HB

85

REPRESENTATIVE KEVIN MEYER

HOUSE DISTRICT 30

MEMORANDUM

DATE: **March 16, 2005**

TO: **Senator Fred Dyson, Chairman**
Senate Health, Educatio and Social Services Committee

FROM: **Representative Kevin Meyer**

RE: **Hearing request for CSHB 85 (JUD) *Prescribed Medication for Students*.**

Please schedule CSHB 85 (JUD) *Prescribed Medication for Students* for a hearing in the Senate Health, Education and Social Services committee at your earliest convenience.

CSHB 85 (JUD) requires schools to allow students' to self-administer medication for asthma and anaphylaxis with certain provisions.

Included in this packet:

- CSHB 85 (JUD) *Prescribed Medication for Students* v. LS-0367\Y
- Sponsor Statement
- Sectional Analysis
- Fiscal Note
- Change Summary
- CSHB 85 (HES) *Prescribed Medication for Students*
- HB 85 *Prescribed Medication for Students*
- Letters of support
    - American Academy of Pediatrics
    - Allergy and Asthma Network
    - Association of Alaska School Boards
    - Alaska Association of School Nurses
    - National Association of School Nurses
- Survey of Alaska School District Policies
- Asthmatic School-children's Treatment and Health Management Act of 2004
- American Journal of Public Health Article

Thank you for your consideration of this request.

Email: Representative_Kevin_Meyer@legis.state.ak.us • **Toll Free:** (866) 465-4945
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REPRESENTATIVE KEVIN MEYER

HOUSE DISTRICT 30

Sponsor Statement

CS for House Bill 85

"An Act relating to self-administration and documentation of certain types of medication prescribed to a child attending school."

Of the 20 million Americans with asthma, 6.3 million are children under the age of 18. This chronic condition is the cause of 728,000 emergency room visits, 214,000 hospitalizations and 223 deaths annually among children.

The "Asthmatic School-children's Treatment and Health Management Act" passed by Congress in 2004 directed the Secretary of Health and Human Services to give preference when awarding grants to states that authorize the self-administration of medication to treat students' asthma or anaphylaxis. Over thirty states have passed legislation to comply with the federal act.

House Bill 85 requires that schools permit students to self-administrate medication for asthma, anaphylaxis. A school must permit self-administration if:

- The school receives written authorization from a parent or legal guardian for the self-administration of the medication;
- Written certification from a pupil's health care provider;
- Release of liability for the school and its employees or agents for injury arising from self-administration.
- A treatment plan is filed with the school.
- An agreement to indemnify and hold harmless the school and its employees for claims arising from self-administration.

In return, schools shall provide a written notice to the pupil's parent or guardian of the school's absence of liability related to the self-administration of medication covered by HB 85.

Asthma and allergy related illnesses can be potentially life threatening and the current prohibition on self-administration in schools puts children at risk. HB 85 is an important step toward addressing a major risk to our children's health.

(Updated 3/07/05)

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MEMORANDUM January 24, 2005

SUBJECT: HB 85 (Work Order No. 24-LS0367\G)

TO: Representative Kevin Meyer
Attn: Mike Pawlowski

FROM: Jean M. Mischel
Legislative Counsel

You have requested a sectional summary of the above-described bill.

As a preliminary matter, note that a sectional summary of a bill should not be considered an authoritative interpretation of the bill and the bill itself is the best statement of its contents. If you would like an interpretation of the bill as it may apply to a particular set of circumstances, please advise.

Section 1. Requires public elementary and secondary schools to allow the self administration by a student of medications needed to treat asthma, anaphylaxis and other potentially life-threatening illness if certain conditions are met. Imposes annual documentation, indemnification, and release requirements on the parent or guardian of a student who wishes to self-administer medication while at school.

