

# Bill as Introduced

HB 1164 - AS INTRODUCED

2010 SESSION

10-2343  
01/05

HOUSE BILL            **1164**

AN ACT                relative to newborn screening tests.

SPONSORS:            Rep. Millham, Belk 5

COMMITTEE:          Health, Human Services and Elderly Affairs

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ANALYSIS

This bill deletes the requirement that the department of health and human services enter into a contract competitively bid and approved by the governor and council for the moneys from the newborn screening fund.

.....

Explanation:          Matter added to current law appears in ***bold italics***.  
                         Matter removed from current law appears ~~[in brackets and struck through]~~  
                         Matter which is either (a) all new or (b) repealed and reenacted appears in regular type.

STATE OF NEW HAMPSHIRE

*In the Year of Our Lord Two Thousand Ten*

AN ACT                   relative to newborn screening tests.

*Be it Enacted by the Senate and House of Representatives in General Court convened:*

1           1 Newborn Screening. Amend RSA 132:10-a, II and III to read as follows:

2           II. Notwithstanding any provision of law to the contrary, the commissioner of the  
3 department of health and human services shall establish fees, pursuant to RSA 541-A, to be paid by  
4 hospitals for the tests required under paragraph I. All such fees shall be paid into the newborn  
5 screening fund, hereby established in the state treasury. Moneys from the newborn screening fund  
6 established under this section shall be nonlapsing and shall be continually appropriated for use by  
7 the department to cover laboratory analysis and related newborn screening program costs [~~under a~~  
8 ~~contract competitively bid and approved by governor and council~~].

9           III. The department of health and human services shall establish a newborn screening  
10 advisory committee which shall include a member of the oversight committee on health and human  
11 services, established in RSA 126-A:13, and representation from health care subspecialties, as  
12 determined by the department. [~~Any proposals for recommending new tests or fees shall require a~~  
13 ~~public hearing to be held on the proposal by the newborn screening advisory committee.~~]

14           2 Effective Date. This act shall take effect July 1, 2010.

HB 1164 - AS AMENDED BY THE HOUSE

03Mar2010... 0615h

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14           ***III-a. The department shall ensure that the providers conducting tests authorized***  
15 ***under paragraph I destroy any samples no later than 6 months following the completion of***  
16 ***testing. Any samples taken for newborn screening shall only be used for tests required***  
17 ***under this section. No such samples may be used for other research or DNA testing***  
18 ***purposes.***

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HB 1164 - FINAL VERSION

03Mar2010... 0615h  
05/05/10 1650s  
02Jun2010... 2138eba

2010 SESSION

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16 ***of testing. Any samples taken for newborn screening shall only be used for tests required***  
17 ***under this section. No such samples may be used for other research or DNA testing***  
18 ***purposes unless authorized by the parent or guardian.***

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# Committee Minutes



**SENATE CALENDAR NOTICE  
HEALTH AND HUMAN SERVICES**

- ✓ Senator Kathleen Sgambati Chairman *AA (in)*
- ✓ Senator Peggy Gilmour V Chairman
- ✓ Senator Molly Kelly
- ✓ Senator John Gallus
- ✓ Senator Michael Downing

For Use by Senate Clerk's Office ONLY	
<input type="checkbox"/>	Bill Status
<input type="checkbox"/>	Docket
<input type="checkbox"/>	Calendar
Proof:	<input type="checkbox"/> Calendar <input type="checkbox"/> Bill Status

**Date: March 31, 2010**

**HEARINGS**

**Tuesday**

**4/13/2010**

HEALTH AND HUMAN SERVICES

SH 103

8:30 AM

(Name of Committee)

(Place)

(Time)

**EXECUTIVE SESSION MAY FOLLOW**

8:30 AM HB1136

requiring a report to be sent to the treatment facility on behalf of a person receiving treatment in the state mental health or developmental services system.

8:45 AM HB1164

relative to newborn screening tests.

9:00 AM HB1169

(New Title) relative to the New Hampshire health care quality assurance commission.

9:15 AM HB1216

relative to the amount of the self-support reserve in child support cases.

**Sponsors:**

**HB1136**

Rep. Stephen Shurtleff

**HB1164**

Rep. Alida Millham

**HB1169**

Rep. James Craig

**HB1216**

Rep. David Bickford

# Health and Human Services Committee

## Hearing Report

**TO:** Members of the Senate

**FROM:** Heidi Mitchell, *Legislative Aide*

**RE:** Hearing report on **HB 1164** - *AN ACT relative to newborn screening tests.*

**HEARING DATE:** April 13, 2010

**MEMBERS OF THE COMMITTEE PRESENT:** Sen. Sgambati; Sen. Gilmour; Sen. Downing; Sen. Gallus; Sen. Kelly.

**MEMBERS OF THE COMMITTEE ABSENT:** No one.

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**Sponsor:** Rep. Millham, Belk. 5.

**What the bill does:** This bill deletes the requirement that the department of health and human services enter into a contract competitively bid and approved by the governor and council for the moneys from the newborn screening fund. The bill also adds requirements for the samples taken for newborn screening.

**Who supports the bill:** Rep. Donovan, Sull. 4; Kate Frey, Department of Health and Human Services, Division of Public Health Services; Lisa Bujno, Department of Health and Human Services, Division of Public Health Services.

