Talking to caregivers about newborn screening

First, make sure that you have a Newborn Screening brochure on hand when speaking with parents and caregivers, so that both you and they can reference it.

Why is it done?

Explain: "There are some medical conditions that can be present at birth without symptoms. These conditions cannot be detected without specialized tests. But if they are not detected within a few days after birth, they can cause permanent disability, learning delays, and even death. Kansas screens for 32 conditions at no cost to you. They screen for, critical congenital heart defects, hearing loss, and 30 other genetic or metabolic conditions."

If they aren't sure what genetic or metabolic conditions are, explain: "A genetic condition is one that is inherited from one or both parents through their DNA, and can impact a variety of body systems. A metabolic condition affects how your baby's body processes food and nutrients."

How is it done?

CCHD

Explain: "To detect heart defects, we look for low levels of oxygen in your baby's blood. We use a combination of two non-invasive devices called pulse-oximeters, one on a hand and one on a foot. By comparing the two readings we can determine if the heart is working correctly to provide your baby's body with enough oxygen."

If they ask how the pulse-ox works – "It uses light to detect small differences in the amount of oxygen in the blood."

Hearing

First, know what *type* of hearing screen *your facility* uses: OAE, AABR, or both.

Explain: "Hearing screen is conducted by using tiny probes or electrodes that detect how your baby's ears or nerves respond to sound. The test takes 5-10 minutes, is painless, and often done while the baby is asleep. We will record whether your baby passes the screen in one or both ears."

If using OAE – "OAE uses a tine probe place just inside the ear canal to measure sound wave echoes when clicks or tones are played into your baby's ears."

If using AABR – "AABR uses electrodes placed on your baby's head to measure the hearing nerve response when click or tones are played into your baby's ears."

If using both – "Our facility uses two types of screening…" then explain as above.

Metabolic

Explain: "Genetic and Metabolic screening is done using dried blood spots. We collect blood from your baby's heel (show them where you will collect from), using a small lancet (show). We'll collect 5 full spots (you can show the collection card WITHOUT you or the parent touching

the calibrated spots). We'll let the specimen dry for 3-4 hours and then package it up to ship to the Kansas State Laboratory."

Responding to questions:

Will it hurt? – "The lance can cause a small amount of discomfort, but this is short lived and there are several methods we can use to decrease discomfort." You can list the ways that your facility typically decreases discomfort, such as: sucrose, swaddling, parents holding while collecting, breastfeeding while collecting, etc.

Remind parents: "While it does cause a small amount of discomfort, this is temporary compared the permanent impacts that can be caused by not detecting these conditions *early*."

What does the state do with the blood spots/specimen? – "The State lab will run several tests on the specimen to detect the various conditions (show the list of conditions in the brochure). After they've completed the testing, they keep normal specimens for no more than 30 days. In that time, it may be used to ensure the quality and consistency of the screening process, but it will be destroyed after 30 days. Abnormal specimens may be kept longer but all identifying information is removed so that it cannot be traced back to your baby. Again these specimens would be used to ensure the quality and consistency of the screening process for all Kansas babies."

Can I object to screening? – "Newborn screening is mandated by state law. Every baby is to be screened, unless the family objects on religious grounds." If comfortable, you can share a story here of your own or a colleague's experience of how newborn screening has saved lives. You can also share our KS NBS Program Information sheet (available in our online toolkits) that demonstrates how effective it is and the cost saving benefits (costs of complications, additional illness, and special education).

When is it done, and when are results ready?

Explain: "Newborn Screening is done as close to 24 hours as possible, but not before. If we collect blood spots too soon, some of the substances that the screening looks for may be still be affected by the mother's levels and result in a false positive screen. In other cases, the baby may simply not have had enough time to produce those substances yet and a true positive screen could be missed. Hearing screen results can also be wrong due to fluid in your baby's ears if it is done too soon.

Blood spot screening results are usually ready between 5 and 7 days after birth, sometimes earlier. Results are sent to the pediatrician that will check up on your baby after you go home. That is why it's important that we record who will be taking care of your baby after you go home. Hearing and CCHD screening results are available as soon as we complete the screenings."

The importance of following up on repeat, positive, and unclear results

Non-negative Results (Unsatisfactory, Invalid, or Repeat Status)

Explain: "If your baby does not pass the screening, it doesn't necessarily mean that your baby has one of the 32 conditions that we screen for. But it does mean that the State lab wasn't able

to rule it out as a possibility. When that happens, it's very important that you follow the directions that we, our lab, or your pediatrician give you to have another screening done quickly. If your baby does have one of the conditions we screen for, getting a clear screening result as soon as possible is the best way for you and your baby's doctor to begin taking the appropriate steps to treat the condition and give your baby the very best chance to have a normal life."

Then explain how your facility is handling return patients for repeat screenings during COVID-19 (separate facility/rooms, scheduling specific days/times, new protocols, etc.). Remind them that with appropriate social distancing and precautions, their risk of COVID-19 exposure is small compared to the risk for permanent impacts of an undiagnosed and untreated genetic or metabolic condition.

Positive Results

Explain: "If your baby has a positive screen, you will get a call from your baby's provider with the result and information on next steps. A positive screen does not always mean your baby has one of the medical conditions, but it's important your baby received further testing as soon as possible."

Kansas Department of Health and Environment

KANSAS NEWBORN SCREENING PROGRAM