JMM:jad
05-047.jad

FISCAL NOTE

STATE OF ALASKA
2005 LEGISLATIVE SESSION

Fiscal Note Number: 2
Bill Version: CSHB 85(JUD)
(H) Publish Date: 3/9/05

Revision Date/Time (Note if correction):
Dept Affected: Education & Early Development
Title "An Act relating to self-administration and documen-
RDU TLS
tation of certain types of medication prescribed to a child
Component Student & School Achievement
Sponsor Representative Meyer
Requester House HES
Component No. 2796

Expenditures/Revenues (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

OPERATING EXPENDITURES	FY 2006	FY 2007	FY 2008	FY 2009	FY 2010	FY 2011
Personal Services						
Travel						
Contractual						
Supplies						
Equipment						
Land & Structures						
Grants & Claims	0.0	0.0	0.0	0.0	0.0	0.0
Miscellaneous						
TOTAL OPERATING	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**
CAPITAL EXPENDITURES						
CHANGE IN REVENUES ( )						

FUND SOURCE (Thousands of Dollars)

1002 Federal Receipts						
1003 GF Match						
1004 GF	0.0	0.0	0.0	0.0	0.0	0.0
1005 GF/Program Receipts						
1037 GF/Mental Health						
Other (Specify Type--Do not abbreviate)						
TOTAL	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**

Estimate of any current year (FY2005) cost: 0.0
Mark this box (X) if funding for this bill is included in the Governor's FY 2006 budget proposal:

POSITIONS

Full-time						
Part-time						
Temporary						

ANALYSIS: *(Attach a separate page if necessary)*

Section 14.30.141 states that a school shall permit self-administration of medication by a pupil for asthma, anaphylaxis, or other potentially life-threatening illnesses, under specific conditions and with written authorization and certification. The Department of Education & Early Development identifies no department costs at this time.

Prepared by: Barbara Thompson, Director
Phone 465-8727
Division Teaching & Learning Support
Date/Time 2/22/05 3:35 PM
Approved by: Karen Rehfeld, Deputy Comissioner
Date 02/22/2005
Agency Education & Early Development

(Revised 9/23/2004 OMB)

Calendar No. 784

108TH CONGRESS *2d Session*	SENATE	REPORT 108–394

ASTHMATIC SCHOOLCHILDREN'S TREATMENT AND HEALTH MANAGEMENT ACT OF 2004

OCTOBER 8, 2004.—Ordered to be printed

Mr. GREGG, from the Committee on Health, Education, Labor, and Pensions, submitted the following

REPORT

[To accompany S. 2815]

The Committee on Health, Education, Labor, and Pensions, to which was referred the bill (S. 2815) to give preference regarding States that require schools to allow students to self-administer medication to treat that student's asthma or anaphylaxis, and for other purposes, having considered the same, reports favorably thereon without an amendment and recommends that the bill do pass.

CONTENTS

I. PURPOSE AND NEED FOR LEGISLATION

According to reports of the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH), of 20 million Americans with asthma, 6.3 million are children under 18 years of age. This chronic condition is the cause of 728,000 emergency room visits, 214,000 hospitalizations and 223 deaths annually among children. It also accounts for 14 million missed schools

days each year. The CDC reports indicate that working parents of children with asthma lose an estimated 1 billion dollars in productivity annually. Unfortunately, the number of persons with asthma has doubled in the United States during the past 15 years.

Consistent with the goals of the Healthy People 2010, the CDC-directed National Asthma Program is based on three public health strategies; (1) tracking, collecting and analyzing data on an ongoing basis to understand the "who, what, and where" of asthma; (2) interventions including translation of scientific information into public health practices to reduce the burden of asthma including school based strategies for children, and (3) partnerships with stakeholders in developing, implementing and evaluating local asthma control programs. The CDC recommends development of asthma friendly school environments designed to help students manage their asthma through a coordinated approach.

The National Asthma Education and Prevention Program, coordinated by the National Heart, Lung and Blood Institute, published a resolution recommending that schools adopt policies for the management of asthma that encourage the active participation of students in the self-management of their condition and allow for the most consistent, active participation in all school activities. In 2002, a committee of experts organized by Rand Corporation for improving childhood asthma outcomes also recommended that the Secretary of the Health and Human Services (HHS) consider giving states incentives to adopt policies that address the needs of children with asthma.

