SB

87

<TARGET><BILL>SB 87</BILL><SUBJECT>SB 87</SUBJECT><COMM>HHSS28</COMM></TARGET>

ALASKA STATE LEGISLATURE

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SENATOR PETER A. MICCICHE

DISTRICT O

Anchor Point
Clam Gulch
Cohoe
Diamond Ridge
Fox River
Fritz Creek
Funny River
Halibut Cove
Happy Valley
Homer
Kachemak City
Kachemak Selo
Kalifornsky
Kasilof
Kenai
Nikolaevsk
Ninilchik
Razdolna
Ridgeway
Seldovia
Soldotna
Voznesenka

SPONSOR STATEMENT
CS SB 87 (HSS) -NEWBORN SCREENING FOR HEART DEFECTS

Every week Alaska babies are discharged from hospitals with undetected heart problems. Approximately 115 Alaska babies will be born this year with congenital heart defects – the number one killer of infants with birth defects, according to the American Heart Association.

In September of 2011, the US Secretary of Health and Human Services recommended that all newborns be screened for critical congenital heart disease (CCHD) prior to being discharged from the birth hospital. That recommendation is endorsed by the American Academy of Pediatrics, March of Dimes, American Heart Association and the Newborn Coalition.

Newborn screening for CCHD uses pulse oximetry – a simple, noninvasive, and effective test to measure the percent of oxygen in the blood. This screening costs less than a diaper change in the newborn nursery and is conducted in most nurseries at bedside, using existing staff and, most often, existing equipment. Pulse oximetry, *recognizable as the finger clip with a blue light affixed on adult hospital patients*, is considered the 5th vital sign by most clinicians – as simple and valuable as a blood pressure or temperature reading.

This bill will require larger hospitals, beginning in January 2014, to test newborns with pulse oximetry. Birthing centers, smaller hospitals, midwives and other birth attendants with fewer than 20 births per year will have until January 2016 in the event they require additional time to acquire the necessary equipment. Parents will have the option of declining the testing.

In the event the tests shows abnormal results, the attending physician, direct-entry midwife or other qualified health care professional will advise the parents of the necessity for intervention treatment.

Most health insurance plans will cover the small cost under AS 21.42.351 Coverage for well-baby exams, and other state statutes. Medicaid patients will see the cost covered as well. Early diagnosis and intervention of those born with CCHD tend to lower cost of treatment.

Additionally, the bill provides a mechanism for the health care professional to report newborn pulse oximetry screening results to the public health community, through the Department of Health and Social Services, a critical step in understanding and treating the detected defect.

This bill is vital to support timely and effective implementation of newborn screening for the most critical heart defects for babies born in the state's hospitals and birthing centers.

This bill is a relatively simple step that will save many young Alaskans' lives.

E-Mail: Senator.Peter.Micciche@akleg.gov

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Sectional Analysis
CS SB 87 Version "Y"-NEWBORN SCREENING FOR HEART DEFECTS

Section 1 – Adds a new section to AS 18.15 Disease Control and Threats to Public Health, AS 18.15.205 is titled: Screening for congenital heart disease

Subsection (a) requires that a provider of birthing services (defined in subsection (f)) in Alaska conduct a pulse oximetry test on newborns as close to 24 hours after birth as reasonably feasible.

(b) requires the provider to conduct or order confirmatory testing in cases where the initial test was abnormal. Also requires physician, midwife or other qualified profession to advise parents of the necessity of intervention treatment.

(c) requires the provider to report test results to the parents and to report to the Department of Health and Social Services, whether the test was performed and the results of the test.

(d) requires the provider to provide information on the screening to the parents and allow parents to opt out.

(e) requires DHSS to set up a system for facilities to submit reports on the number of screenings performed and the results of those screenings.

(f) defines "provider of birthing services" as a physician, midwife, nurse or other qualified professional who attends births as part of their normal practice.

Section 2 – provides smaller hospitals, clinics, birthing centers and home delivery providers – providers who attend to less than 20 births annually, an extra two years (until January 1, 2016) to comply with the law in the event new equipment must be acquired.

Section 3 – provides larger hospitals and the department at least six months to implement the testing, setting the effective date at January 1, 2014.