**Who opposes the bill:** No one.

**Summary of testimony received:** Rep. Donovan introduced the bill to the committee on behalf of its prime sponsor, Rep. Millham, who was unable to make the hearing.

### Rep. Donovan

- Brought forth Amendment #1299h. It is a friendly amendment that specifies that the laboratory doing the analysis testing will be responsible for destroying the samples. It also changes the last sentence of the bill to read: "No such samples may be used for other research or DNA testing purposes *unless authorized by the parent or guardian.*" (Pg. 1, lines 17-18).

### Kate Frey & Lisa Bujno, DHHS, DPHS

- In support of the bill and Amendment #1299h.
- Gave background on newborn screenings in NH – 99.7% of all births in NH get screened. Parents can refuse screenings. Newborn screening is a preventive, public health program aimed at identifying newborns with medical disorders for which early detection, diagnosis, and treatment can prevent disability and death.

- HB 1164 amends RSA 132:10-a, to allow for self-funding of other program costs through a \$10 increase in the fee which would allow for the salary of 1.5 full time employees.
- In response to questions from the committee:
  - Most babies are screened within 2 days of birth, including home births. In 2008, 13,952 babies were screened.
  - The laboratory that does the testing is located at UMass. There is a specific clause in the Department's contract that stipulates that the lab must follow NH laws when processing samples from NH babies.
  - The current fee is \$50 per baby – this covers all 32 tests and any follow-up testing that might be needed.
  - There is a special filter paper that the hospitals pay the Department for use of associated with this testing.
  - The reason for the increase in fee would be to pay for new staff and to pay for the tyvek envelopes needed to send the filter paper to the lab, which are expensive.
  - The cost of testing uninsured babies would be absorbed by the hospitals. Last year, the hospital with the fewest births (82 total) had 42 that were uncompensated. The hospital paid \$882 for the tests. The hospital with the highest births (2,211 total) had 660 uncompensated births and paid \$13,860 for the tests. There were 27 babies with disorders confirmed of the 13,000+ that were tested.
  - Hospitals were uncompensated in cases where the mother had no insurance. Most insurance covers screenings and Medicaid covers screenings, it's usually part of their global fee for the birth.

**Funding:** Not applicable.

**Future Action:** The committee took the bill under advisement.

hmm  
[file: HB 1164 report]  
Date: April 16, 2010

*doc*

Date: April 13, 2010  
Time: 8:48 A.M.  
Room: SH RM 103

The Senate Committee on Health and Human Services held a hearing on the following:

HB 1164 relative to newborn screening tests.

Members of Committee present: Senator Sgambati  
Senator Gilmour  
Senator Kelly  
Senator Gallus  
Senator Downing

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The Vice Chair, Senator Peggy Gilmour, opened the hearing on HB 1164 and invited Representative Thomas Donovan, to introduce the legislation.

Representative Thomas Donovan: Thank you, Madam Chair. For the record, my name is Tom Donovan. I represent Sullivan County District 4, Claremont, Unity, and Lempster and I'm here to introduce HB 1164, a bill relative to the newborn screening tests. And, I am here on behalf of Representative Alida Millham who was in a conflict today and couldn't make it to the hearing, so she asked me to sit in and introduce the bill.

And, I also have brought an amendment in. It's being copied and will be circulated shortly, that was going to be done in the House, but it was done to clarify some issues of the samples of the test and what they could be used for and the intent of the samples, and how long they could be kept before they were destroyed, etc.

So, basically we have two people from the Department here to testify.

This bill went through, again, went through our Committee and was unanimous.

Senator Peggy Gilmour, D. 12: Any questions for Representative Donovan?

Senator Molly Kelly, D. 10: Are we getting the amendment?

Senator Peggy Gilmour, D. 12: Is it ready?

Deborah A. Chroniak: It's right here. It had to be copied.

Senator Molly Kelly, D. 10: Thank you.

Senator Peggy Gilmour, D. 12: I realized when he said that amendment.

Senator Molly Kelly, D. 10: I just have a question. Can you just explain to us how this amendment changes the bill here?

Representative Donovan: I said the amendment was going to be brought in as a friendly amendment, I believe in the House...

Senator Molly Kelly, D. 10: Hm-hmm.

Representative Donovan: ...with Representative Millham and Representative Kurk who had some concerns about privacy and issues of how long the samples could be kept, and didn't want them to get into anyone else's hands.

Senator Molly Kelly, D. 10: I was just going to say that the bill that I'm, that I'm looking at here in front of me, as amended by the House looks like it has similar language.

Senator Peggy Gilmour, D. 12: I see the difference.

Senator Molly Kelly, D. 10: In paragraph...

Senator Peggy Gilmour, D. 12: It's the laboratory in III-a.

Senator Molly Kelly, D. 10: And, I just want to know what the exact difference is, and kind of compare it. Is the bill that I'm looking at, is that the same language or is there something different on this amendment?

Representative Donovan: I believe it's the same language. I believe that's just a...could be a...

Senator Peggy Gilmour, D. 12: I think this one has, is the lab...it requires the laboratory.

Senator Michael W. Downing, D. 22: I think that you're right.

Representative Donovan: Right.

Senator Molly Kelly, D. 10: Okay.

Senator Peggy Gilmour, D. 12: In this one, it says that the providers, and this one is very clear that it goes to the lab and that the lab destroys it. Is that correct?