Schools should be a safe place where children learn and play; that should be true for children with asthma also. Thirty-one states have laws protecting the rights of asthmatic children to carry and self-administer metered-dose inhalers. Nineteen states expand this protection to include auto-injectable epinephrine. Furthermore, additional states have pending legislation to allow children to carry their inhalers and anaphylaxis medication at school. Experts, including the NIH and CDC report that self-administration of asthma medication reduces unnecessary emergency room visits, reduces missed school days, promotes participation in school activities and even saves lives. However, many schools do not allow and many states do not require schools to allow students to manage their asthma during school hours. The goal of this legislation is to build on the successful momentum that many states are currently experiencing in implementing comprehensive and effective asthma-related programs in schools.

II. Summary

The bill, as passed by the committee, requires that the Secretary of Health and Human Services, in making any grant to States that is asthma-related, shall give preference to any State with statutory or regulatory provisions described in the proposed bill. The State must require each public elementary and secondary school to grant an authorization for self-administration of asthma medication if the student has demonstrated the skill level necessary to use the asthma medication and any device that is necessary to administer the medication. The State must also require schools to grant an authorization for self- administration of the asthma medication in accordance with a written treatment plan prescribed by the health care

practitioner with documentation from parents. The authorization granted to asthmatic children to possess and use medications must extend to any school sponsored activity such as before-school and after-school activities, and transit to and from school and school-sponsored activities. The plan must be renewed annually and the back up medication, if provided by parents or guardians, must be kept at a student's school in a location easily accessible to the student in event of an emergency.

The grant preferences are to apply to public-health-oriented, asthma-related grants to States generally awarded by the CDC. The bill gives the Secretary the discretion to determine which asthma-related grants to States would receive preference described in the Act. NIH grants to researchers or grants from other agencies to health care institutions for basic and clinical research, new diagnostic and therapeutic innovation, surveillance and epidemiology, and community approaches by health care institutions to achieve reduction in asthma-related morbidity and mortality are not made through States and will not be affected by this bill. The committee does not intend for this legislation to have an adverse funding impact on current grants and continuation funding of those grants solely due to a lack of statutory or regulatory provisions described in this legislation.

The bill includes a rule of construction that states that nothing in the subsection creates a cause of action or in any other way increases or diminishes the liability of any person under the law. The purpose of this rule is to address concerns of school administrators about potential increase in their liability, for example from errors in self-administration of drugs by asthmatic children that may result from the provisions of this bill.

The amendment made by this statute shall apply to grants made on or after the date that is 9 months after the date of the enactment of this Act. This will allow time for any State that currently does not have appropriate statutes or regulations in place to make necessary changes in their statutes. The committee anticipates that 9 months is sufficient time for any State to put in place provisions necessary to meet the conditions of the Act.

The bill expresses the sense of the Senate in commending the CDC for creating strategies for addressing asthma in a coordinated school program and encourages all schools to review the CDC recommendations and adopt the policies that best meet their students' needs.

III. History of Legislation and Votes in Committee

On July 14, 2004, the House Committee on Energy and Commerce, reported favorably a bill (H.R. 2023) to give preferences to states that require schools to allow students to self-administer medication to treat their asthma or anaphylaxis. On September 20, 2004, Senator DeWine (for himself) and Senators Corzine, Durbin and Kennedy introduced S.2815, which is identical to H.R.2023 as passed by the House committee. The committee passed the bill (S.2815) by unanimous consent on September 22, 2004.

IV. Explanation of the Bill and Committee Views

The committee intends to ensure that asthmatic children are able to remain healthy, attend schools and participate in learning and play activities. To achieve these goals, they should be able to take the medications prescribed by their health care providers. Schools should be aware of the management plan prescribed by the child's physician and keep the back-up medication where the child can have access to it in the event of emergency.

The bill, as passed by the committee, will build on the successful momentum that many States are currently experiencing in developing asthma-related programs in schools. Federal asthma-related grants will be awarded by the Secretary to assist these States in continuing to develop effective asthma-related programs in the school system. Preference for those grants will go to States with demonstrated, comprehensive, and effective asthma programs-including provisions regarding self-medication in schools. The committee notes that this legislation does not affect whether States pass laws that require schools to allow self-medication for diseases and health conditions other than asthma and anaphylaxis.

V. Cost Estimate

U.S. Congress,
Congressional Budget Office,
Washington, DC, September 27, 2004.