E-Mail: Senator.PeterMicciche@akleg.gov

Fiscal Note

State of Alaska
2013 Legislative Session

Bill Version: CSSB 87(HSS)
Fiscal Note Number: 1
(S) Publish Date: 4/6/13

Identifier: CSSB087(HSS)-WCFH-4-4-13
Title: NEWBORN SCREENING FOR HEART DEFECTS
Sponsor: MICCICHE
Requester: Senate Health & Social Services Committee

Department: Department of Health and Social Services
Appropriation: Public Health
Allocation: Women, Children and Family Health
OMB Component Number: 2788

Expenditures/Revenues

Note: Amounts do not include inflation unless otherwise noted below. (Thousands of Dollars)

	FY2014 Appropriation Requested	Included in Governor's FY2014 Request	Out-Year Cost Estimates				
OPERATING EXPENDITURES	**FY 2014**	**FY 2014**	**FY 2015**	**FY 2016**	**FY 2017**	**FY 2018**	**FY 2019**
Personal Services							
Travel							
Services							
Commodities							
Capital Outlay							
Grants & Benefits							
Miscellaneous							
Total Operating	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**

Fund Source (Operating Only)

None							
Total	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**

Positions

Full-time							
Part-time							
Temporary							

Change in Revenues							

Estimated SUPPLEMENTAL (FY2013) cost: 0.0

Estimated CAPITAL (FY2014) cost: 0.0

ASSOCIATED REGULATIONS

Does the bill direct, or will the bill result in, regulation changes adopted by your agency? Yes
If yes, by what date are the regulations to be adopted, amended or repealed? 06/30/14

Why this fiscal note differs from previous version:

This fiscal note reflects the most current CSSB087(HSS) version which removes most of the reporting requirements and clarifies the department's role. The result is a zero fiscal note.

Prepared By: Kerre Fisher, Acting Director — Phone: (907)269-2042
Division: Public Health — Date: 04/02/2013 12:00 PM
Approved By: Sarah Woods, Deputy Director — Date: 04/04/13
Finance & Management Services

STATE OF ALASKA
2013 LEGISLATIVE SESSION

BILL NO. CSSB 87(HSS)

Analysis

This bill amends AS 18.15 to add a new section (AS 18.15.205) to require all providers of birthing services to screen all newborns for congenital heart defects as close to 24 hours after birth as is feasible, or before discharge; order or perform confirmatory testing and intervention for all infants who have abnormal screening results; and report screening results to the parents/guardians and department. Parents or legal guardians are provided information on screening/testing by the provider and may refuse screening or testing. The department is required to establish procedures for submitting reports and summarizing data. Providers who attend fewer than 20 births a year do not have to implement the practice for two years.

The previous fiscal note (Version "C") assumed that the department would implement this bill as a comprehensive newborn screening program modeled on existing newborn hearing and metabolic screening programs in the Division of Public Health. The most current version clarifies that the department's role is limited to collecting and summarizing data. This fiscal note assumes that aggregate data will be reported annually by facility and analysis by the division is limited to counts of births and screenings. The currrent version applies to all providers of birthing services. The previous version applied only to licensed providers. This increases the volume of data the department will collect. Based on experience with other newborn screening programs, likely most parents/guardians will opt to have the pulse oximetry test. It is expected this volume of aggregate annual data can be handled with existing resources, if limited data is reported.

Costs for the screening test would be billed to insurance companies by providers of birthing services if the parent's insurance provides coverage. For Medicaid enrollees, costs would be included in global fees already paid for delivery services so no additional cost for benefits is anticipated.

New regulations will need to be established following national standard of care guidelines surrounding the screening, referral, and diagnosis of congenital heart defects for children with abnormal screening results and the data reporting.

Sectional Analysis

CS SB 87 (HSS)-NEWBORN SCREENING FOR HEART DEFECTS

Section 1 – Adds a new section to AS 18.15 Disease Control and Threats to Public Health, AS 18.15.205 is titled: Screening for congenital heart disease

Subsection (a) requires that a provider of birthing services (defined in subsection (f)) in Alaska conduct a pulse oximetry test on newborns as close to 24 hours after birth as reasonably feasible.

(b) requires the provider to conduct or order confirmatory testing in cases where the initial test was abnormal. Also requires physician, midwife or other qualified profession to advise parents of the necessity of intervention treatment.

