Critical Congenital Heart Disease is a condition that uses non-invasive, pulse oximetry to screen newborns for potentially life-threatening heart defects. The blood spot screen takes blood from the baby’s heel. The blood is used to screen for many conditions. These conditions impact about 1 in every 900 babies in Oregon.

Heels
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Hearts
Critical Congenital Heart Disease is a condition that uses non-invasive, pulse oximetry to screen newborns for potentially life-threatening heart defects.

Hearing
The hearing screen identifies babies who are deaf or hard of hearing.

WHY IS THIS IMPORTANT TO REMEMBER?
Being a new parent of a child with an abnormal newborn screen can be overwhelming. It is important to provide consistent, accurate information to families about the newborn screening process to minimize anxiety, confusion and misinformation.

If you have further questions about newborn screening or the conditions screened in your state, please visit BabysFirstTest.org

A STATE NBS STORY:
WHY YOUR WORDS MATTER
A family received an urgent call informing them that their child needed follow-up for an abnormal newborn screen. Arriving at the lab, a staffer came up to them and said “You must be the people here for the PKU test.” Returning home, this family spent all weekend researching PKU. Arriving at the metabolic clinic, they were surprised to find their newborn was not suspected of having PKU at all. Instead, their child was actually at risk for an entirely different condition.

Clinic staff had to spend a lot of time helping the family “unlearn” all the information they had gathered, a time-consuming task which could have been avoided had the correct terminology for newborn screening been used from the beginning. Iowa NBS staff have been discussing this issue for several years now in their presentations to perinatal staff. After presentations, staff will often say, “We didn’t know we weren’t supposed to say PKU test.”

What can we learn from this story?
1. The term ‘newborn screen’ should be used in place of PKU test.
2. Using the incorrect terminology for newborn screening is an important issue in clinical practice.
3. Using the term PKU test has tangible consequences.
4. Using inaccurate terminology may lead to incorrect follow-up testing.