

## Newborn Screening (NBS) Program Upcoming Changes

Texas Department of State Health Services (DSHS)

### Changes to Healthcare Provider Requirements Regarding the Use and Storage of Newborn Screening Blood Spot Cards

**Effective Date:** On **(not before)** June 1, 2012.

**Why:** House Bill 411 (82<sup>nd</sup> Session)

#### What Changes?

- Beginning on **(not before)** June 1, 2012, healthcare providers **MUST** distribute a new decision form to parents with each NBS specimen collection. An example of this new form is on the 2<sup>nd</sup> page of this notice.
- The new decision form will be part (page 2) of the 2012 NBS specimen collection kits. The decision form will also be available (8½ X 11 format) on the DSHS NBS laboratory website.
- Changes are also made to the Parent Information Form (page 1) of the 2012 NBS kits to include information about the new decision form (page 2). An example of the revised Parent Information Form is on the 3<sup>rd</sup> page of this notice.

#### Can healthcare providers start giving the new Decision forms to parents now?

**NO.** The information on the new forms is not valid for specimens collected prior to June 1, 2012. The healthcare provider is required to continue distributing the current Disclosure / Directive to Destroy form for all specimens collected prior to June 1, 2012.

#### What happens to the current kits on June 1, 2012?

Current 2010 and 2011 NBS collection kits can and should still be used after June 1, 2012, through the expiration date on the kit. Healthcare providers **MUST** discard page 2 and distribute the 8½ X 11 version of the new decision form to parents with each NBS specimen collection.

#### Where can healthcare providers get the 8½ X 11 version of the new Decision form?

The 8½ X 11 version of the form will be made available in English, Spanish and Vietnamese on the DSHS NBS laboratory website (web address below) in May of 2012.

#### Can healthcare providers order the 2012 kits now?

No. The 2012 kits will not be available for distribution to healthcare providers until May of 2012. Healthcare providers are asked to use up any 2010 and 2011 NBS kits prior to moving to the new 2012 kits.

#### Additional Questions / Comments / Sign up for Email Notices

Call toll free: 1-888-963-7111 ext. 7333 or for local calls 512-776-7333

Email: [NewbornScreeningLab@dshs.state.tx.us](mailto:NewbornScreeningLab@dshs.state.tx.us)

Website: <http://www.dshs.state.tx.us/lab/newbornscreening.shtm>

Parental Decision for Storage and Use of Newborn Screening Blood Spot Cards (Page 2 of 2012 Kits)

**For informational purposes ONLY.  
DO NOT distribute this form to parents prior to June 1, 2012.**

Parental Decision for Storage and Use of Newborn Screening Blood Spot Cards Effective: June 1, 2012



X

TX 12-2000001

Please read below to decide what you would like DSHS to do with your baby's blood spot card when the Newborn Screening tests are finished.

If you check the 'OK' box **AND** sign this form:

- All of your baby's blood spot cards will be kept safe and secure for up to 25 years.
- The blood spot cards may be used for public health research. The research may take place outside of DSHS. This research would study public health problems like cancer, birth defects, or other diseases.
- You can change your mind at any time. Call DSHS (see number below) for details.

If you check the 'NO' box **OR** do not sign **OR** do not fill out **OR** do not return this form:

- The Newborn Screening tests will still be done in accordance with Texas law.
- Your baby's blood spot cards will be kept safe and secure. They will all be destroyed within two years.
- The blood spot cards will NOT be used for public health research outside DSHS.

Can information about me or my child be released without my OK?

No matter your choice on this form, no information that identifies you or your child can be released outside DSHS without your additional written OK. There are a few exceptions, as provided by law.

I've already sent this decision form. Do I need to send it again? NO.

One form applies to all of your baby's newborn screening blood spot cards.

For questions or more information: Call 1(888) 963-7111 ext. 7333 or visit the web site: [www.dshs.state.tx.us/lab/newbornscreening.shtm](http://www.dshs.state.tx.us/lab/newbornscreening.shtm)

DSHS Laboratory Services Section

NBS Form EF14-13689 (June 2012)

PARENT: Please read this form. Select an option. Sign and return.