Senator Molly Kelly, D. 10: And, it looks like the last sentence may be different; "no such samples may be used for other research or DNA testing purposes unless authorized by the parent or guardian". So that is, so this is different than what's on the original bill here. Okay.

Representative Donovan: Yes.

Senator Molly Kelly, D. 10: They're all nodding their heads. You're going to speak to that? Okay, great. I'll...we'll ask you then. Thank you.

Senator Peggy Gilmour, D. 12: Are there any more questions of Representative Donovan or, if not, we'll hear from the Department.

Representative Donovan: Thank you.

**Please see Attachment #1 – Proposed Amendment to HB 1164,  
Representative Millham, dated April 9, 2010, 2010-1299h, submitted  
by Representative Thomas Donovan**

Senator Peggy Gilmour, D. 12: Thank you.

Kate Frey and Lisa.

Lisa Bujno: Good morning, members of the Committee. I will try to speak loudly, but I have a soft voice, so just let me know if you can't hear me when I do mine.

For the record, my name is Lisa Bujno and I'm Bureau Chief for Community Health Services in the Commission of Public Health Services. I'm here today to speak in support of HB 1164, relative to newborn screening tests. The Division of Public Health Services requested this bill, and I would like to thank Representative Millham for sponsoring this legislation on our behalf. We are going to ask for the amendment to this bill, and Kate will explain that at the end of the testimony.

First, I'd like to provide some background on the Newborn Screening Program. Newborn screening is a preventive, public health program aimed

at identifying newborns with medical disorders for which early detection, diagnosis, and treatment can prevent disability and death. Every year about four million infants are screened in the United States. In New Hampshire, about 99.7% of all infants born each year are screened, which is about 13,500 infants.

RSA 132:10-a requires all infants born in New Hampshire be screened at birth for a panel of 32 disorders, as determined by the State, but that includes a clause which allows parents or guardians to refuse the screening if they so desire.

Now, I'd like to explain HB 1164. RSA 132:10-a currently requires the Department to establish fees for newborn screening, which are paid by hospitals into the Newborn Screening Fund. The RSA states, "Moneys from the Newborn Screening Fund shall be nonlapsing and shall be continually appropriated for use by the Department to cover laboratory analysis and related newborn screening program costs under a contract competitively bid and approved by Governor and Council". Currently, only the laboratory analysis is paid through these fees and a mix of federal and general funds pay for other program costs. This bill amends this part of the current statute in order to allow for self-funding of other program costs through an increase in the fee. Increasing the fee by about \$10 per test would allow self-funding of the program, including salary and benefits for 1.5 FTEs that currently work in the program.

The Department has been asked over the last few years to identify areas where fees could cover some General Fund costs. For newborn screening, this makes sense. Our program activities focus on assuring that hospital staff appropriately screen, that hospital labs and physicians appropriately follow up on results, and that babies access the care and treatment they need. These activities assure healthier outcomes for affected babies and also reduce risk for hospitals.

HB 1164 also deletes the line, "Any proposals for recommending new tests or fees shall require a public hearing to be held on the proposal by the Newborn Screening Advisory Committee," in section III of RSA 132:10-a. This currently requires the Department to hold two separate hearings on the same issue, as we are required to have a public hearing under RSA 541-A when we pursue rulemaking on additional tests and fees. Deleting the reference that requires us to hold a second public hearing will allow us to use scarce staff resources more efficiently.

And, I think Kate will speak to the amendment.

Kate Frey: For the...

Senator Molly Kelly, D. 10: I'm sorry.

Kate Frey: Hm-hmm.

Senator Molly Kelly, D. 10: I just wanted to ask you a question, Lisa, just so I understand the process. So, currently, a newborn would be tested and the hospital pays a lab?

Kate Frey: Well...

Senator Molly Kelly, D. 10: ...for an outside, a contracted?

Bureau Chief Bujno: No. The newborn, as part of the contract with the laboratory that does the analysis...

Senator Molly Kelly, D. 10: Which is not in the hospital.

Bureau Chief Bujno: Which is not in the hospital; it's the University of Massachusetts, currently. And, they're the only lab that can do those tests that's in this region.

But, there's a certain special filter paper that the specimen needs to be collected on. The University of Massachusetts provides those to our program, and the hospitals buy those from us, and that's where the fee is incurred. So, they would pay the fee to the Department, and then they would get the filter papers that they need to collect the specimen.

Senator Molly Kelly, D. 10: And, just curious. Who pays the hospital?

Bureau Chief Bujno: The insurers pay the hospitals.

Senator Molly Kelly, D. 10: Okay. Thank you.

Kate Frey: For the record, my name is Kate Frey. I'm with the Division of Public Health Services, as well. And, I'll just speak to that...to the amendment.

So, the House passed a floor amendment on this bill, which is now section III-a in the bill you have in front of you. And, it states that, "The Department shall ensure that the providers conducting tests authorized under paragraph I destroy any samples no later than six months following the completion of testing. And, any samples taken for newborn screening shall only be used for



tests required under this section. No such samples may be used for other research or DNA purposes”.

The Division has no problem with the intent behind the amendment, and its current practice, per administrative rule, to destroy all samples after six months. So, we support, wholly, that it's stated in statute; it's just that we needed to clarify a few things, and so, that is the amendment that is in front of you from Representative Donovan.

