

Newborn Screening Rule Comments – Emails received on February 12, 2007 by 4:30 p.m.

From: Tom Roman [mailto:tom@aeiomed.com]
Sent: Monday, February 12, 2007 4:22 PM
To: Maria.Lindstrom@state.mn.us
Cc: tom@iwe.us.com
Subject: Request thast MN parents be fully informed about the genetic testingof
newborn babies, and their opt out options
Importance: High

Hello to Judge Barbara Neilson,

I ask that any proposed revision of the newborn genetic testing rules include
the following:

1, Revisions to such rules need to require that parents be informed about these
items listed here.

- a. Newborn screening is genetic testing.
- b. The medical procedure tests for a roster of conditions, not just
PKU.
- c. The State of MN, not the hospital, is doing the testing.
- d. MDH creates a database of all children tested.
- e. The baby's blood contains the baby's DNA and complete genetic
profile.
- f. MDH retains the blood, and makes it available to genetic
researchers without consent.
- g. Retained blood is considered state property.
- h. Retained blood is susceptible to future legislative decisions.
- i. If a diagnosis is made, MDH will annually contact parents to
monitor the child.
- j. The test results, added to the medical record, could negatively
affect the baby's future.

2. That the MDH work to restore the parent's rights to their baby's blood samples and related info
3. That the MDH recognize that it is the parent's who are to be asked consent for any thing that the State of MN does with their blood samples and related information and with any information that MDH has about their baby.

Thank you.

Tom Roman

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email: tom@iwe.us <mailto:tom@iwe.us> [for reference only]or

tom@iwe.us.com <mailto:tom@iwe.us.com> [use this email for all future messages].

-----Original Message-----

From: easylivinginc@netzero.com [mailto:easylivinginc@netzero.com]

Sent: Monday, February 12, 2007 4:36 PM

To: Maria.Lindstrom@state.mn.us

Cc: easylivinginc@netzero.com

Subject: Newborn Screening

The problems with this law are as follows:

- no requirement to tell parents that newborn screening is genetic testing
- no requirement that parents be told that government does the testing, not the hospital
- no requirement that hospitals tell parents that the blood spot enters a government data bank
- no requirement that parents be informed that genetic researchers can be given access to their baby's blood for genetic research
- no requirement that the department publish and hospitals provide to parents a list of all the tests that will be done
- no requirement that parents be told that the baby's blood becomes government property
- no requirement that genetic counseling be made available to parents prior to making a decision

- no requirement that the opt-out options and all information be given prior to the mother's arrival at the hospital

This information NEEDS to be known to all parents / guardians that have children being tested!

From: Patricia.Segal Freeman [mailto:Patricia.Segal.Freeman@state.mn.us]
Sent: Monday, February 12, 2007 12:11 PM
To: Maria.Lindstrom@state.mn.us
Cc: Mark McCann; Maria.Lindstrom@state.mn.us
Subject: MDH newborn screening rule comments

Dear Judge Neilson,

Attached is the department's response to comments and testimony given either during or after the January 23, 2007 hearing on the proposed modifications to the Newborn Screening rules. I also sent an attachment (attachment A), which is referred to in our comments. Maria Lindstrom said that I should also send you a hard copy of the department's response, which I will put in the mail today.

If you have any questions, please let me know.

Patricia Segal-Freeman, J.D., M.P.H.
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NOTE: The Department Response and Attachment are posted separately on the website.