

EDUCATION RE: DRIED BLOOD SPOT/TEST RESULT STORAGE AND USE IN MINNESOTA

Minnesota Newborn Screening Program

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BACKGROUND

- **Lawsuit 2009 to 2014**
- **Legislative Change in 2012**
 - Negative DBS at 71 days
 - Positive DBS at 2 years
 - All Test Results at 2 years
- **Legislative Change in 2014**
 - Stored Indefinitely
 - Program Operations Use Only



Barriers to Robust Education

- Constant changing of storage and use practices
- Media and other information outlets
- Competing provider priorities
- Staff time and funding



MN Current Law Addresses Education

Subd 3. Information provided to parents and legal guardians.

The department shall make information and forms available to childbirth education programs and health care providers who provide prenatal care



MN Current Law Addresses Education

- The department shall **promote** the materials describing the newborn screening program and **encourage** providers and education programs to thoroughly discuss the program with expectant parents and parents with newborns. The department shall make information and forms about newborn screening **available** to the persons with a duty to perform testing under this section and to expectant parents and parents of newborns using electronic and other means.



MN Current Law Addresses Education

- Upon request, [birth facilities] must promptly provide parents or legal guardians of infants with forms necessary to request that the infant not have blood collected for testing or to request to have the newborn screening performed, but not have the blood samples and test results stored; and...



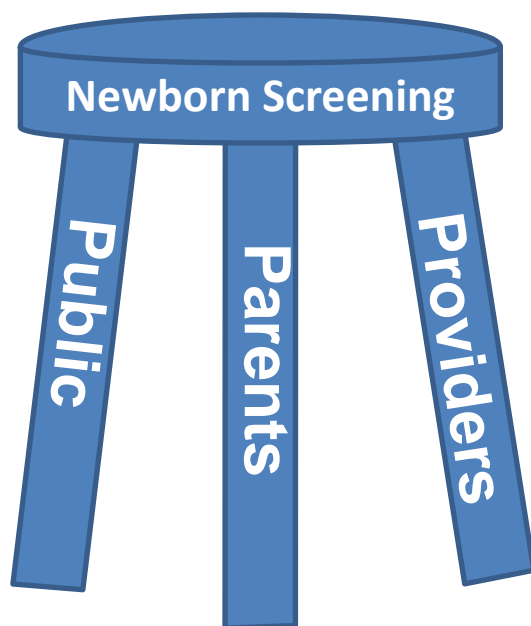
MN Current Law Addresses Education

- [Providers must] record in the infant's medical record that a parent or legal guardian of the infant has received the information provided pursuant to this subdivision and has had an opportunity to ask questions.



Educational Plans

- Most plans take a 3-pronged approach:



But...



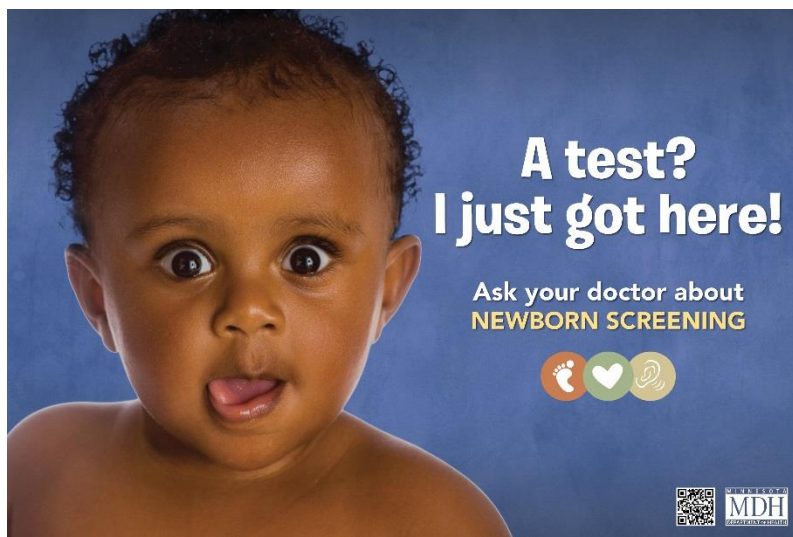
... each prong needs several parts!