And, you were right on Senator Gilmour, in that what it did is just clarify that it's the laboratories analyzing the tests, it is their responsibility to destroy the samples. It was just confusing with the original language that just said “providers”, and referred back to RSA 132:10-a, I because that inferred it was the healthcare provider. So, it just clarifies that it's the laboratory that has the responsibility to dispose of those samples.

And then, Senator Kelly, you were correct. It also adds that, “no such samples may be used for other research or DNA testing”. And, it adds, “Unless authorized by the parent or guardian”. Actually, it just seemed to make sense that the parent or guardian have the option, that if it was found that that sample could be used for other purposes that would be necessary for that child's health, that they have that decision instead of just going ahead and destroying that sample and then maybe having to prick that baby again. And, there was no problem with the Representatives on that issue. So, it's just a clarification.

Senator Molly Kelly, D. 10: No, go ahead.

Senator Peggy Gilmour, D. 12: Go ahead.

Senator Molly Kelly, D. 10: Kate, I thank you.

Kate Frey: Hm-hmm.

Senator Molly Kelly, D. 10: I just wanted to know, how many babies are screened, and is that done right after birth or is there a particular time?

Kate Frey: Hm-hmm

Senator Molly Kelly, D. 10: Or, if you're not born in a hospital, how does that all fit?

Bureau Chief Bujno: It's a very time-sensitive process.

Kate Frey: Yeah.

Bureau Chief Bujno: And, it's supposed to be done within two days after birth.

Senator Molly Kelly, D. 10: Hm-hmm.

Bureau Chief Bujno: The test can be of value if it's done later than that, but that's the optimal time. And, actually, in home births or birthing centers, usually the nurse midwives either will do it there or refer the baby to the hospital or their healthcare provider to have the test done.

Senator Molly Kelly, D. 10: Okay. Thank you.

Kate Frey: And, the number screened is 13,952 infants have been screened for 2008.

Bureau Chief Bujno: We...

Kate Frey: So, that's about...

Bureau Chief Bujno: ...usually run about 99...

Kate Frey: 99...

Bureau Chief Bujno: ...to 100%

Ms. Frey: Yep.

Bureau Chief Bujno: Yeah.

Senator Molly Kelly, D. 10: Thank you.

Senator Peggy Gilmour, D. 12: I do have a question. You said that currently they're done in a laboratory at the University of Massachusetts.

Bureau Chief Bujno: Yes.

Senator Peggy Gilmour, D. 12: Help me. Can our statute require a Massachusetts laboratory?

Bureau Chief Bujno: We have that in our contract with them. Destroying the specimens at six months is something that we've had in practice...

Senator Peggy Gilmour, D. 12: In rule.

Bureau Chief Bujno: ...for several years already...

Senator Peggy Gilmour, D. 12: Hm-hmm.

Bureau Chief Bujno: ...and it is one of the clauses in that contract.

Senator Peggy Gilmour, D. 12: Okay. Senator Downing?

Senator Michael W. Downing, D. 22: Thank you, Madam Chairman. What is the fee now that they're charging for the test?

Bureau Chief Bujno: Now the fee is \$50. I have some information on that.

Senator Michael W. Downing, D. 22: And, is that per test? I noticed there's, what, 32 disorders that they're testing for. That's not \$50 per disorder, that's \$50 per test.

Bureau Chief Bujno: Yes.

Senator Michael W. Downing, D. 22: And, then they test 32 on that one sample?

Bureau Chief Bujno: Exactly. And, it's actually \$50 per baby. We were able to negotiate with the University of Massachusetts. Sometimes the analysis needs to be run again for quality purposes or to recheck a result. And, so, we were able to negotiate that, you know, for that one specimen and for any follow up testing the baby might need subsequently to that. That fee is for the baby.

Senator Michael W. Downing, D. 22: Another question. And, if I understand you, the reason for the \$10 increase is to provide funding for one and one-half persons at HHS.

Bureau Chief Bujno: And, some other program costs. It actually looks at the possible increase in the lab cost over the period of this year through state fiscal year '14, and looks at the small amount of other program expenses. For example, the filter papers have to be mailed in Tyvek envelopes that are pretty expensive; that kind of thing. We fax results to providers sometimes, so they can follow up on the results. So, those kinds of small amount of program fees; expenses.

Senator Michael W. Downing, D. 22: And, a follow up?

*doc*

Senator Peggy Gilmour, D. 12: Follow up, yes.

Senator Michael W. Downing, D. 22: And, you said that the insurance companies pretty much pay for all of these tests, and it directs with the costs and ends up going to a...How about the uninsured and that kind of thing?

Bureau Chief Bujno: Well, those costs need to be absorbed by the hospitals if there's not an alternate payer. And, we did do some analysis before bringing this forward to look at the number of births in the hospitals, and what that would mean in terms of a fiscal impact to the hospitals for uncompensated births. For the hospital that has the fewest births, which, in '08-'09 is 82 births for the year. Only 42 of those births were uncompensated, which would mean an increase of \$882 for that hospital. And, then, for the hospital with the most births, which had 2,211 births for that same year, but only 660 uncompensated births, that would be an increase of \$13,860.

Senator Peggy Gilmour, D. 12: Wait, could you say those numbers again. They had 800 live births?

Bureau Chief Bujno: They had...the hospital...

Senator Michael W. Downing, D. 22: Twenty-two hundred.

Bureau Chief Bujno: ...with the fewest births had 82.

Senator Peggy Gilmour, D. 12: Yep.