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(d) requires the provider to provide information on the screening to the parents and allow parents to opt out.

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(f) defines "provider of birthing services" as a physician, midwife, nurse or other qualified professional who attends births as part of their normal practice.

Section 2 – provides smaller hospitals, clinics, birthing centers and home delivery providers – providers who attend to less than 20 births annually, an extra two years (until January 1, 2016) to comply with the law in the event new equipment must be acquired.

Section 3 – provides larger hospitals and the department at least six months to implement the testing, setting the effective date at January 1, 2014.

American Heart Association.
Learn and Live℠

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www.heart.org

April 10, 2013

The Honorable Pete Higgins, Chair
House Health and Social Services Committee
State Capitol, Room 424
Juneau, AK 99801

RE: SB 87 (Micciche) – Support

Dear Chair Higgins:

On behalf of the American Heart Association (AHA), I urge your support of SB 87. As you know, this bill will require all newborns to be screened for critical congenital heart disease (CCHD) prior to discharge from the hospital.

CCHD can range in severity from simple holes in the heart or murmurs to severe malformations, such as the complete absence of one or more chambers or valves. Some CCHD can cause severe and life-threatening symptoms that require intervention within the first days of life.

Congenital heart defects are the leading birth defects affecting newborns in the United States, but early detection using pulse oximetry and prompt treatment can make all the difference. In fact, new research suggests wider use of pulse oximetry screening could help identify more than 90 percent of heart defects.

Pulse oximetry is a non-invasive test that measures the amount of oxygen in the baby's blood, as well as pulse rate. It is relatively quick, costs are minimal, and it has been proven to be effective in detecting CCHD. Many hospitals have begun screening every newborn. However, we need to ensure that all babies are afforded the same opportunity and that there is consistency in how the test is administered across hospitals.

The AHA supports SB 87 because requiring pulse oximetry screening for all newborn babies will save lives and will substantially reduce the long-term economic impact of CCHD. Please vote "aye" on this bill when it comes before you.

Sincerely,

Jamie Morgan

Jamie Morgan
Senior Government Relations Director

Cc: Members of the House Health and Social Services Committee, Senator Micciche

American Heart Association | American Stroke Association

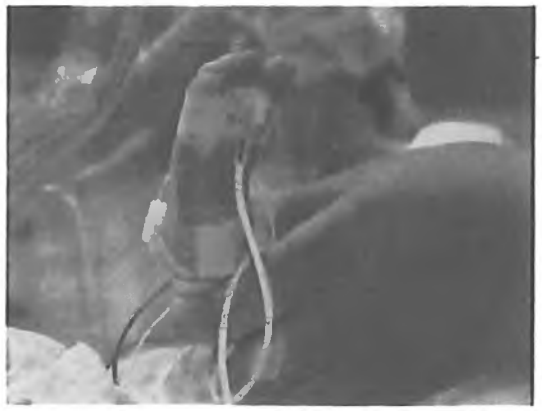
Newborn Screening of Heart Defects- Pulse Oximetry Screening for Critical Congenital Heart Defects (CCHD)

Congenital heart defects are the number one killer of infants with birth defects.[1]
Congenital heart defects are structural abnormalities of the heart that are present at birth. These defects range in severity from simple holes or murmurs to severe malformations, such as the complete absence of one or more chambers or valves. Some critical congenital heart defects can cause severe and life-threatening symptoms which require intervention within the first days of life.

Pulse oximetry screening is effective at determining life-threatening heart defects.[4]
Pulse oximetry screening is a non-invasive test that estimates the percentage of hemoglobin in blood that is saturated with oxygen. When performed on newborns in the delivery center it is effective at detecting life-threatening defects which otherwise can go undetected by current screening methods.

'Positive' screenings require additional follow-up.
If a baby's test results show low levels of oxygen in the blood this can be a sign of a CCHD. This does not always mean that the baby has a CCHD, it just means that more testing is needed.

