MINNESOTA
MDH
DEPARTMENT OF HEALTH

Protecting, maintaining and improving the health of all Minnesotans

September 23, 2008

Nathan M. Hansen
Attorney at Law
2440 North Charles Street, Suite 224
North Saint Paul, MN 55109

Re: Data Practices Request

Dear Mr. Hansen:

This letter is to update you on the status of your data practices act request to inspect documents related to the Minnesota Department of Health's collection and dissemination of newborn bloodspots. Your request was referred to me as the department's data practices coordinator. I have been working with staff from the Public Health Laboratory Division, Legal Unit, Infectious Disease Epidemiology, Prevention, and Control Division, and Office of Legislative Relations to identify and gather department documents responsive to your request.

At this point we have gathered what we believe to be responsive to your request, with the following exceptions and clarifications:

Item 1) "Documents and correspondence relating to SF 3138, and the Governor's pocket veto thereof" are available except to the extent they are classified as protected nonpublic data under Minnesota Statutes section 13.605.

Item 3) "Documents and correspondence relating to rule-making and attempted rule-making regarding the collection of infant bloodspots" is not yet ready. However, a number of documents related to the rule-making are available on the department's website at: http://www.health.state.mn.us/divs/phl/newborn/rulechange.html .

Item 4) of your request refers to "Documents and correspondence relating to communications with members of the legislative branch relating to the collection of DNA from infants." For clarification purposes, the Minnesota Department of Health does not "collect DNA" from infants; the department collects dried infant bloodspots, of which DNA is one constituent. We have therefore interpreted this part of the request to mean documents and correspondence relating to communications with members of the legislative branch relating to the collection of infant bloodspots for the newborn screening program and have gathered such documents and correspondence.

Item 5) of your request refers to "Documents and correspondence relating to the information given to parents relating to their right to opt-out of DNA collection from their infant children, and the development thereof of these materials." For clarification purposes, the Minnesota

Department of Health does not conduct "DNA collection" from infant children; the department collects dried infant bloodspots, of which DNA is one constituent. We have therefore interpreted this part of the request to mean documents and correspondence relating to the information given to parents relating to their right to opt-out of newborn screening of their infant children, and the development thereof of these materials and have gathered such documents and correspondence.

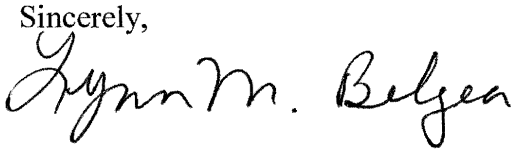
Item 6) requests "The copies of parent objections (redacted obviously) opt-outs and requests for destruction of testing results and blood samples." Much of the information you are requesting is classified as private data under Minnesota Statutes section 13.3805. Because the private data and public data are inextricably intertwined in each document, in that redaction would leave little informational value, we are not performing the redaction of each individual document. However, the department uses standard forms for parents to sign and submit in order to refuse newborn screening or to direct the department to destroy the test results and/or the blood samples, so I have included copies of these forms with this letter. There is no charge for providing the copies of these two documents.

Item 7) appears to be a combination of two separate items, so we are interpreting your letter as conveying 10 separate items, rather than the 9 numbered.

Item 9) "A copy of all complaints, litigation, or legal actions and the like regarding Minn. Stat. §§ 144.125 - 144.128 and 13.386." Our internal Chief Legal Counsel has not identified any department documents responsive to this item.

Please let me know if you wish to wait until all documents responsive to your request letter are gathered or if you wish to inspect what we have thus far and the remainder when they are available. Please note that the department's website also contains substantial information regarding the newborn screening program, including information contained in the parental brochure and related forms, at: http://www.health.state.mn.us/divs/fh/mcshn/nbshome.htm

Sincerely,



Lynn M. Belgea
Data Practices Coordinator
MDH Commissioner's Office Legal Unit
P.O. Box 64975
Saint Paul, MN 55164-0975
(651) 201-5741

Encl

Parental Refusal of Newborn Screening

Name of infant: _____ Birth date: _____

Hospital of birth: _____

By signing below, I acknowledge that:

I have received and read the Minnesota Department of Health (MDH) brochure explaining newborn screening testing for heritable and congenital disorders and have been informed of the risk of not screening a newborn.

I understand that delays in treatment of diseases detectable by newborn screening may result in permanent damage to my child, which may include profound mental retardation, growth failure, hearing loss, and/or death, and that diseases detectable by newborn screening may not cause symptoms for several weeks or months.

I understand that I also have the option of having my child screened and having his or her blood sample and test results destroyed within 24 months of testing.

(Parent or guardian: Check the box or boxes below indicating your directive.)

☐ I do not want _____ to receive blood testing for the diseases
Name of child
screened for by the Minnesota Newborn Screening Program.

☐ I do not want _____ to receive screening for hearing loss.
Name of child

Parent or guardian signature: _____

Parent or guardian printed name: _____

Relationship to child: _____ Date: _____

Street address: _____

City: _____ Zip: _____ Phone: _____

The parent or guardian must present photo identification to a public health or medical professional, who must then sign as a witness. Alternatively, the parent or guardian's signature (i.e., identity) may be authenticated by a notary public.

Witness signature: _____ Witness phone: _____

Witness printed name and position: _____

Send completed form to:

Minnesota Department of Health
Newborn Screening Program
P.O. Box 64899
St. Paul, MN 55164-0899

Phone: (800) 664-7772
Fax: (651) 201-5471
E-mail: newbornscreening@health.state.mn.us
Website: www.health.state.mn.us/newbornscreening

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