

NEWBORN SCREENING PRENATAL CURRICULUM

- GOAL 1: Explain why newborn screening is important**
- GOAL 2: How newborn screening is performed**
- GOAL 3: The newborn screening test results**
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- GOAL 5: A false-positive result**
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GOAL 1: Why is universal newborn screening important?

OBJECTIVES:

- * Describe basic benefits of newborn screening for parents and infants.
 - a. Disorders are rare and can be detected.
 - b. Babies with disorders may look healthy at birth, and the symptoms may not present themselves until outcomes have happened.
 - c. Early detection and treatment can prevent serious health problems, such as mental retardation, physical disability or even death.

GOAL 2: How is newborn screening performed?

OBJECTIVES:

- * Describe the details of how the blood sample is taken
 - a. A small heel prick is used to take blood from the baby. It is not painful. This blood sample is then transferred onto a card that will be read by a device called the Tandem Mass Spectrometer.
 - b. A small bandage will be placed on the baby's heel.
 - c. The sample is usually taken 24 to 48 hours after birth.

GOAL 3: How will the parents receive the newborn screening results?

OBJECTIVES:

* Describe the process that the New England Newborn Screening program uses for giving the results.

- a. After the lab runs the tests, a lab representative will contact the baby's pediatrician and give them the results. The pediatrician will then inform the family of the newborn screening test results.
- b. Some doctors do not inform parents of the results if follow-up is not needed.
- c. Parent's may ask for their results if they are not contacted by their doctor.

GOAL 4: What should parents do if their baby needs follow-up to newborn screening?

OBJECTIVES:

* Describe the importance and possibility of timely follow-up if needed.

- a. If needed the pediatrician will inform parents of three possible actions for follow-up:
 - The need to be re-screened
 - An immediate referral to a metabolic clinic
 - An emergency room visit
- b. If a baby needs to be rescreened, the abnormal results are often due to:
 - Premature birth
 - A blood sample taken incorrectly
 - A transient finding

GOAL 5: What about false-positive newborn screening results?

OBJECTIVES:

* Describe the likelihood of a false-positive test results and alleviate parental anxiety when follow-up to newborn screening is needed.

- a. The majority of repeat tests do not indicate a metabolic disorder.
- b. It is important to stress the importance of timely follow-up but explain that re-testing is common with newborn screening.

GOAL 6: What about positive newborn screening results?

OBJECTIVES:

* Describe that a positive newborn screening result still does not mean that an infant has a metabolic disorder.

- a. If screening indicates a true positive result the family is referred to a metabolic specialist.
- b. The specialist will do additional laboratory and/or genetic tests to confirm the diagnosis.
- c. Through their clinic infants and families will then receive treatment and a care plan to help prevent the consequences of an untreated metabolic disorder.

GOAL 7: How much does newborn screening cost for parents?

OBJECTIVES:

* Describe that newborn screening and follow-up screening are at no cost to parents.

GOAL 8: Are there any special considerations to newborn screening?

OBJECTIVES:

* Describe the special circumstances that can affect newborn screening results and what actions should be taken.

- a. If a blood transfusion is needed, the nurse will wait at least 24 hours to take the blood sample. Additional samples may need to be taken for these infants.
- b. Premature or sick infants will receive newborn screening just before they leave the hospital or at 4 to 6 weeks after birth. This increases the accuracy of the testing and ensures that a delayed release of hormones has affected their metabolism.

GOAL 9: New England's state newborn screening programs

OBJECTIVES:

* Describe the New England area's screening program methods of testing.

- a. The American College of Medical Genetics recommends 29 for expanded newborn screening and every state in New England offers screening for all of these.
- b. Some states only mandate some of the tests while others require all 29. Know your states regulations and inform your class of their choices for newborn screening.
- c. Newborn screening can be refused for reasons of religion in all states in New England.

GOAL 10: Questions about disorders

OBJECTIVES:

* Describe that you can answer disorder specific questions about the 29 metabolic disorders included in the panel for screening.

*See Newborn Screening: A Guidebook for Prenatal Educators for descriptions of:

- The incidence rate of each disorder
- A brief definition of each disorder
- What the treatment options are for each disorder recommended