Pulse oximetry screening is cost effective and offers a positive return on investment.
One study calculated that the savings in healthcare costs from the prevention of one case of complications of circulatory collapse resulting from an undiagnosed CCHD may exceed the cost of screening two thousand newborns.[5]



Current, commonly used, detection methods identify less than half of all newborn cases.[2]
Current methods for detecting congenital heart defects generally include prenatal ultrasound screening and repeated clinical examinations can identify many affected newborns. However, these screenings alone, identify less than half of all cases, and critical heart defect cases are often missed during routine clinical exams performed prior to a newborns discharge from a birthing facility.

Secretary of Health & Human Services recommends pulse oximetry screening.[3]
In a September 21, 2011 letter, HHS Secretary Kathleen Sebelius recommended that pulse oximetry screening to be included as part of the Recommended Uniform Screening Panel for Newborns (RUSP). The American Heart Association stands ready to serve as a resource for those states that move forward to implement the Secretary's recommendations.

References

1. Xu J, Kochanek KD, Murphy SL, Tejada-Vera B. Deaths: Final data for 2007. National Vital Statistics Reports. 2010;58(19). Hyattsville, MD: National Center for Health Statistics. [Read article]

2. Knapp, AA, Metterville, DR, Kemper, AR, Prosser, L, Perrin, JM. Evidence review: Critical congenital cyanotic heart disease, Final Draft, September 3, 2010. Prepared for the Maternal and Child Health Bureau, Health Resources and Services Administration http://archpedi.ama-assn.org/cgi/content/full/162/10/969

3. http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/recommendations/correspondence/cyanoticheartsecre09212011.pdf

4. http://www.cdc.gov/ncbddd/pediatricgenetics/documents/CCHD_one_pager.pdf

5. de-Wahl Granelli A, Wennergren M, Sandberg K, Mellander M, Bejlum C, et al. Impact of pulse-oximetry screening on the detection of duct-dependent congenital heart disease: a Swedish prospective screening study in 39,821 newborns. *BMJ.* 2009;338:a3037

About Congenital Heart Defects

Congenital Heart Defects (CHDs) are both the most common and the most lethal birth defects, accounting for 24% of all infant deaths due to birth defects and affecting more than 650 newborn infants and their families each year in Minnesota. Approximately 25% of heart defects are referred to as Critical Congenital Heart Defects (CCHD), requiring intervention in the first days, weeks or months of life. A major cause of infant mortality as a result of CCHD is that a significant number of children appear healthy at first and are not detected as having heart disease in the newborn nursery.

Two babies are born each day in Minnesota with a heart defect. Only one of them will be diagnosed prenatally. The other baby has a 30-40% risk of being discharged from the hospital with an undiagnosed heart defect.

Early diagnosis can reduce rates of death or disability and the costs associated with delayed diagnosis - including surgical compromise, neurological impairment, developmental delay, organ failure, and long-term feeding issues. Rural and underserved populations are particularly vulnerable to missed or delayed diagnosis - and have significantly lower rates of prenatal detection.

Pulse oximetry is simple, non-invasive, and painless, requiring no blood draw or specimen collection.

About Newborn Screening for CCHD using Pulse Oximetry

Referred to by clinicians as the "5th vital sign", pulse oximetry is a simple, non-invasive, bedside where sensors are placed on the baby's hand and foot to determine their pulse rate and the amount of oxygen in their blood. Pulse oximetry takes just minutes, is about the cost of a diaper change, and is as simple as taking a baby's temperature or blood pressure.

Pulse oximetry is effective at detecting critical, life-threatening CCHD when performed at approximately 24 hours of age and used along with physical examination. These heart defects would otherwise go undetected by current screening methods. Newborns with abnormal pulse oximetry results require immediate confirmatory testing, intervention, and specialized care to help prevent disability and death early in life.

"It's a rare day when you know a piece of legislation you signed saved a life,"

Baby Dylan's life-threatening heart defect was detected with pulse ox screening on the very first day of implementation in New Jersey.

Universal Support

CCHD screening of newborns has been recently adopted by the Secretary of Health and Human Services for inclusion in the Uniform Screening Panel (RUSP), and has also been endorsed by the American Academy of Pediatrics, the American Heart Association and the American College of Cardiology.