- Education, Awareness, and Training
 - ARE NOT SYNONYMOUS!
- **Education:**
 - Imparting fundamental knowledge and tools that can be used to grow and expand the concept.
- **Awareness:**
 - Exposure to information
- **Training:**
 - Imparting “how to” knowledge



Public

- Focus on Awareness
 - Need to be familiar with the program
 - State Fair, PSAs, posters, billboards





Newborn For Parents



Helping babies

Every parent-to-be wants to make sure their newborn baby is healthy. Health care providers check babies for serious hearing, and pulse oximetry early through one of the ways to help give these

Blood spot screening for treatable disorders of the blood system, how to do it, and why it's an important part of preventing serious

Hearing screening range where speech and language develop and

Pulse oximetry for congenital heart disease; early, babies with surgery or other

Newborn screening and intervention: babies

Newborn FACT SHEET

What is newborn screening?

Newborn screening identifies rare disorders. Most can be treated or prevented. It includes blood spot, hearing, and pulse oximetry.

Blood spot screening for treatable disorders of the blood system. The box on the screening card in Minnesota

Hearing screening range where speech and language develop and

Pulse oximetry for congenital heart disease; babies with surgery or other

When will I get results?

Your baby's hearing available on the same day as the birth provider or the hearing center.

The blood spot screening results are available to your baby's primary care provider as soon as possible if the result is also a good time to talk to your provider about results.

What happens to the remaining blood spots and results after screening?

Following newborn screening, test results and any leftover blood spots are stored to allow for follow-up testing, if needed. Stored blood spots and test results are also used for general program operations, such as making sure screening is accurate, improving test methods, and developing new newborn screening tests. They are not used for research or public health studies without the parent's written informed consent.

Parents have options regarding the storage of their child's blood spots and test results. You may request that your child's blood spots and results be destroyed, or you may request to obtain the blood spots through your child's primary care provider at any time. You may also choose to allow your child's blood spots and results to be used for public health studies or research. Ask your provider or visit the Newborn Screening Program website for forms and instructions on how to request these options and for the most up-to-date storage and use practices.

What personal information is written on the screening card and sent to the Minnesota Department of Health (MDH)?

The newborn screening card that is sent to MDH for testing contains only the information about mom and baby that will help staff interpret test results and contact your baby's primary care provider if more testing or follow-up is needed. This includes, but is not limited to, baby's name, date of birth, time of birth, mom's name, and the name of baby's primary care provider or clinic.

Can I refuse screening for my baby?

Yes. If you do not want your baby screened, you must complete the *Parental Refusal of Newborn Screening* form. You can ask your birth provider for a copy of the form or download it from the Newborn Screening Program website. You may also choose to arrange for blood spot screening through a private laboratory.

For more information on newborn screening:

Minnesota Newborn Screening Program
www.health.state.mn.us/newbornscreening

MN Early Hearing Detection & Intervention Program
www.improveehdi.org/mn

Save Babies Through Screening Foundation
www.savebabies.org

Baby's First Test
www.babysfirsttest.org

occurs



Newborn Screening Facts for Health Care Providers

Facts for Health Care Providers

Blood Spot Screening

- A few drops of blood are collected 24-48 hours of age. The blood is tested for several but treatable disorders such as sickle cell disease, phenylketonuria, and congenital hypothyroidism.
- The Department of Health provides training and resources for screening methods. Visit the Newborn Screening website for more information.
- Newborns affected with the disorder may not be identified. Without screening, the disorder can cause permanent damage and even death.

Hearing Screening

- Hearing is ideally screened before the baby is discharged from the hospital.
- There are two methods used: otoacoustic emissions (OAE) and automated auditory brainstem response (AABR).
- Hearing loss in infants is often identified by providers because they still have hearing loss but can't talk or stay on track with speech.

