Request to Dispose of Newborn Screening Test Results and/or Blood Sample

Minnesota Department of Health
Newborn Screening Program
Public Health Laboratory
Phone: (800)-664-7772
Revised 12/05

Name of Child: ___________________________ Date of birth: ___________________

Hospital of Birth: ___________________________

PARENTS: Please read the newborn screening policies below before signing this form.

Data privacy protections:
The Minnesota Department of Health classifies newborn screening information as private. This means that only those involved in the newborn screening program, the patient/parents/legal guardian(s) and the medical provider(s) caring for that child have access to the newborn screening information on an individual. Sharing individually identifiable information with anyone else requires the patient, parent or guardian to sign a consent allowing the release of such information.

The results of newborn screening are kept and stored securely by the Minnesota Department of Health Newborn Screening Program. This is necessary to provide a permanent record that the screening was completed, of the results of that screening, and of any outcomes that are relevant to the screening results.

Individuals who are screened and have abnormal results are followed up on by newborn screening staff. This is done to make sure that newborns with abnormal results receive appropriate diagnosis and treatment. This information is kept to help provide seamless, comprehensive care to children and their families.

Blood sample storage policy:
Blood samples and newborn screening information are securely stored by the Minnesota Department of Health Newborn Screening Program for an indefinite period of time.

Authorized uses of samples:
Portions of the blood sample may be used (without identifiers on them) within the Minnesota Department of Health Newborn Screening Program to assist in test development or quality control.
A portion of the blood sample may be used for research purposes outside of the Minnesota Department of Health. This only happens when the project is approved by the Minnesota Department of Health Institutional Review Board and all information identifying the individual has been removed from the sample.

The blood sample with identification cannot otherwise be released or tested outside the Minnesota Department of Health Newborn Screening Program without the written consent of the patient or legal designee.

The reasons for blood sample storage include:
1. Quality Assurance: If the Minnesota Department of Health Newborn Screening Program is notified about a child with one of the disorders detected by the panel, the initial blood sample is re-tested to make sure that the results originally reported were accurate.
2. To develop new tests: The Minnesota Department of Health Newborn Screening Program is continuously developing new tests for treatable conditions. Anonymous newborn blood spots are used to be sure that new tests are accurate and determine the ranges of “normal” values.
3. Use by parents/legal guardians: Some families have used stored blood samples to make a diagnosis after a child died. This helps families understand what happened, the chances of it happening again and options for dealing with those chances.

By signing below, you agree that:

Blood sample storage:
I have received and read the information about data practices and blood sample storage policies (described above) of the Newborn Screening Program of the Minnesota Department of Health.

I have been informed that saving the blood samples from the Minnesota Department of Health Newborn Screening Program serves many functions, including possible access to the blood sample for identification purposes; use in future diagnostic testing when no other blood sample is available, development of new tests and verification of the original results of newborn screening.

I have been informed that saving of the newborn screening blood sample and results is for the purpose of providing a permanent record of this testing.

I acknowledge that destroying this blood sample will make the blood sample unavailable for any future potential use for medical or identification purposes.

Screening results:
I acknowledge that destruction of the Minnesota Department of Health’s copy of the newborn blood screening test results will make them unavailable from Minnesota Department of Health and that the only copies of these results will reside with me and my child’s primary care provider.

I understand that the risks involved in destroying my child’s newborn blood screening test results may include duplicative testing in the future and limited access to these results by clinicians.
I understand that the risks involved in destroying my child’s newborn screening blood sample will result in loss of the blood sample for medical or identification purposes.

I request my child’s newborn screening blood sample be destroyed immediately or within twenty-four months of testing, whichever is later.

I request my child’s newborn blood screening test results stored at the Minnesota Department of Health’s Newborn Screening Program be destroyed immediately or within twenty-four months of testing, whichever is later.

Requestor’s Signature: ___________________________ Print Name: ___________________________

Relationship to Child: ___________________________ Date: ___________________________

Address: ___________________________ City: ________________ Zip: __________

Phone: ___________________________

Verification code: ___________________________

(Enter a code that you will be asked to verify the request)

Request Verification:
1. Parent/guardian must have signature notarized, indicating that they have the legal authority to make the request
   OR
2. Parent/guardian must present appropriate documentation of authority to enact request (i.e., copy of birth certificate) and photo ID to Public Health or medical personnel. This person must then sign as a witness:

I witness the signature of the above named person who possesses the legal authority to make this request and have verified the identity of the person through photo identification

Witness Name: ___________________________

Witness Position: ___________________________

Witness Phone: ___________________________

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