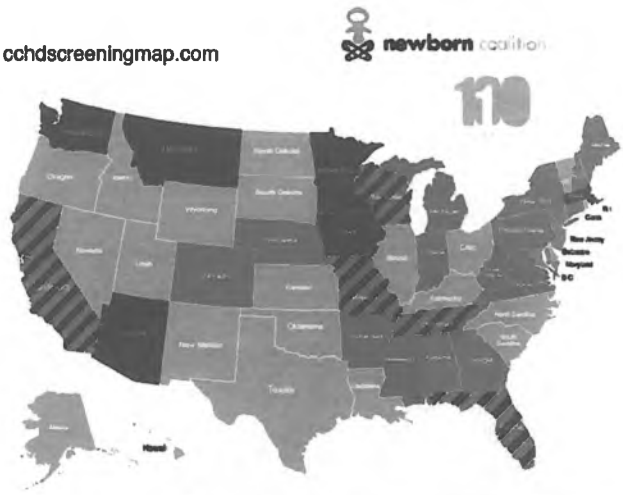
This simple, non-blood-spot screening has now been implemented for all newborns in 3 states, required in 6 states, and an additional 12 states have legislation introduced. http://www.cchdscreeningmap.com/.

"My baby went 4 and a half weeks undiagnosed despite our complaints of poor eating, and breathing strangely! He saw 4 different pediatricians, after the two he saw in the hospital and no one bothered with a pulse ox because I was a first time, very tired mother. He nearly died in our arms 3 days after his one-month check up! Inexcusable!!! What is the extra expense of babies like Gunner who then was so critical that he required a life flight and weeks of life support? Had the defect been caught initially, our entire family could have endured less trauma. Thank God we still have him and he is healthy, that is ONLY because of God's grace. I know there are too many others who are not so lucky."

Minnesota Model

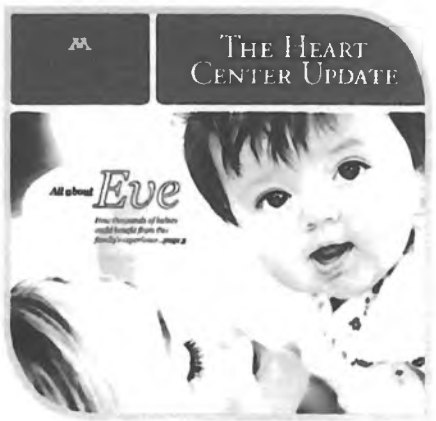
Physicians, hospitals, and advocates clearly understand the importance of early detection of newborn diseases and disorders in saving lives and reducing healthcare cost burdens associated with late diagnosis. Minnesota can build on its successful **Newborn Heart Screening Pilot Program** by requiring each licensed hospital or birthing facility to provide that all newborns are, prior to discharge, but as much as is feasible, at 24 hours of age or later, screened for congenital heart disease as a standard of care.

Within less than two years, Minnesota's evidence-based protocol and implementation toolkit was developed, resulting in nearly 20% of Minnesota newborns being screened for heart defects before discharge. This program has garnered national attention, and was critical to the recent federal recommendation from the U.S. Department of Health and Human Services that all newborns be screened for CCHD.



- Newborn heart screening would not require testing to be done in the health department laboratory, eliminating the need to purchase additional equipment or provide staff for this screening.
- It is assumed that the immediate follow up of patients with failed screens will occur within the provider setting, with limited resources required by the Department of Health.
- Pulse oximetry testing is currently a covered benefit when determined medically necessary by most public and private payers.

Sources: Centers for Disease Control and Prevention, U.S. Department of Health and Human Services, Newborn Coalition, 1in100



"CHD is the most common birth defect leading frequently to death or severe morbidity. Studies suggest that early recognition of critical congenital heart disease (CCHD) is a significant and potentially modifiable risk factor, but tragically, the diagnosis of a CCHD is often missed. Newborn screening with pulse oximetry is a promising tool to narrow the diagnostic gap. We continue to make progress in our region, implementing pulse oximetry screening one hospital at a time. This piecemeal approach leaves too many newborns and their parents vulnerable. Leadership is needed to ensure all newborns, regardless of which hospital they are born in, are screened for critical congenital heart disease." ~ Lazaros Kochilas, MD, U of M Pediatric Cardiology, MN Newborn Heart Screening Pilot Program

