

Parent Decision Form for Storage and Use of Newborn Screening Blood Spot Cards

What happens to the blood spot card after testing?

- DSHS keeps the blood spot cards in a secure place for up to two years. By Texas law (Health & Safety Code Sec. 33.018(b)-(c)), the blood spots may be used during that time. Uses include:
 - o DSHS and external quality assurance to make sure tests, equipment, and supplies are working right
 - o Developing new tests; and/or
 - o 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.

Please read below. Then you can 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 <u>AND</u> sign this form:

- o <u>All</u> 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.
- \circ $\;$ You can change your mind at any time. Call DSHS (see number below) for details.
- If you check the 'NO' box <u>OR</u> do not sign <u>OR</u> do not fill out <u>OR</u> do not return this form:
 - o The Newborn Screening tests will still be done as required by Texas law.
 - Your baby's blood spot cards will be kept safe and secure. They will 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 have 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.

More information: Call 1(888) 963-7111 ext. 7333 or visit the web site: www.dshs.state.tx.us/lab/newbornscreening.shtm

| PARENT : Please <u>read</u> this form. <u>Select</u> an option. <u>Sign</u> and <u>return</u> . | |
|---|--|
| 1. <u>FILL OUT</u> the form below. | |
| Specimen Form Serial Number (if available): | Baby's Date of Birth: |
| Baby's First and Last Name: | |
| Mother's First and Last Name: | |
| Parent Phone Number: | |
| 2. <u>CHECK</u> one box only and SIGN below. OK' I give my <u>OK</u> 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 <u>NOT</u> want my baby's blood spot cards to be used for any research outside of DSHS. I understand the blood spot cards will be destroyed 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 | |