1. **FILL OUT** the form below.

Baby's First and Last Name: \_\_\_\_\_

Baby's Date of Birth: \_\_\_\_\_

Parent Phone Number: \_\_\_\_\_

Mother's First and Last Name: \_\_\_\_\_

2. **CHECK** one box only and SIGN below.

'OK' I give my **OK** for my baby's blood spot cards to be kept by DSHS after the Newborn Screen tests are complete. The de-identified blood spots may be used for public health research outside of DSHS.

'NO' I do **NOT** give my ok for my baby's blood spot cards to be used for any research outside of DSHS after the Newborn Screen tests are complete. I understand the blood spot cards will be destroyed by DSHS within 2 years.

\_\_\_\_\_  
(Parent Signature)

\_\_\_\_\_  
(Date)

3. **RETURN** this form to hospital or doctor's office staff. They will send it in with the blood spot cards. Or, you may **MAIL** it to:

Texas Department of State Health Services (DSHS)  
Newborn Screening Laboratory, MC 1947  
PO Box 149341  
Austin, Texas 78714-9341

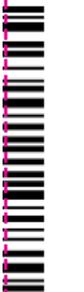


Veá el reverso para Español

PROVIDER: Give form to parent & Return with blood spot cards if requested.

Example

## Texas Newborn Screening Parent Information Form (Page 1 of 2012 Kits)



MM/DD/YYYY

Baby's Last Name                      Baby's First Name                      Baby's Date of Birth

Serial Number SN TX 12-2000001

### Texas Newborn Screening Parent Information

**PROVIDER:** Fill out baby's information above. Give this form to a parent.

**Parent,**  
Congratulations on your new baby!

Take your baby to your baby's doctor when your baby is 7 to 14 days old. **Also, take this form!** This is important. This will help the doctor get the newborn screening test results.

**What is newborn screening?** It is a simple blood test to look for some diseases. These diseases can cause a baby to get really sick or die.

**Why should my baby be tested?** If we find and treat these diseases early, we can keep babies from getting sick or dying.

**When is my baby tested?** In Texas, babies have a newborn screening test when they are 1 to 2 days old. This test is done again at 7 to 14 days old. The test is done in accordance with Texas law.

**How is newborn screening done?** A little blood from your baby's foot is put on a blood spot card. The cards are sent to be tested at the Department of State Health Services (DSHS).

**How do I get results?** You can get the test results from your baby's doctor. The results are sent to the doctor from DSHS in one to two weeks.

**Is more testing available?** DSHS screens for many but not all diseases your baby may have. More tests can be done. Ask your baby's doctor and see [www.babysfirsttest.org/find-condition](http://www.babysfirsttest.org/find-condition).

**What happens to the blood spot card after testing?**  
Starting June 1, 2012:

- DSHS keeps the blood spot cards in a secure place for up to two years. By Texas law (Health & Safety Code Sec. 33.017(b)-(c)), the blood spots may be used during that time. Uses include:
  - DSHS and external quality assurance to make sure tests, equipment, and supplies are working right;
  - Developing new tests; and/or
  - DSHS studies of diseases that affect public health.
- If you give your OK, your baby's blood spot cards will be stored for up to 25 years, and they may be used for public health research outside of DSHS.

**Complete, sign, and return the "Parental Decision for Storage and Use of Newborn Screening Blood Spot Cards" form to make your choice.**

No matter your choice, no information that identifies you or your child can be released outside DSHS without your additional written OK. There are a few exceptions, as provided by law.

You can change your mind at any time.

**For more information, call 1(888) 963-7111 ext. 7333 or visit:**  
[www.dshs.state.tx.us/lab/newbornscreening.shtm](http://www.dshs.state.tx.us/lab/newbornscreening.shtm)

SN TX 12-2000001 X

**INSURANCE / SELF-PAY**

Texas Department of State Health Services – Newborn Screening Program  
P.O. Box 149341, Austin, Texas 78714 – 9341                      (800) 252-8023

PARENT COPY

Kit Expires 11/30/2014



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# Example