Hon. Judd Gregg,
Chairman, Committee on Health, Education, Labor and Pensions, U.S. Senate, Washington, DC.

Dear Mr. Chairman: The Congressional Budget Office has prepared the enclosed cost estimate for S. 2815, the Asthmatic Schoolchildren's Treatment and Health Management Act of 2004.

If you wish further details on this estimate, we will be pleased to provide them. The CBO staff contacts are Tim Gronniger (for federal costs), and Leo Lex (for the state and local impact).

Sincerely,

Elizabeth Robinson
(For Douglas Holtz-Eakin, Director).

Enclosure.

S. 2815—Asthmatic Schoolchildren's Treatment and Health Management Act of 2004

S. 2815 would modify the Public Health Service Act by directing the Secretary of Health and Human Services, in making any asthma-related grant to a state, to give preference to states that require schools to permit students to self-administer medication for asthma and anaphylaxis.

The bill would not change the purposes for which the Secretary makes asthma-related grants. CBO estimates that enacting S. 2815 would not have a significant effect on the federal budget. Enacting S. 2815 would not affect direct spending or revenues.

S. 2815 contains no intergovernmental or private-sector mandates as defined in the Unfunded Mandates Reform Act, but it would alter conditions for the Children's Asthma Treatment Grants Program and other asthma-related grants, giving preferences to

states who allow schoolchildren to self-administer asthma medication. While the bill would not alter the total amount of grants available, the new preference could change the distribution of funds among states.

The CBO staff contacts are Tim Gronniger (for federal costs), and Leo Lex (for the state and local impact. This estimate was approved by Peter H. Fontaine, Deputy Assistant Director for Budget Analysis.

VI. Regulatory Impact Statement

The committee has determined that there will be de minimus changes in the regulatory burden imposed by the bill.

VII. Application of Law to the Legislative Branch

Section 102(b)(3) of Public Law 104–1, the Congressional Accountability Act (CAA) requires a description of the application of this bill to the legislative branch. This bill does not amend any act that applies to the legislative branch.

VIII. Section-by-Section Analysis

Section 1. Short title

The short title of the Act is "Asthmatic School Children's Treatment and Health Management Act of 2004".

Section 2. Findings

The Section 2 reviews the findings of the Congress with respect to prevalence of asthma, and the impact of this chronic disease on the use of health care facilities, attendance at schools, and costs. The section reviews the current status of regulation in states and problems encountered by children who attend schools that do not allow self-management of asthma. These problems, in addition to missed school days, include many instances of illness, emergency room visits, hospitalization, and death. The section provides a rationale for the bill.

Section 3. Preference for States that allow students to self-administer medication to treat asthma and anaphylaxis

Section 3991 of the Public Health Service Act (42 U.S.C. 280g) is amended by redesignating subsection (d) as subsection (e) and inserting after the subsection (c) a subsection (d) to include the following.

The Secretary, in awarding any grant under this section or any other grant that is asthma-related (as determined by the Secretary) to a State, shall give preference to any State that satisfies specific criteria. The State must require each public elementary and secondary school to grant an authorization for self-administration of asthma medication in accordance with a written treatment plan prescribed by the health care practitioner with documentation from parents including documents related to liability. The authorization extends to any school sponsored activity such as before-school and after-school activities. The plan must be renewed annually and the back up medication, if provided by parents or guardians, must be kept at a student's school in a location easily accessible to the stu-

dent in event of an emergency. The authorization must be effective only for the same school and the same year for which it is granted and renewed by the parent or guardian each subsequent school year.

The section will be applicable after 9 months from the date of enactment to allow States to pass appropriate legislation.

Section 4. Sense of Congress commending CDC for its strategies for addressing asthma within a coordinated school health programs

The section commends the CDC for identifying and creating strategies for addressing asthma with a coordinated school program for schools to address asthma and encourages all schools to review these policies to meet the needs of their student population.

IX. Changes in Existing Law

In compliance with rule XXVI paragraph 12 of the Standing Rules of the Senate, the following provides a print of the statute or the part or section thereof to be amended or replaced (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italic, existing law in which no change is proposed is shown in roman):

PUBLIC HEALTH SERVICE ACT

* * * * * * *

PART P—ADDITIONAL PROGRAMS

SEC. 399L. CHILDREN'S ASTHMA TREATMENT GRANTS PROGRAM.

