

H.639

Vt. Dept. of Health-- no statutory authority to mandate infant screenings

Committee,

Thank you very much for the opportunity to testify on this important bill yesterday. As a follow up to my testimony, I have forwarded the email from VDH legal counsel David Englander which explains why VDH does not currently have the statutory authority to mandate the infant screenings.

I know the committee expressed an interest in hearing from VDH on this issue. I believe both David Englander and VDH newborn screening program chief Cindy Ingham would be good resources.

Regarding the interest by the committee in extending this requirement to midwives, I did some quick follow up with our national office and in WA last year, the midwives actually asked to be included in the legislation and CO is working on a bill now that adds them into the already passed pulse ox language. As I noted during my testimony, VDH has been working with midwives in Vermont to provide both pulse oximetry devices and training.

Please let me know if there is anything further I can provide.

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

From: Tina Zuk
Sent: Tuesday, December 22, 2015 11:56 AM
To: Englander, David <David.Englander@vermont.gov>
Subject: RE: clarification requested on infant screening issue

That is fantastic. Of course we'll support it.

Tina Zuk
Government Relations Director, Vermont

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

From: Englander, David [mailto:David.Englander@vermont.gov]
Sent: Tuesday, December 22, 2015 11:55 AM
To: Tina Zuk <tina.zuk@heart.org>

Subject: RE: clarification requested on infant screening issue

Tina:

The Department agrees and we are drafting a legislative proposal to this effect, which is part of a larger proposal, all of which we hope the American Heart Association will support. I will be in touch at the beginning of the Session with language.

Thank you for your thoughtful engagement on this issue.

Best,
David

David Englander
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From: Tina Zuk [tina.zuk@heart.org]
Sent: Tuesday, December 22, 2015 11:35 AM
To: Englander, David
Subject: RE: clarification requested on infant screening issue

Hi David,

I really appreciate this feedback concerning what Vermont statutes actually require and allow VDH to do regarding infant screening.

The American Heart Association and American College of Cardiology has discussed this and very much appreciates VDH's intent to include CCHD in the infant screenings, however, our organizations still do not believe the proposed rule goes far enough since VDH does not have the authority to require hospitals to do the screening. In fact, the statutes actually require the health commissioner to collect the data but doesn't give the commissioner the tools that he/she needs to be compliant with the statute, i.e. the ability to require hospitals to submit it to VDH.

We need to ensure that these infant screenings are performed at Vermont hospitals and not risk the case that there may ever be a time that a hospital CEO may for some reason choose to only submit data that they are required to submit and therefore not perform an infant screening such as CCHD that we believe is critical. Therefore, we will also be pursuing legislation to give VDH the authority it needs. Will VDH support such legislation?

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[http://www.healthierkidsbrighterfutures.org/images/Header.png]

Preventing obesity is why

[cid:image006.jpg@01CFACA2.0B004440]

From: Englander, David [mailto:David.Englander@vermont.gov]
Sent: Tuesday, December 22, 2015 8:51 AM
To: Tina Zuk <tina.zuk@heart.org>
Subject: RE: clarification requested on infant screening issue

Tina:

I completely understand; I too was confused when we first starting digging into the issue not having read this section of statute. (And, for my part, the reason I never mentioned it in our earlier discussions.) To know one's surprise, the relevant sections are quirkily drafted. The Department of Health is authorized to work with the medical profession to develop and early case-finding system (See 18 V.S.A. § 115) and collect information related to identified conditions (See 18 V.S.A. § 5087). That is, we can request that certain screenings be done, but can require the reporting of the results of such screenings.

Best,
David

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§ 115. Chronic diseases; study; program

(a) The Department of Health may, in the discretion of the Commissioner, accept for treatment children who have chronic diseases such as cystic fibrosis and severe hemophilia.

(b) The State Board of Health is authorized to:

(1) study the prevalence of chronic disease;

(2) make such morbidity studies as may be necessary to evaluate the over-all problem of chronic disease;

- (3) develop an early case-finding program, in cooperation with the medical profession;
 - (4) develop and carry on an educational program as to the causes, prevention and alleviation of chronic disease;
 - (5) integrate this program with that of the State rehabilitation center where possible, by seeking the early referral of persons with chronic disease, who could benefit from the State rehabilitation program.
- (c) The State Board of Health is directed to consult and cooperate with the medical profession and interested official and voluntary agencies and societies in the development of this program.
- (d) The Board is authorized to accept contributions or gifts which are given to the State for any of the purposes as stated in this section, and the Department is authorized to charge and retain monies to offset the cost of providing newborn screening program services.

