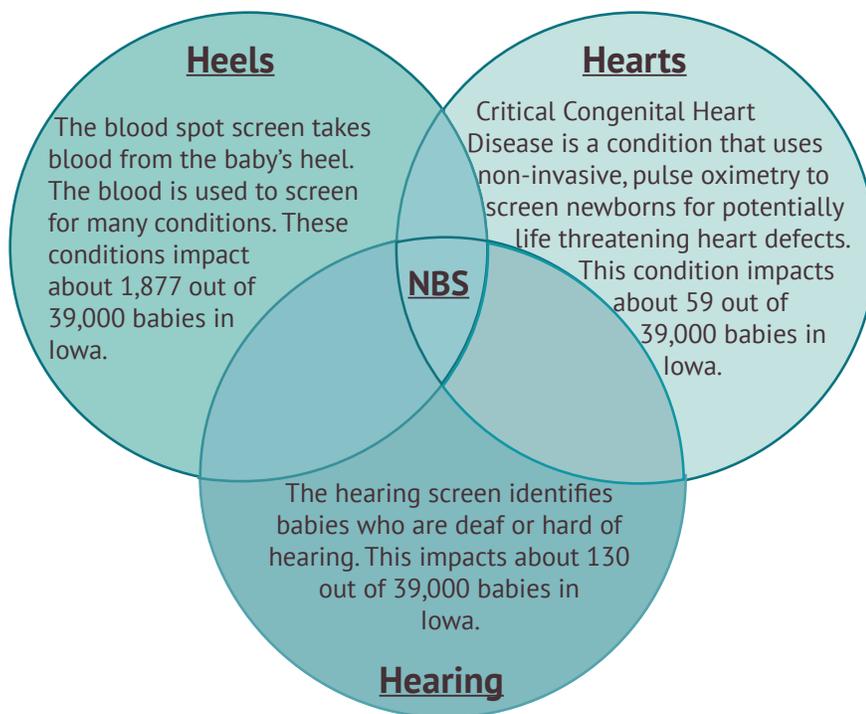


Newborn Screening: More Than a PKU Screen

Newborn screening (NBS) began in the 1960s with a screen for Phenylketonuria (PKU), but over the years, NBS has expanded to screen babies for many conditions. Despite this growth, many healthcare professionals still use the term “PKU test”. With more conditions added to newborn screening panels, this term is no longer accurate and is confusing for parents and clinicians.

REMEMBER:

State and national health programs have accepted and widely use the term **NEWBORN SCREEN** to refer to the collective group of conditions screened for at birth. References to the ‘PKU test’ should be updated to **NEWBORN SCREEN** - including any language found in textbooks, reporting systems, or in daily use.



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.**