



Detach This Copy and Give to Mother of Newborn!

Dear Parents of Newborn Baby:

To help give your baby a good start, Missouri law requires your baby's blood to be tested for more than 70 disorders. A few small drops of blood taken from the baby's heel are put on special paper and then sent to the State Public Health Laboratory for testing.

Many disorders are not noticed at birth. Yet they can put the baby at risk for disability or death if not found early. If results from this screening test are not normal, your healthcare provider will tell you about more testing that needs to be done. Please make sure the hospital staff gives you a Newborn Screening pamphlet.

Once the newborn screening test is done, the Missouri State Public Health Laboratory will store the remaining newborn screening sample for five (5) years. The storage is secure. Missouri state law allows for the stored sample to be used for research. The research may help improve methods for spotting illnesses. The research may also find better ways to test, treat and cure major childhood diseases. Your baby is not identified to the researcher in any way. After five years, the rest of the newborn screening sample will be destroyed.

The law allows the parent or legal guardian the option of not having their baby's leftover newborn screening sample stored or studied. You may ask the State Laboratory to:

- Give the leftover newborn screening sample back to you
- Destroy the leftover newborn screening sample after the newborn tests are done
- Store the leftover newborn screening sample for 5 years but do not release it for study

If you choose NOT to allow your baby's leftover newborn screening sample to be studied, select one of the above three options. Then write to the Laboratory Director at:

Missouri State Public Health Laboratory
Newborn Screening Laboratory
P.O. Box 570
Jefferson City, MO 65102-0570

If you have questions or need assistance, please contact the
Newborn Screening Laboratory at 573-751-2662.

Give this information:

Baby's name
Baby's date of birth
Mother's first and last name
Place where baby was born
The option you selected from above
State if you are the parent and legal guardian
Your current address
Your signature and current date



Benefits of storing newborn screening samples:

There are many reasons why newborn screening samples are kept, many of which benefit your family and other Missouri families.

- In some cases, samples are requested by the family or the baby's health care team.
- The baby's sample is available to you for other health-related testing within five years of storage.
- The baby's sample is available to help identify a missing or deceased child within five years of storage.
- If your child has an illness and is enrolled in a research study, parents may request that their baby's newborn screening sample be returned to them in order that they may send it to the researcher within five years of storage.

For research purposes, all identifying information is removed from the samples (baby's name, parent's name, parent's address, hospital of birth, etc.). The researcher does not know who the baby is. These samples may be used to:

- Provide quality assurance in the screening.
- Do public health studies and research to help develop newborn screening tests and better understand diseases for the benefit of the general public.
- Search for new markers for chronic diseases such as childhood leukemia, sickle cell disease, autism and diabetes.

Only those research projects that undergo careful scientific and ethical review will be given approval to use newborn screening samples.