



Form to Refuse the Newborn Screening Blood Test

- The test finds certain serious illnesses and your child may look well for weeks or months with these illnesses. Your child may need to be treated to keep from dying or having handicaps.
- Texas Law requires the test for your baby. You can refuse the blood test if it is against the teachings or practices of your church. (Health and Safety Code, Section 33).
- I have heard the benefits of the newborn screening blood test.
- I know I can only refuse this test if it is against my religious teachings or practices church.
- For more information:
 - look at <https://www.dshs.texas.gov/lab/nbsParentRes.shtm>; or
 - call toll free at (888) 963-7111 ext. 7333.

_____ I do not want my baby tested now. I will take a copy of this form to show to my baby's doctor.

Medical record number of baby: _____

Name and Address of Place of Baby's Birth: _____

Signature of Parent: _____ Date: _____

Printed Name of Parent: _____

Signature of Staff: _____ Date: _____

Printed Name of Staff: _____

Give one copy of this form to the family and put one in the medical record.

Refusal Form Subcommittee Report and Recommendations to the NBSAC

Background - Current Texas Law:

The Texas Health and Safety Code, Sec. 33 requires that all babies must be screened but Sec. 33.012 states:

"(a) Screening tests may not be administered to a newborn child whose parents, managing conservator, or guardian objects on the ground that the tests conflict with the religious tenets or practices of an organized church of which they are adherents.

(b) If a parent, managing conservator, or guardian objects to the screening tests, the physician or the person attending the newborn child that is not attended by a physician shall ensure that the objection of the parent, managing conservator, or guardian is entered into the medical record of the child. The parent, managing conservator, or guardian shall sign the entry."

Subcommittee Goals and objectives:

An estimated 6,000 babies are not screened annually in Texas (1.5 % of all births of 400,000 births in 2014). Based on the overall incidence of NBS conditions (1 in 400 live births), about 16 babies with NBS conditions are missed due to not being screened every year.

To help reduce the number of babies not screened, the subcommittee's goals were to make recommendations to:

- 1) simplify and improve the readability and understandability of the refusal form; and
- 2) improve the notification process so that the state could ensure that 100% of babies are either screened or accounted for if screening is refused.

With reference to goal #2, the subcommittee discussed ideas for accounting that would comply with the statute, utilize existing practices, be low cost, and utilize existing resources.

Refusal Form Revision Progress Summary:

The parental refusal form was previously approved by the Newborn Screening Advisory Committee. It is available online for clinicians to complete and included in the baby's medical record when the newborn screening is refused.

The attached revised form is proposed to replace the current parental refusal form. The readability indices will be reported in the committee meeting.

Notification Process Improvement Summary:

Things that the subcommittee discussed included:

- The perfect process would link the lab, birth certificates, the newborn screening database and refusal records to ensure every baby is screened or a refusal is documented;
- The statute is silent on what can be done once a parent refuses;
- The refusal form would be subject to open records if submitted to DSHS;
- Consent would be needed to allow the refusal form to be sent to DSHS;
- Getting parental consent for submitting refusal forms to the state would not guarantee a full accounting for all babies;
- Using the refusal form doesn't account for those babies not screened for other reasons;
- A flag or a communication back to DSHS that the newborn screen was not done for whatever reason would need to be done within existing workflows in order to be successful;
- A potential solution is to advise and educate, or mandate, that clinicians submit a card without the blood spots for refusals. The card would have to be modified to have a box such as "Not Intentionally Missed".
- The current price for one card is 50 cents, so 6,000 missed or refused screens totals about ~\$3,000. Medicaid cards could be used if available to eliminate cost considerations. If no Medicaid card is available, birth facilities and clinicians could use a private insurance card and the State could implement a mechanism to give credit for that card similar to what exists for defective cards.

Recommendations to NBSAC for consideration, comment and approval:

- DSHS should submit the revised refusal form through internal channels for review and approval and a form number;
- Once the refusal form approved, DSHS should make it available to birth facilities and clinicians (online or paper);
- Reiterate to birth facilities and clinicians that the signed refusal form must be included in medical record;
- As a quality improvement project, consider including a requirement send in a blank blood spot card for each refusal, with appropriate wording.

Motions:

- 1) The NBSAC recommends that DSHS replace the parental refusal form with the modified form;**
- 2) The NBSAC recommends that DSHS move forward on a quality improvement project to ensure that all babies born in Texas are screened or otherwise counted.**

Recognition:

The subcommittee wants to thank DSHS staff for the work and support on this project. Among others, Beth Rider was instrumental in helping the subcommittee stay on track and Natalie Adelaja, Assistant General Counsel, was invited to give input from the legal department's perspective and to guide the subcommittee as appropriate.