Eve's Story

Eve Isley Saarinen was diagnosed at two days old with critical congenital heart disese (CCHD) and associated Wolff-Parkinson-White Syndrome. Eve spent her first 5 months in 4 different hospitals and underwent two heart surgeries, 6 transfusions, and more than 120 episodes of SupraVentricular Tachycardia. Because of early intervention and excellent medical care, Eve is expected to lead a full and normal life. Although she may still have to undergo more cardiac care or surgeries, she has proven to be a very resilient and happy child. Following her surgeries, Eve's family established the CHD community 1in100, and collaborated with Minnesota physicians, advocates, and the state Department of Health in establishing a landmark pilot program to screen newborns for heart defects using pulse oximetry. Eve's mother, Annamarie Saarinen, went on to spearhead a federal recommendation from the Department of Health and Human Services which has resulted in the recommendation that all newborns in the United States should be screened for CCHD. That recommendation has also been formally endorsed by the American Academy of Pediatrics, the American Heart Association, and the American College of Cardiology.

National Conference of State Legislatures

LEGISBRIEF

BRIEFING PAPERS ON THE IMPORTANT ISSUES OF THE DAY

DECEMBER 2012

VOL. 20, NO. 47

Newborn Health Screenings

By Austin Rueschhoff

Every year, thousands of infants are born with serious genetic disorders that can be identified by testing just a few drops of blood. State newborn screening programs test about 4 million infants annually for genetic disorders and other health problems that are not apparent at birth. Early detection of many disorders can not only prevent disabilities, additional health problems or death, they may also save states and families money by avoiding high medical costs and using other state services.

Did You Know?

- Newborn screening first started when a screen was developed for phenylketonuria (PKU) in the 1960s. Today, screening is available for more than 60 conditions.
- Each year, about 12,500 infants are diagnosed with a core condition on the Uniform Newborn Screening Panel.
- Early detection of genetic disorders can save money for states and families.

Newborn screening also detects conditions such as hearing, hormonal and blood disorders. By the time symptoms for these conditions appear, they often are irreversible and can lead to severe health problems, developmental disabilities, mental retardation or even death. To identify most of these problems soon after birth, blood samples are collected from newborns through a small heel-prick—typically before the baby leaves the hospital. According to a 2003 study by the Government Accountability Office, states spend an average of $30 per infant on screening. Early detection and treatment of newborn conditions, however, often can prevent future state costs for medical, educational and support services.

Although states determine newborn screening requirements, they often rely on national recommendations. In 2006, the U.S. Department of Health and Human Services (HHS) developed the Uniform Newborn Screening Panel, a list of tests based on recommendations by the American College of Medical Genetics and supported by the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children. Today, the recommended panel consists of 31 core and 26 secondary conditions. Guidelines for selecting core conditions consider the tests' ability to detect the condition soon after birth, the availability of an effective test, and the benefits of early detection and treatment. Secondary conditions are disorders that may be detected through further examination of core condition screening results.

State Action

Each state determines the disorders required for screening, appropriates funding sources for the programs and designs initiatives to educate parents. Currently, all states require screens for at least 26 of the federally recommended core conditions; state testing requirements for secondary conditions range from none to all 26.

Because the federal advisory committee has added recommendations, some states have included these conditions in their requirements. In 2010 and 2011, for example, the committee added screenings for critical congenital heart disease (CCHD) and severe combined immunodeficiency disorder (SCID) to the Uniform Newborn Screening panel. Since 2011, Connecticut, Indiana, Maryland, New Hampshire, New Jersey, Tennessee and West Virginia

National Conference of State Legislatures

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have passed laws requiring newborn screening for CCHD, while a California law requires that the test be offered. During the 2011-2012 legislative session, California, Illinois and Missouri enacted legislation to include screening for SCID. Some other states have required the screens through state agency regulations or other means; a few states are studying or considering the issue.

After testing is complete, some states retain blood samples for research, data collection and birth defect registries to help identify birth defect causes and prevalence. To protect patient privacy, many state laws require that genetic material remain private unless parents give informed consent for the sample to be used for purposes other than screening their child. Some states also regulate how long the samples should be stored—some for only a few weeks, and some indefinitely—and proper disposal methods to ensure genetic information remains private. Finally, laws in many states allow parents to opt out of newborn screening programs entirely if it is against their religious or philosophical beliefs.