Pulse Oximetry Screening

- Screening for critical congenital heart disease when a newborn is at least 24 hours old.
- A simple test using sensors on the foot to measure oxygen levels in the blood. Low oxygen levels may indicate other health issues.
- Not all heart defects can be identified by screening after birth, but early identification allows for treatment and often a better health outcome.

What will my baby be screened for?

Your baby will be checked for hearing loss and heart problems on the Newborn Screening.

Where will screening happen?

Screening happens at the hospital unless you choose not to.

Will screening hurt my baby?

Your baby will not experience any pain. Some babies may feel a little uncomfortable during the pulse oximetry screen.

How long does it take?

You can get your baby's blood spot the day of screening.

How do I get the results?

You can ask your birth hospital's healthcare provider for a well-child check.

What happens if my baby is not screened?

Screening can only identify problems if you know for sure. If the blood spot screen is not done, your healthcare provider will not know if there is a problem.

Visit our website for more information and to learn about the screening process.

www.health.state.mn.us

Newborn Screening PROVIDER MANUAL



Blood Spot
Screening



Pulse Oximetry
Screening



Hearing
Screening



Infographic Use

Newborn Screening

How does it work?

Baby is born!

12-48 hours after birth

3 tests are done to check your baby's health:

- Hearing screening
- Heart screening
- Blood spot screening

Blood spot screening takes a few days. Your baby's dried blood spots are sent to the Minnesota Department of Health lab for testing.

Hearing screening and heart screening take only a few minutes. Ask for your baby's results when the tests are done.

Negative Results: If everything looks ok, the results are sent to your baby's doctor. Ask for your baby's results at the first newborn visit!

Positive Results: If there might be a problem, the lab will call your baby's doctor. Screening can only tell us if a baby *might* have a health problem. We won't know for sure until the doctor does more tests. Your baby's doctor will talk to you about what needs to happen next.

At the lab, blood spots are cut into smaller circles for each of the tests. Your baby is tested for more than 50 health problems.

After Newborn Screening

What happens to leftover blood spots and results?

Parents can choose what happens with the leftover blood spots and results.

Each spot is smaller than the size of a dime.

Option A: The blood spots and results can go into safe storage at the Department of Health. This is what normally happens. You do not have to do anything to choose this option.

Option B: The blood spots and results can go into safe storage, and they also can be used for research to help improve the public's health. To choose this option, you have to give permission by signing a consent form. If you do not give permission, the blood spots and results will never be used for research.

Option C: You can ask the Department of Health to destroy the blood spots and results. To choose this option, you have to fill out a destruction request form. If you choose this option, blood spots will no longer be available for testing if you or your doctor needs them.

If you choose Option A or Option B, you can change your mind and choose a different option at anytime. Just contact the Department of Health.

Ask your doctor, nurse, or midwife for the form you need for Option B or Option C. Or you can find forms on the website at the bottom of this page.

There are a few reasons why it is helpful to keep leftover blood spots and results at the Department of Health. These reasons include:

Testing Improvement: To make sure we find all babies who might have one of these health problems, we need to make sure that our tests and equipment are working the way they should. This process is called quality control or assurance.

Family Needs: Some families ask for them later to do testing if their child gets sick. Looking at blood spots can help give clues to whether something at birth made the child sick.

New Test Development: We use them to help develop new tests so that babies with other health problems can be found and treated early too. All blood spots used to make new tests are de-identified, meaning the baby's name, date of birth, or any other identifying information is not attached to the blood spots.

Want to know more?

Call us: 1-800-864-7772
 Email us: health.newbornscreening@state.mn.us
 Visit us: www.health.state.mn.us/newbornscreening

Newborn Screening Program
 601 Robert St. N., St. Paul, MN 55105

DP 64 068
 REV 092016



Lessons Learned & Next Steps

- Public, Parents, and Providers need to be informed equally
- Success of materials are dependent upon use
- Management of up-to-date materials
- Digital and electronic means are necessary



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