Bureau Chief Bujno: Of those, 42 were uncompensated; they had no Medicaid coverage or insurance coverage. And, so, the increase would be \$882, more or less for that hospital. The hospital with the most births had 2,211 births, 660 of those were uncompensated, and the increase would be about \$13,860 a year.

Senator Peggy Gilmour, D. 12: Do you have that data you could share?

Bureau Chief Bujno: Sure.

Senator Peggy Gilmour, D. 12: Yeah. Okay.

Bureau Chief Bujno: Hm-hmm.

*pac*

Senator Peggy Gilmour, D. 12: I can have a question. Okay? Just curiosity, out of those 13,000 testings done last year, how many abnormal findings do you get?

Bureau Chief Bujno: It varies. I'm trying to think last year, there were...do you have that? I know there were about 15 to 18 babies that were born that missed testing, and our staff followed up. And, that was not because the parents refused; it was because they were just overlooked. And then, last year we had 27 confirmed disorders, but, of course there was relatively more tests that were out of the normal range and needed to be followed up on.

Senator Peggy Gilmour, D. 12: Okay. Senator Kelly.

Senator Molly Kelly, D. 10: Lisa, of the numbers that you just gave us, of those that were uncompensated...

Bureau Chief Bujno: Hm-hmm.

Senator Molly Kelly, D. 10: ...and the hospitals picked up. How many of those were uncompensated because there was no insurance coverage, or how many were uncompensated because the insurance company does not cover screenings?

Bureau Chief Bujno: Those...that information was taken from the vital records data, and so, that would be the number of births that did not have a reported insurance or Medicaid. So.

Senator Molly Kelly, D. 10: Just a follow up. So, I just wondered, do most insurance companies cover that screening?

Bureau Chief Bujno: Yes. Yeah.

Senator Molly Kelly, D. 10: So, it really is a statement more about those that are uninsured...

Bureau Chief Bujno: Exactly.

Kate Frey: Uninsured, exactly.

Senator Molly Kelly, D. 10: Those are uninsured parents.

Kate Frey: Correct.

*aac*

Senator Molly Kelly, D. 10: Because it would come through the mother's insurance...

Bureau Chief Bujno: Yes.

Kate Frey: Yes.

Senator Molly Kelly, D. 10: ...or Medicaid, one or the other.

Bureau Chief Bujno: Yes.

Kate Frey: Yes.

Senator Molly Kelly, D. 10: Which is insurance?

Bureau Chief Bujno: And, generally, the newborn screening costs are covered in a global fee for delivery.

Senator Molly Kelly, D. 10: Hm-hmm.

Bureau Chief Bujno: And, so, that would be something that the hospitals would individually negotiate with the individual insurance companies.

Senator Molly Kelly, D. 10: Okay, thank you.

Senator Peggy Gilmour, D. 12: Senator Downing?

Senator Michael W. Downing, D. 22: Further question. Thank you. Does Medicaid and Medicare cover this test?

Bureau Chief Bujno: Medicaid, yes. And, it's part of their global fee.

Senator Michael W. Downing, D. 22: Okay. Thank you.

Senator Peggy Gilmour, D. 12: Further questions? Senator Sgambati?

Senator Kathleen G. Sgambati, D. 4: I think I'm all set.

Senator Peggy Gilmour, D. 12: Thank you. Thank you very much.

Kate Frey: Thank you.

Senator Peggy Gilmour, D. 12: And, you'll share your...

Kate Frey: We will, yes.

**Please see Attachment #3 – Cost Data information sheet submitted by Kate Frey.**

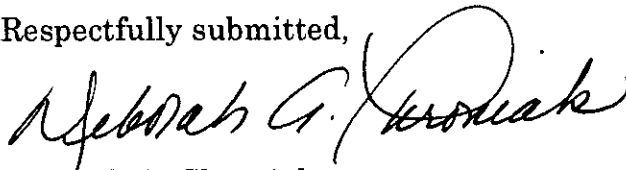
Bureau Chief Bujno: Information.

Senator Peggy Gilmour, D. 12: Your cost data.

Is there anyone further to testify on HB 1164? Hearing none, I will close the Public Hearing on HB 1164.

Hearing concluded at 9:08 a.m.

Respectfully submitted,

A handwritten signature in black ink that reads "Deborah A. Chroniak". The signature is written in a cursive style with a large, looping initial 'D'.

Deborah A. Chroniak  
Committee Secretary  
5-25-10

3 Attachments



Rep. Millham, Belk. 5  
April 9, 2010  
2010-1299h  
01/05

Amendment to HB 1164

1 Amend RSA 132:10-a, III-a as inserted by section 1 of the bill by replacing it with the following:

2

3 *III-a. The department shall ensure that the laboratory analyzing tests authorized*  
4 *under paragraph I destroy any samples no later than 6 months following the completion of*  
5 *testing. Any samples taken for newborn screening shall only be used for tests required*  
6 *under this section. No such samples may be used for other research or DNA testing*  
7 *purposes unless authorized by the parent or guardian.*





Nicholas A. Toumpas  
Commissioner

José Thier Montero  
Director

STATE OF NEW HAMPSHIRE  
DEPARTMENT OF HEALTH AND HUMAN SERVICES  
DIVISION OF PUBLIC HEALTH SERVICES

29 HAZEN DRIVE, CONCORD, NH 03301-6504  
603-271-4593 1-800-852-3345 Ext. 4593  
Fax: 603-271-4827 TDD Access: 1-800-735-2964

