



THIS GUIDE WILL HELP YOU EFFECTIVELY COMMUNICATE [POSITIVE]* NEWBORN SCREENING RESULTS TO PARENTS.



Because this type of communication is not a routine activity for the primary care provider, the information below may be used to help frame the discussion with families to improve understanding of the screening result, adherence to follow-up recommendations, and the family's overall experience with newborn screening.

Families who have had [positive]* newborn screening results have suggested that the following key points are important in helping families cope with the uncertainty of a [positive]* newborn screening result and understand the next steps needed to gain certainty.

Share the specific [positive]* newborn screening result and associated condition(s) with the family.

- Help the family understand that a [positive]* newborn screening result is serious, but that you are there to help guide them through the next steps.

Comprehension: Assess the family's understanding of newborn screening.

- Assess if the family recalls and understands the process of newborn screening.

Reiterate what screening is and is not.

- Remind the family about the purpose of newborn screening and that it is not a diagnostic test, so it is important that timely follow-up confirmatory testing be done.

Engage with the family and provide information at their desired level and pace.

- Offer to provide the family additional result-specific information provided by the state newborn screening program.
- Discuss information using non-medical terms, at the family's pace and desired level of detail.

Explore the family's emotions.

- Explore with the family how they might use their support system or other support resources now and as they go through the diagnostic process.
- Remember there is a wide spectrum of how families may cope with this result (anxiety to denial). Tailor your discussion to help the family hear and retain the information discussed.

Next steps: Discuss a shared plan and provide resources.

- Discuss with the family a shared plan that is concrete, specific, and includes the following:
 - Where, when, and with whom is the next appointment?
 - What testing will be considered and/or done?
 - What should they watch for in their child while they wait?
 - Who can they contact if they have additional questions or concerns?
- Assess the family's understanding of the visit and information provided using teach-back methods, and provide valid websites for them to get more information.

**A positive newborn screening result can also be referred to as an abnormal result, an out-of-range result, or presumptive positive result.*