## Important Newborn Screening (NBS) Program Changes

### Use and Storage of Newborn Screening Blood Spot Cards

House Bill 411 (Texas legislative 82\textsuperscript{nd} Session) includes new requirements for the Department of State Health Services (DSHS) Newborn Screening (NBS) Program and newborn screening healthcare providers. These new requirements took effect on June 1, 2012 and change the actions for which Healthcare Providers are responsible.

### What are the differences in Texas law before and after June 1, 2012?

<table>
<thead>
<tr>
<th>Date of Specimen Collection</th>
<th>On or Before May 31, 2012</th>
<th>June 1, 2012 or Later</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood Spot Storage after Completion of the Newborn Screening Test</td>
<td>TO BE DETERMINED</td>
<td>All blood spots are stored for up to 2 years and then destroyed unless the parent submits a completed decision form allowing for longer storage.</td>
</tr>
<tr>
<td>De-identified Public Health Research Uses outside of DSHS</td>
<td>Not allowed without study specific parental consent</td>
<td>Allowed only if parent provides written consent (decision form). Uses must follow DSHS policy for required management and IRB approvals.</td>
</tr>
<tr>
<td>Parent Options</td>
<td>Parents may direct DSHS to destroy their child’s blood spots.</td>
<td>Parents may choose to have the blood spots stored for up to 25 years and to possibly be used for de-identified public health research uses outside of DSHS.</td>
</tr>
</tbody>
</table>

### What doesn’t change?

- No information identifying a parent or child can be released without specific written consent from the parent.
- Stored blood spots are kept safe and secure.
- Allowed uses include:
  - 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.

### WEB ADDRESS TO ACCESS FORMS:

All forms referenced in this document are available for download in 8½ X 11 format in English, Spanish, and Vietnamese at: [http://www.dshs.state.tx.us/lab/nbsBloodspots.shtm](http://www.dshs.state.tx.us/lab/nbsBloodspots.shtm)

Visit the website or contact the laboratory for additional information:
- Email: NewbornScreeningLab@dshs.state.tx.us
- Phone: 1-888-963-7111 Ext. 3198
What are the Healthcare Provider Responsibilities?

Upon collection of each newborn screening specimen:

- Distribute “*Texas Newborn Screening Parent Information*” (Page 1 of 2012 NBS collection kits)

- Distribute the form “*Parental Decision for Storage and Use of Newborn Screening Blood Spot Cards*” (Page 2 of 2012 NBS collection kits).

- Advise parents that the parents should:
  - Read Page 1 “*Texas Newborn Screening Parent Information*”. Take the form given to them upon collection of the first screen to their child’s healthcare provider when the child is 7 to 14 days of age.
  - Read Page 2, “*Parental Decision for Storage and Use of Newborn Screening Blood Spot Cards*”, select an option, and sign the form. Parents may give the form to the healthcare provider at the time of collection or mail it to DSHS at a later date.

- If requested by the parent, return the completed Parental Decision form to DSHS along with any regular newborn screening specimen shipment.

What do Healthcare Providers do with the older collection kits (2010 and 2011) starting on June 1, 2012?

- Continue to use the 2010 and 2011 specimen collection kits to collect Newborn Screening specimens until the kit expiration date (can be found on each kit).

- Remove and discard Page 2, “*Use and Storage of Newborn Screening Blood Spot Cards / Directive to Destroy Newborn Screening Blood Spot Card Following Testing*”.

- Distribute Page 1 of the 2010 and 2011 specimen collection kits to parents.

- Distribute an 8½ X 11 *Parental Decision for Storage and Use of Newborn Screening Blood Spot Cards* form with each specimen collected.
First 2 digits of serial number indicate year of kit manufacture.
Use and Storage of Newborn Screening Bloodspot Cards / Directive to Destroy Newborn Screening Blood Spot Card Following Testing (Page 2 of 2010 and 2011 Kits)

THIS FORM IS **ONLY VALID ON SPECIMENS COLLECTED BEFORE JUNE 1, 2012.**

DO NOT DISTRIBUTE THIS FORM FOR SPECIMENS COLLECTED AFTER JUNE 1, 2012.

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

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

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/conditions.

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.shtml

Kit Expires 11/30/2014

Vea el reverso para Español