Senate Health Human Services Committee  
HB 1164, Relative to Newborn Screening Tests  
Testimony  
April 13, 2010

- Good morning Chair Sgambati and members of the Committee. My name is Lisa Bujno and I am the Bureau Chief for Community Health Services. I am here today to speak in support of HB 1164, relative to Newborn Screening Tests. The Division of Public Health Services requested this bill and I would like to thank Representative Millham for sponsoring this legislation on our behalf.
- I would like to ask this committee for an amendment to this bill in order to clarify the House floor amendment. I will review that at the end of my testimony.
- First I'd like to provide some background on the Newborn Screening Program. Newborn screening is a preventive, public health program aimed at identifying newborns with medical disorders for which early detection, diagnosis, and treatment can prevent disability and death. Every year, approximately four million infants are screened in the United States. In 2008, New Hampshire screened 13,592 infants, which represented 99.7% of all births.
- RSA 132:10-a requires that all infants born in New Hampshire be screened at birth for a panel of 32 disorders, as determined by the State. This statute includes a clause, 132:10-c, which allows parents or guardians to refuse this screening if they so desire.
- Now I'd like to explain HB 1164. RSA 132:10-a currently requires the Department to establish fees for newborn screening, which are paid by hospitals into the newborn screening fund. The RSA states, "Moneys from the newborn screening fund .....shall be non-lapsing and shall be continually appropriated for use by the department to cover laboratory analysis and related newborn screening program costs *under a contract competitively bid and approved by governor and council.*" Currently, only the laboratory analysis is paid through these fees and a mix of Federal and General funds pay for other program costs. HB 1164 amends this part of the current statute in order to allow for self-funding of other program costs through an increase in the fee. Increasing the fee by about \$10 per test would allow self-funding of the program, including salary and benefits for 1.5 FTE.

- The Department has been asked over the last few years to identify areas where fees could cover some general fund costs. For newborn screening, this makes sense. Our program activities focus on assuring that hospital staff appropriately screen, that hospital labs and physicians appropriately follow up on results, and that babies access the care and treatment they need. These activities assure healthier outcomes for affected babies and also reduce risk for hospitals.
- HB 1164 also deletes the line “Any proposals for recommending new tests or fees shall **require a public hearing** to be held on the proposal by the newborn screening advisory committee,” in section III of RSA 132:10-a. This currently requires the Department to hold two separate public hearing on the same issue, as we are required to have a public hearing under RSA 541:A when we pursue rulemaking on additional tests and fees. Deleting the reference that requires the program to hold a second public hearing will allow the Division to use scarce staff resources more efficiently.
- Now to speak to the requested amendment. The House passed a floor amendment on this bill, which is now section III-a and states: “The department shall ensure that the providers conducting tests authorized under paragraph I destroy any samples no later than 6 months following the completion of testing. Any samples taken for newborn screening shall only be used for tests required under this section. No such samples may be used for other research or DNA testing purposes.”
- The Division has no problem with the intent behind this amendment as it is current practice per administrative rules to destroy all samples after 6 months and we support that it is stated in statute as well.
- However, we would like to clarify that it is the **laboratory** that has the samples and are responsible for destroying them in the time period required. By using the term “providers” in the current bill and referring back to RSA 132:10-a 1, it infers it is the health care provider’s responsibility. Although they conduct the test, the samples are then sent to the laboratory at UMass for analysis and eventual disposal.
- Also we would like to add that the test sample may be used for other research and DNA testing **IF** “authorized by the parent or guardian”. This only seems to make sense to have the parent or guardian have that option if it was found that the sample could be used for other purposes that would be necessary for that child's health.
- The suggested language would be as follows: “ The department shall ensure that the **laboratory** ~~providers conducting~~ **analyzing** tests authorized under paragraph I destroy any samples no later than 6 months following the completion of testing. Any samples taken for newborn screening shall only be used for tests required under this section. No such samples may be used for other research or DNA testing purposes ***unless authorized by the parent or guardian*** ”
- Thank you for this opportunity to testify. I would be happy to answer any questions you may have at this time.

NH Department of Health and Human Services  
Conference Call  
*regarding changes to the newborn screening panel  
and an increase in the filter paper fee*

December 7, 2009  
1:00 PM – 3:00 PM

### Why this call?

- Brief presentation regarding the Newborn Screening Program (NSP)
- Opportunity for public comment on planned changes

### What is Newborn Screening?

- An essential preventive public health program
- A complex, integrated system aimed at early identification of disorders that can cause significant and sometimes catastrophic health problems

### How does it work?

- A few drops of blood are obtained from the infant through a heel stick procedure
- The blood is applied to a *filter paper* which is then sent to a laboratory for analysis
- This process is done before the infant leaves the hospital
- Timing is everything!
  - Some conditions need to be identified in the first week of life

### More than just PKU

- Due to advanced science and technology, newborns today can be screened for an increasing number of disorders

### A Complex System

- Newborn screening is a complex, integrated system involving several critical components:
  - screening
  - follow-up
  - diagnosis
  - management
  - evaluation
- **Education** is an important part of each of these components

### Screening Panels Vary by State

- ✓ Individual states set their own screening panels
- ✓ NH currently screens for 32 disorders
- ✓ National efforts are underway to standardize newborn screening practices, including screening panels

