite common. While PKU is found in 1:25,000 births, Congenital Hypothyroidism and Sickle Cell Anemia are found in 1:5000 births. In Arizona we detect over 100 newborn screening disorders each year.

If the newborn is sick I will know it—newborns often look well and feed normally but have rare conditions that are life threatening but can be treated with medication or food supplementation.

The baby will have to go to the hospital or outside lab to have the blood drawn—the health care provider can draw the blood for both screens, receive all results, and counsel on next steps. Often baby can remain in mom's arms.

I am concerned about the cost and don't want to receive a bill—there is a small cost of \$30.00 for the first screen and \$65.00 for the second to cover analysis, education, and follow-up; however, this cost is usually covered by AHCCCS or insurance or can be included in a birth package price so that the family does not receive an additional bill. Newborn Screens will be processed and parents notified regardless of ability to pay.

I can ring a bell or make loud noises in the presence of a newborn to determine hearing loss—many babies with significant hearing loss will respond to sounds. The newborn hearing screen is completely non-invasive, widely available, inexpensive, and effective. The incidence of hearing loss is 1-3:1000 at birth and doubles by school age.

Phone: 602-364-1409 • Toll free: 1-800-548-8381 • Fax: 602-364-1495

Visit the Newborn Screening website: www.aznewborn.com for more detailed information