Policymakers play important roles in follow-up activities—ensuring additional diagnostic tests or specialty care, providing access to needed treatment and informing parents about services available to children with special health care needs. For example, many states require insurance companies to provide coverage for infant formula specifically designed for metabolic disorders, at an average annual cost of $7,100.

Federal Action

Medicaid covers newborn screening as one of the many services required by the Early Periodic Screening, Diagnosis and Treatment benefit. Under the benefit, states have some flexibility. They are not required to cover all the recommended tests in the Uniform Screening Panel. The benefit requires Medicaid to cover further testing services and medically necessary care for treatable abnormal screening results.

The Patient Protection and Affordable Care Act also expands access to newborn screening by requiring insurance coverage of specified preventive services for children without cost sharing (such as copayments and co-insurance, for example). Under this provision, most private health insurance plans now must cover all newborn screens on the Uniform Screening Panel without cost sharing, even in states that do not require screens for all listed conditions.

NCSL Contacts and Resources

Austin Rueschhoff
NCSL—Denver
(303) 856-1395

Insurance Coverage of Medically Necessary Foods and Formula to Treat Disorders Identified Through Newborn Screening

Newborn Genetic and Metabolic Screening State Laws

Newborn Hearing Screening State Laws

Other Resources

Centers for Disease Control and Prevention: Newborn Screening

National Newborn Screening and Genetics Resource Center

Baby's First Test

American Heart Association.
Learn and Live.

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April 4, 2013

The Honorable Peter Micciche
State Senator, District O
State Capitol, Room 125
Juneau, AK 99801

RE: SB 87 (Micciche) – Support

Dear Senator Micciche:

The American Heart Association (AHA) is pleased to support SB 87. As you know, this bill will require all newborns to be screened for critical congenital heart disease (CCHD) prior to discharge from the hospital.

CCHD can range in severity from simple holes in the heart or murmurs to severe malformations, such as the complete absence of one or more chambers or valves. Some CCHD can cause severe and life-threatening symptoms that require intervention within the first days of life and directly correspond with extensive and expensive treatment.

Congenital heart defects are the leading birth defects affecting newborns in the United States, but early detection using pulse oximetry and prompt treatment can make all the difference. In fact, new research suggests wider use of pulse oximetry screening could help identify more than 90 percent of heart defects.

Pulse oximetry is a non-invasive test that measures the amount of oxygen in the baby's blood, as well as pulse rate. It is relatively quick, costs are minimal, and it has been proven to be effective in detecting CCHD. Many hospitals have begun screening every newborn. However, we need to ensure that all babies are afforded the same opportunity and that there is consistency in how the test is administered across hospitals.

The AHA supports SB 87 because requiring pulse oximetry screening for all newborn babies will save lives and will substantially reduce the long-term economic impact of CCHD. Thank you for your leadership on this issue.

Sincerely,

Jamie Morgan

Jamie Morgan
Senior Government Relations Director

Cc: Members of the State Senate

March of Dimes Foundation

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Telephone (907) 276-4111
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marchofdimes.com/alaska

Janie Odgers
State Director

April 4, 2013

To the Alaska Legislature:

On behalf of the March of Dimes, we are honored to support HB184 & SB87 and respectfully ask for your "yes" vote when this bill comes before your committee. This legislation would require all newborns in Alaska to be screened for Critical Congenital Heart Disease (CCHD).

Quite simply, HB184 & SB87 will save lives. According to the Alaska Department of Health & Social Services is it estimated 1 in 100 babies will be born in the state with a congenital heart defect. For those infants, death can be prevented if the CCHD is detected and treated earlier.

The mission of the March of Dimes is to improve the health of women of childbearing age, infants, and children by preventing birth defects, premature birth, and infant mortality. March of Dimes has been instrumental in expanding newborn screening and is supportive where there is a documented medical benefit to early detection, a reliable screening test, and early detection can be done through specific means, all of which exist for CCHD screening.

Congenital heart disease is the number one cause of infant deaths from birth defects. CCHD is a subgroup of congenital heart disease that affects approximately 4,800 babies born in the United States each year. Babies with CCHD have a heart defect that requires intervention, such as surgery, in the first few hours, days, or months of life. In September 2011, the Secretary of the U.S. Department of Health and Human Services added screening for CCHD to the Recommended Uniform Screening Panel (RUSP). CCHD screening is done through a simple, non-invasive test called "pulse oximetry" that can detect CCHD before a baby shows signs of the condition, allowing for the proper treatment to be given to prevent disability or death.