### Newborn Screening History & Law

- ✓ Began in the 1960's with the development of a screening test for phenylketonuria (PKU)
- ✓ Has greatly evolved since 1960, with better technology and ability to screen for more disorders
- ✓ RSA 132:10a requires that all infants born in New Hampshire be screened, though parents can refuse

### What Legislation Authorizes

- ✓ A designated newborn screening fund
  - Revenue from filter papers to support program
- ✓ DHHS Commissioner authority to set fees
- ✓ Creation of the NSP Advisory Committee
- ✓ Establishes criteria by which additional conditions can be added to the state screening panel

### NBS Advisory Committee Role

- ✓ Advises the Department on clinical, educational, and operational aspects of the Newborn Screening Program, and
- ✓ Provides recommendations regarding additional disorders to be included in the newborn screening panel

### NH Newborn Screening Program Proposed Legislative Changes 2010

### Proposed Law Change

- ✓ LSR 2010-2343, relative to newborn screening tests

### Proposed Rule Changes

- ☑ He-P 3008, Newborn Screening and Newborn Hearing Screening pursuant to RSA 132:10a, effective 12/23/05

### Proposed Panel Change

- ☑ In 2009, the NH NSP Advisory Committee recommended adding Tyrosinemia to our screening panel
- ☑ Tyrosinemia was not added with the last expansion in 2007 because the screening algorithm was not felt to be sensitive and specific enough to identify cases

### Proposed Panel Change

- ☑ Screening algorithm for Tyrosinemia has been improved and is now uses succinylacetone as the primary marker
- ☑ This change means that the process is now both specific and sensitive enough to identify cases accurately

### Proposed Fee Change

- ☑ Filter paper fee will increase from \$50.00 to \$71.00
- ☑ Increase includes:
  - Adding Tyrosinemia to panel
  - Normal projected increase for lab screening contract through 2014
  - Other program costs

### Proposed Fee - Detail

	SFY10 PROJECTED	SFY11 PROJECTED	SFY12 PROJECTED	SFY13 PROJECTED	SFY14 PROJECTED	AVG FEE
Contracts	\$55.81	\$57.88	\$60.87	\$63.59	\$66.64	\$60.88
Other Expenses	\$1.09	\$1.09	\$1.19	\$1.14	\$1.15	\$1.14
Personnel	\$8.34	\$8.34	\$8.70	\$8.79	\$9.02	\$8.64
<b>Total Fee</b>	<b>\$65.24</b>	<b>\$67.11</b>	<b>\$70.56</b>	<b>\$73.52</b>	<b>\$76.81</b>	<b>\$70.65</b>

### Proposed Fee - Increase Impact

HOSPITAL	ALL BIRTHS, 10/08 - 9/09	TOTAL ANNUAL INCREASE	UNCOMPENSATED BIRTHS	ANNUAL INCREASE UNCOMPENSATED BIRTHS
Fewest Births	82	\$1,722	42	\$882
Average	599	\$12,584	200	\$4,193
Most Births	2211	\$46,431	660	\$13,860



# Speakers





# Voting Sheets

# Senate Health and Human Services Committee

## EXECUTIVE SESSION

Bill # HB 1164

Hearing date: 4-13-10

Executive session date: 4-27-10

Motion of: OTP

VOTE: 4-0

<u>Made by</u>	Sgambati <input checked="" type="checkbox"/>	<u>Seconded</u>	Sgambati <input type="checkbox"/>	<u>Reported</u>	Sgambati <input type="checkbox"/>
<u>Senator:</u>	Gilmour <input type="checkbox"/>	<u>by Senator:</u>	Gilmour <input type="checkbox"/>	<u>by Senator:</u>	Gilmour <input type="checkbox"/>
	Kelly <input type="checkbox"/>		Kelly <input type="checkbox"/>		Kelly <input type="checkbox"/>
	Gallus <input type="checkbox"/>		Gallus <input checked="" type="checkbox"/>		Gallus <input checked="" type="checkbox"/>
	Downing <input type="checkbox"/>		Downing <input type="checkbox"/>		Downing <input type="checkbox"/>

Motion of: \_\_\_\_\_

VOTE: \_\_\_\_\_

<u>Made by</u>	Sgambati <input type="checkbox"/>	<u>Seconded</u>	Sgambati <input type="checkbox"/>	<u>Reported</u>	Sgambati <input type="checkbox"/>
<u>Senator:</u>	Gilmour <input type="checkbox"/>	<u>by Senator:</u>	Gilmour <input type="checkbox"/>	<u>by Senator:</u>	Gilmour <input type="checkbox"/>
	Kelly <input type="checkbox"/>		Kelly <input type="checkbox"/>		Kelly <input type="checkbox"/>
	Gallus <input type="checkbox"/>		Gallus <input type="checkbox"/>		Gallus <input type="checkbox"/>
	Downing <input type="checkbox"/>		Downing <input type="checkbox"/>		Downing <input type="checkbox"/>

<u>Committee Member</u>	<u>Present</u>	<u>Yes</u>	<u>No</u>	<u>Reported out by</u>
Senator Sgambati, Chairman	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Senator Gilmour, Vice-Chair	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Senator Kelly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Senator Gallus	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Senator Downing	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\*Amendments: \_\_\_\_\_

Notes: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# Committee Report

STATE OF NEW HAMPSHIRE  
SENATE  
REPORT OF THE COMMITTEE

Date: April 27, 2010

THE COMMITTEE ON Health and Human Services  
to which was referred House Bill 1164

AN ACT                   relative to newborn screening tests.

