

House Floor Discussion on Rep. Mary Liz Holberg's Newborn Screening and Baby DNA Parent Consent Amendments to SF 1212

May 3, 2012

Transcribed by Sam Larson 5/22/2012

Representative Mary Liz Holberg- Chair of Ways and Means Committee

Representative Kurt Zellers- Speaker of the House

Representative Phyllis Kahn- DFL Lead State Government Finance

Representative Tina Liebling- DFL Lead Health and Human Service Reform

Albin A. Mathiowetz- Chief Clerk

Introduction

Kahn: Do you know, would the federal rule take, and specifically there's always the ability to refuse it if there are any living descendents or anyone like the people listed there, but do you know how that interplays with this?

Zellers: Representative Holberg will yield. Member from Dakota, Representative Holberg.

Holberg: Thank you Mr. Speaker and Representative Kahn. Well I haven't filed the issue on a federal level, but I would be hopeful that they would not undo the wishes of our healthcare directive. It's a pretty standard process with some variations across all 50 states. I'm guessing that even the federal politicians wouldn't want to undo that.

Zellers: Further discussion to the author's amendment? Further discussion...seeing no further discussion all those in favor of the author's amendment signify by saying 'aye', opposed 'nay'. The amendment is adopted. There is an amendment at the desk the clerk will report the next amendment.

Length Department May Hold DNA

Mathiowetz: Holberg and others moving to amend Senate File 1212 the ‘delete everything’ amendment as follows the amendment is coded A8.

Zellers: Call on the member from Dakota Representative Holberg, to your amendment.

Holberg: Well Mr. Speaker, I might need help from the front desk this should not be a delete all amendment. It should be to the DE, I believe it’s drafted to the DE-1 amendment.

Zellers: Representative Holberg, the Chief Clerk assures me this is to the delete all amendment. The amendment is before us to the amendment the member from Dakota Representative Holberg.

Holberg: Thank you Mr. Speaker, just making sure. Members, some of you may be aware of a long history in this legislature about struggling over issues around a newborn screening program. All fifty states have a program whereby after a child is born, their heel is pricked and blood is placed on a sample card and is tests for various conditions. Lack of performing this test, in fact, may cause the death of some children. In the state of Minnesota we have a provision in current law that allows a parent to opt-out of the test or have it done privately and then...

Zellers: Representative Holberg, one minute please. Members if you could please. If you could take your conversations to the alcove or better yet the retiring room; there are members on both sides of the aisle trying to hear Representative Holberg. Thank you members, Representative Holberg you have the floor.

Holberg: Thank you Mr. Speaker and what a point of contention over the years is what happens to the blood samples and test results after that initial screening is completed and for some of us for many many years have been trying to get into place the opportunity for parent consent for any activities beyond the initial screening. And I in fact question the Department of Health, had the authority to do, what they were doing.

What happened a number of years ago and Representative Kahn and I worked together to try and address the issue to genetic testing information, technical advances, in the medical arena that really haven’t been dealt with, with any public policy at any state level. And there was a genetic privacy information task force that made recommendations to the legislature and as a result of that we had that the genetic privacy act, which was implemented in law.

Fast forward a couple years and there was a lawsuit brought forward in the state of Minnesota on behalf of children that had been tested, questioning the Department of Health’s right to store and use for research those samples and test results. There was a Supreme Court ruling in November of 2011 that in fact held that the Department of

Health did not have the authority beyond the initial screening to use the blood samples and test results for other purposes and in fact currently under court agreement they are destroying all blood samples at 71 days and test results at 2 years with the exception of the material that they had prior to the court decision which is being held by court order.

So, what we're trying to do here with this particular amendment is after the court decision the Department of Health began to look at the various programs being conducted. And had some concerns whether they really had the express authority either through rule or law to conduct the activities that they have been conducting for a number of years, so in plain English this amendment, actually I call it the, 'get out of court' provision. In other words we are going to give the Department of Health a pass for their activities between now and July of 2013, in the meantime they are going to have to comb through the laws and rules relative to the programs that they implement and conduct and determine whether or not they need additional authority given to them by the legislature in order to continue their work and so members

I would ask for support on the A8 amendment it allows the Health Department to continue their operations this particular language does not apply to the newborn screening program, we'll get to that with the next amendment. But does allow them to continue their operations and we'll have an opportunity to discuss this important issue in more detail in the next legislative session. And I'd be happy to stand for questions.

Zellers: Discussion to the Holberg Amendment, the member from Olmstead, Representative Liebling.

Liebling: Thank you Mr. Speaker and members. And just to let members know that I also support this amendment. Representative Holberg's done a lot of work on this and we'll continue to work in the future, but this amendment represents a compromise and we need to get this enacted.

Zellers: Further discussion, seeing no further discussion all those in favor of the author's amendment signify by saying 'aye', opposed 'nay'. The motion prevails. There is an amendment at the desk; the clerk will report the next amendment.

Newborn Screening Amendment

Mathiowetz: Holberg and others moving to amend Senate File 1212 as amended by the 'delete everything' amendment the amendment is coded A9.

Zellers: Call on member from Dakota, Representative Holberg to present your amendment.

Holberg: Thank you Mr. Speaker and members. Well this amendment deals directly with the newborn screening program in an effort to comply to the ruling of the Supreme Court from last Fall. And in general terms it's still the provision or the standard for newborn

screening is an opt-out. Parents still have the right to opt-out and/or use a private firm for testing. Then they will provide for a process for consent for storage and use and dissemination it will be a robust consent process that will include a Tennessee Warning.

It is the intent of the Health Department to not seek this authority in the hospital, but to rather work with prenatal classes and pediatricians in order to have this decision making phase be done in an environment with a little bit less stress than the actual hospital setting at the time of birth. In addition there will be an information sheet similar to what people receive saying at the time of immunization that will be given to the parents at the time of the newborn screening at the hospital that will be a basic information sheet about the tests and what their rights are in regard to the actual newborn screening program.

And then it also provides for protection for the current court cases that have already been filed. That these changes do not negate any claims of action that have already been filed for result of behavior or actions in the past.

And in addition to that we also make it very clear that the new born screening program continues to be governed by the Genetic Privacy Act and the penalties in chapter 13 for violations of that act. And I would be happy to stand for any questions.

Zellers: Discussion? The member from Olmstead, Representative Liebling.

Liebling: Thank you Mr. Speaker and members and once again I appreciate Representative Holberg's work on this. Certainly from my point of view it's not perfect, but it represents a lot of work on her part to reach a compromise and so, I urge members to support it.

Zellers: Further discussion. All those in favor of the author's amendment, signify by saying 'aye', opposed 'nay'. The motion prevails.

THE AMENDMENTS PASSED, BUT DID NOT BECOME LAW THROUGH SF 1212. INSTEAD, HF 2967 (Robling) WITH SAME AMENDMENTS WAS ENACTED AND SIGNED INTO LAW MAY 10, 2012.