Therefore, in order to ensure Alaska's newborn screening panel include all conditions recommended by the RUSP, we respectfully ask that HB184 & SB87 be amended to include the word "critical" before "congenital heart disease" and that you vote in favor of HB184 & SB87. Thank you for your efforts to protect the lives of babies born in Alaska and we look forward to working with you on this critical legislation.

Sincerely,

Janie Odgers
State Director

march of dimes

Paul Verhagen

From: Christiansen, James <james.christiansen@seattlechildrens.org>
Sent: Thursday, March 28, 2013 9:23 AM
To: Sen. Peter Micciche
Subject: Pulse oximetry screening legislation

Dear Senator Micciche,

I was surprised but heartened at the announcement of your legislation aimed at improving the detection of critical congenital heart disease in Alaska newborns. I have a very strong passion for this endeavor and would be happy to offer any assistance to you or your staff to educate and enlighten your fellow legislators about this important project. Recently we were involved with a baby who failed screening in the Fairbanks area who was discovered to have critical congenital heart disease. He subsequently had life-saving surgery and is doing very well.
Thank you for this important effort. Please don't hesitate to call me.

Sincerely,
James L. Christiansen MD
Pediatric Cardiology of Alaska
907-212-3655

Paul Verhagen

From: advocacy@mylegislators.com on behalf of R. Goodrich <scribing@hotmail.com>
Sent: Monday, April 01, 2013 7:01 PM
To: Sen. Peter Micciche
Subject: Please Support Pulse Oximetry Screening for Newborns

Dear Senator Peter Micciche:

Congenital heart defects are the leading birth defects affecting newborns in the United States. While some families are lucky to have their newborns screened before leaving the hospital, many will leave the hospital undiagnosed. Some of these babies won't live to see their first birthday and others will face a lifetime of surgeries, developmental delays and other complications.

Early detection and treatment of congenital heart defects can make all the difference. Recent science supports the use of pulse oximetry for the detection of certain critical congenital heart defects. Please support legislation to ensure all Alaska babies are screened for critical congenital heart defects at birth using pulse oximetry, an inexpensive, non-invasive screening tool.

Today advocates will testify at the Senate Health and Social Services Committee hearing, urging the legislature to adopt statewide pulse oximetry screening for newborns.

As a constituent and an American Heart Association volunteer, I urge you to help ensure every newborn is screened for critical congenital heart defects using pulse oximetry.

Sincerely,
R. Goodrich
9607 Musket Ball Cir
Anchorage, AK 99507-5389

Dr. Lily Lou, MD 1:30 pm, Monday April 1st **1-855-463-5009**

Medical Director of the Newborn Intensive Care Unit at The Children's Hospital at Providence (Anchorage)

Vice President of the Alaska Chapter of the American Academy of Pediatrics (AAP). **District VIII representative** to the executive committee of the AAP Section on Perinatal Pediatrics.

1) It puts evidence based medical practices into statute (evidence based medical practices change)

- **I believe that there is now strong evidence for this practice as a standard of care for newborns**

- **Legislating "evidence-based practice" is not necessarily the best way to assure up-to-date medical practice by physicians, but I would support any way of accomplishing the goal of screening for this serious and (usually) treatable condition for babies born in our state, where early detection greatly impacts outcomes. This is an example of a condition where early diagnosis makes a real difference in outcomes.**

2) It mandates pulse oximetry as the testing method, but does not address what happens if a new technology/new method is developed to detect CCHD

- **If we do pursue this route, there are two important points to consider:**

1. **Pulse oximetry is the *current* gold standard. If new technology is developed, the legislation must accommodate a way to update practice to the improved technique**

3) It says nothing about home births

2. **The bill, as written, does not address the important issue of babies born at home. If this is the right thing to do for babies, then it should include *ALL* infants born in Alaska.**

4) There is no fiscal note, or provision for support of this new activity

3. **Unfunded mandates place an unreasonable burden on the practitioner, and have limited practical success of achieving the desired goal of testing our babies**