Having considered the same, the committee recommends that the Bill:

**OUGHT TO PASS**

BY A VOTE OF:   4-0

AMENDMENT #        s

Senator John T. Gallus  
For the Committee

Deb Chroniak 271-3096

## New Hampshire General Court - Bill Status System

**Docket of HB1164**

Docket Abbreviations

**Bill Title:** relative to newborn screening tests.*Official Docket of HB1164:*

<b>Date</b>	<b>Body</b>	<b>Description</b>
12/10/2009	H	Introduced 1/6/2010 and Referred to Health, Human Services and Elderly Affairs; <b>HJ 6</b> , PG.231
01/06/2010	H	Public Hearing: 1/27/2010 11:00 AM LOB 205
01/20/2010	H	Executive Session: 2/2/2010 10:00 AM LOB 205
02/02/2010	H	Committee Report: Ought to Pass for Feb 10 CC (vote 19-0); <b>HC 13</b> , PG.528
02/10/2010	H	Removed from Consent Calendar (Rep Vaillancourt); <b>HJ 16</b> , PG.748
02/10/2010	H	Special Ordered to Regular Place in Feb 17 Consent Calendar: MA Without Objection; <b>HJ 16</b> , PG.783
02/17/2010	H	Removed from Consent Calendar (Rep Kurk); <b>HJ 18</b> , PG.927
02/17/2010	H	Special Ordered to Next Session Day Beginning of Calendar: MA Without Objection; <b>HJ 18</b> , PG.1015
03/03/2010	H	Floor Amendment #0615h (Rep Kurk) Adopted, VV; <b>HJ 20</b> , PG.1090
03/03/2010	H	Ought to Pass with Amendment #0615h: MA VV; <b>HJ 20</b> , PG.1090
03/24/2010	S	Introduced and Referred to Health and Human Services; <b>SJ 11</b> , Pg.260
03/31/2010	S	Hearing: April 13, 2010, Room 103, State House, 8:45 a.m.; <b>SC14</b>
04/28/2010	S	Committee Report: Ought to Pass, 5/5/10; <b>SC18</b>
05/05/2010	S	Sen. Sgambati Floor Amendment 1650s, AA, VV
05/05/2010	S	Ought to Pass with Amendment 1650s, MA, VV; OT3rdg
05/05/2010	S	Passed by Third Reading Resolution
05/19/2010	H	House Concurs with Senate AM 1650s (Rep Rosenwald): MA VV
06/02/2010	H	Enrolled Bill Amendment #2138 Adopted
06/02/2010	S	Enrolled Bill Amendment #2138 Adopted
06/02/2010	H	Enrolled

NH House

NH Senate

Contact Us

*New Hampshire General Court Information Systems*  
 107 North Main Street - State House Room 31, Concord NH 03301

# Other Referrals

# COMMITTEE REPORT FILE INVENTORY

HB 1164 ORIGINAL REFERRAL \_\_\_\_\_ RE-REFERRAL

1. THIS INVENTORY IS TO BE SIGNED AND DATED BY THE COMMITTEE SECRETARY AND PLACED INSIDE THE FOLDER AS THE FIRST ITEM IN THE COMMITTEE FILE.
2. PLACE ALL DOCUMENTS IN THE FOLDER FOLLOWING THE INVENTORY IN THE ORDER LISTED.
3. THE DOCUMENTS WHICH HAVE AN "X" BESIDE THEM ARE CONFIRMED AS BEING IN THE FOLDER.
4. THE COMPLETED FILE IS THEN DELIVERED TO THE CALENDAR CLERK.

- DOCKET (Submit only the latest docket found in Bill Status)
- COMMITTEE REPORT
- CALENDAR NOTICE on which you have taken attendance
- HEARING REPORT (written summary of hearing testimony)
- HEARING TRANSCRIPT (verbatim transcript of hearing)  
List attachments (testimony and submissions which are part of the transcript) by number [1 thru 4 or 1, 2, 3, 4] here: \_\_\_\_\_
- SIGN-UP SHEET

ALL AMENDMENTS (passed or not) CONSIDERED BY COMMITTEE:  
\_\_\_\_ - AMENDMENT # \_\_\_\_\_ - AMENDMENT # \_\_\_\_\_  
\_\_\_\_ - AMENDMENT # \_\_\_\_\_ - AMENDMENT # \_\_\_\_\_

ALL AVAILABLE VERSIONS OF THE BILL:  
 AS INTRODUCED  AS AMENDED BY THE HOUSE  
 FINAL VERSION  AS AMENDED BY THE SENATE

\_\_\_\_ PREPARED TESTIMONY AND OTHER SUBMISSIONS (Which are not part of the transcript)  
List by letter [a thru g or a, b, c, d] here: \_\_\_\_\_

- EXECUTIVE SESSION REPORT
- \_\_\_\_ OTHER (Anything else deemed important but not listed above, such as amended fiscal notes):

IF YOU HAVE A RE-REFERRED BILL, YOU ARE GOING TO MAKE UP A DUPLICATE FILE FOLDER

DATE DELIVERED TO SENATE CLERK 8-5-10 *N. Deborah Kowal*  
COMMITTEE SECRETARY