

Documenting NBS Parental Refusals

NBSAC Meeting
July 16, 2018

7/16/2018

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TX Births with No NBS

Year	Total Births	Not linked to NBS	% No NBS
2014	409,111	8,241	2.0%

* Data from Center for Health Statistics

- 645 out of state births
- 901 deaths within 24 hours of birth

Are the remaining missed screens or
Parental Refusals?

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Options for Documenting Refusals

- Send a copy of refusal form
- Send Medicaid card marked "Parental Refusal"
- Send a separate barcoded form – assign and distribute to submitters
- Periodically send a total volume of parental refusals
- Submit parental refusal in electronic order
- Add section to refusal form with submitter info only that can be separated and returned to DSHS

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Options for Documenting Refusals

Option	Concerns
Copy of Refusal Form	- Personal Information on form
Medicaid Kit	- Possible incorrect Kit type usage \$\$ - Cost to manufacture Medicaid cards - Lab confusion if card not documented as refusal
Submitter Assigned Barcoded Form	- Distribution of forms - Regular tracking and restocking - Development and cost of form
Periodic Provider Volume Reporting	- Additional process for providers - Compliance of >2100 providers - Process development and provider training
Electronic Order	- Incomplete adoption of electronic ordering - Low volume provider access
Add Section to Refusal Form	- Cost of form with perforation - Lack of perforation if downloaded from web site

Proposed Form Revision



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 practices.
- 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: _____

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.

Complete and Send* to DSHS

Facility/Provider Name: _____

NBS Submitter ID#: _____

Address: _____

City/State/Zip: _____

Date: _____

* This portion can be returned to DSHS with other NBS specimens.

DSHS Use Only:

Rev. 4/2/2018

Form # - EF14-13549

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Quotes obtained from HHS Printing for 25,000 forms are as follows:

- 8.5x11, 2 sided (English/Spanish), 1 color (black), 60# white paper, perforate at the bottom = \$944.53
- 8.5x11, 2 sided (English/Spanish), 4 color (logo), 60# white paper, perforate at the bottom = \$2,784.25

Proposed Form Revision

Complete and Send* to DSHS

Facility/Provider Name: _____

NBS Submitter ID#: _____

Address: _____

City/State/Zip: _____

Date: _____

* This portion can be returned to DSHS with other NBS specimens.

DSHS Use Only:

Rev. 4/1/2018

Form # - EF14-13549

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Proposed Process

Parent / provider

- Parent / provider complete refusal form
- Provider makes copy for medical record
- Separates DSHS portion and sends to DSHS with specimens.

DSHS Laboratory

- Generates unique barcode identifier for form
- Scans into information system to generate a unique record
- Documents submitter information and date of refusal in database

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Survey Response -

To ensure all newborns in TX receive newborn screening, DSHS is considering a new process to request submitters to send in a blank Medicaid/CHIP/Charity kit when a parent refuses newborn screening, do you have any concern with this proposed new process?

Response	# Facilities
Yes	39 (27.3 %)
No	104 (72.7 %)

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Concerns:

- Never had a parent refuse
- Don't understand why this is needed
- Parent's concern about privacy/confidentiality
- Waste of resource and time
- Takes time to complete form
- Better if complete online
- Logistics to make sure it gets done
- Financial burden – cost of card and postage

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Thank you

Rachel Lee
Rachel.Lee@dshs.texas.gov

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