§ 5087. Establishment of birth information network

- (a) The Commissioner of Health shall establish a statewide birth information network designed to identify newborns who have specified health conditions which may respond to early intervention and treatment by the health care system.
- (b) The Department of Health is authorized to collect information for the birth information network for the purpose of preventing and controlling disease, injury, and disability. The Commissioner of Health, in collaboration with appropriate partners, shall coordinate existing data systems and records to enhance the network's comprehensiveness and effectiveness, including:
- (1) vital records (birth, death, and fetal death certificates);
 - (2) the children with special health needs database;
 - (3) newborn metabolic screening;
 - (4) universal newborn hearing screening;
 - (5) the Hearing Outreach Program;
 - (6) the cancer registry;
 - (7) the lead screening registry;
 - (8) the immunization registry;
 - (9) the special supplemental nutrition program for women, infants, and children;
 - (10) the Medicaid claims database;
 - (11) the hospital discharge data system;
 - (12) health records (such as discharge summaries, disease indexes, nursery logs, pediatric logs, and neonatal intensive care unit logs) from hospitals, outpatient specialty clinics, genetics clinics, and cytogenetics laboratories; and
 - (13) the Vermont health care claims uniform reporting and evaluation system.
- (c) [Repealed.]
- (d) The network shall provide information on public health activities, such as surveillance, assessment, and planning for interventions to improve the health and quality of life for Vermont's infants and children and their families. This information shall be used for improving health care delivery systems and outreach and referral services for families with children with special health needs and for determining measures that can be taken to prevent further medical conditions.
- (e) The network shall be designed to follow infants and children up to one year of age with the 40 medical conditions listed in the matrix developed by the Birth Information Council which have been selected as identifiable via existing Vermont data systems and are considered to be representative of the most significant health conditions of newborns in Vermont, including

conditions relating to upper and lower limbs. The Department of Health is authorized to amend the list of medical conditions through rulemaking pursuant to 3 V.S.A. chapter 25 to meet the objectives of this section.

(f) The network's data system shall be designed to coordinate with the data systems of other states so that data on out-of-state births to Vermont residents will be captured for vital records, case ascertainment, and follow-up services. The Commissioner of Health is authorized to enter into interstate agreements containing the necessary conditions for information transmission.

(g) The Commissioner of Health shall compile information every two years to document possible links between environmental and chemical exposure with the special health conditions of Vermont's infants and children.

(h) The Department of Health shall develop a form that contains a description of the birth information network and the purpose of the network. The form shall include a statement that the parent or guardian of a child may contact the Department of Health and have his or her child's personally identifying information removed from the network, using a process developed by the Advisory Committee.

From: Tina Zuk [mailto:tina.zuk@heart.org]
Sent: Tuesday, December 22, 2015 5:39 AM
To: Englander, David
Subject: clarification requested on infant screening issue
Importance: High

Hi David,

Can you provide me with additional information on the following regarding what authority VDH has in requiring hospitals to screen for diseases?

When I testified Friday at the public hearing on the newborn screening rule, Lillian and Cindy were surprised to hear that we interpreted the proposed rule to mean that the 29 diseases listed first were required to be tested for and that CCHD and hearing loss were only recommended. They noted that they understood how we could interpret the rule that way but then Lillian explained the following.

She said that VDH actually doesn't have the authority by statute to say hospitals "shall" test for any disease, but that VDH can recommend what diseases should be included on a newborn screening panel and it is recommending that all of the diseases and conditions mentioned in the proposed rule, including CCHD, be included in Vermont's infant screening panel.

However, she said the "shall" that is noted in section 4.2 means that the lab that does the testing from the dried blood spots shall test for those listed diseases from the blood spots and that VDH has the authority to require the lab to test for the diseases but can't mandate that hospitals test for the diseases.

Lilian said VDH is saying in the rule that those 29 diseases and CCHD and hearing loss all "should" be included in the infant screenings, and that the word "should" in section 4.1 in the following sentence, is where they are saying all of the diseases "should" be tested for.

Health care providers should perform screening tests on newborn infants unless the parent, guardian or custodian of the newborn refuses screening.

I'm glad that VDH is recommending that CCHD be included in the newborn screening panel, but found it odd that this statute/authority issue was never mentioned before in any of our discussions with VDH about pulse oximetry testing and VDH rulemaking so I wanted to reach out further and ask if you could clarify and direct me to the statute that Lilian referred to. Thanks so much.

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