(a) AUTHORITY TO MAKE GRANTS.—

(1) IN GENERAL.—* * *

* * * * * * *

(d) PREFERENCE FOR STATES THAT ALLOW STUDENTS TO SELF-ADMINISTER MEDICATION TO TREAT ASTHMA AND ANAPHYLAXIS.—

(1) PREFERENCE.—The Secretary, in awarding any grant under this section or any other grant that is asthma-related (as determined by the Secretary) to a State, shall give preference to any State that satisfies the following:

(A) IN GENERAL.—The State must require that each public elementary school and secondary school in that State will grant to any student in the school an authorization for the self-administration of medication to treat that student's asthma or anaphylaxis, if—

(i) a health care practitioner prescribed the medication for use by the student during school hours and instructed the student in the correct and responsible use of the medication;

(ii) the student has demonstrated to the health care practitioner (or such practitioner's designee) and the school nurse (if available) the skill level necessary to use the medication and any device that is necessary to administer such medication as prescribed;

(iii) the health care practitioner formulates a written treatment plan for managing asthma or anaphylaxis episodes of the student and for medication use by the student during school hours; and

(iv) the student's parent or guardian has completed and submitted to the school any written documentation required by the school, including the treatment plan formulated under clause (iii) and other documents related to liability.

(B) SCOPE.—An authorization granted under subparagraph (A) must allow the student involved to possess and use his or her medication—

(i) while in school;

(ii) while at a school-sponsored activity, such as a sporting event; and

(iii) in transit to or from school or school-sponsored activities.

(C) DURATION OF AUTHORIZATION.—An authorization granted under subparagraph (A)—

(i) must be effective only for the same school and school year fro which it is granted; and

(ii) must be renewed by the parent or guardian each subsequent school year in accordance with this subsection.

(D) BACKUP MEDICATION.—The State must require that backup medication, if provided by a student's parent or guardian, be kept at a student's school in a location to which the student has immediate access in the event of an asthma or anaphylaxis emergency.

(E) MAINTENANCE OF INFORMATION.—The State must require that information described in clauses (iii) and (iv) of subparagraph (A) be kept on file at the student's school in a location easily accessible in the event of an asthma or anaphylaxis emergency.

(2) RULE OF CONSTRUCTION.—Nothing in this subsection creates a cause of action or in any other way increases or diminishes the liability of any person under any other law.

(3) DEFINITIONS.—For purposes of this subsection:

(A) ELEMENTARY SCHOOL AND SECONDARY SCHOOL.—The terms 'elementary school' and 'secondary school' have the meanings given to those terms in section 9101 of the Elementary and Secondary Education Act of 1965.

(B) HEALTH CARE PRACTITIONER.—The term 'health care practitioner' means a person authorized under law to prescribe drugs subject to section 503(b) of the Federal Food, Drug, and Cosmetic Act.

(C) MEDICATION.—The term 'medication' means a drug as that term is defined in section 201 of the Federal Food, Drug, and Cosmetic Act and includes inhaled bronchodilators and auto-injectable epinephrine.

(D) SELF-ADMINISTRATION.—The term 'self-administration' means a student's discretionary use of his or her prescribed asthma or anaphylaxis medication, pursuant to a

prescription or written direction from a health care practitioner.

* * * * * * *

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and willingness to treat potential victims of bioterror. *Health Aff*. 2003; 22(5):189–197.

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Asthma Inhalers in Schools: Rights of Students with Asthma to a Free Appropriate Education

Sherry Everett Jones, PhD, JD, MPH, and Lani Wheeler, MD

Students who possess and self-administer their asthma medications can prevent or reduce the severity of asthma episodes. In many states, laws or policies allow students to possess and self-administer asthma medications at school.

In the absence of a state or local law or policy allowing public school students to possess inhalers and self-medicate to treat asthma, 3 federal statutes may require public schools to permit the carrying of such medications by students: the Individuals With Disabilities Education Act, Section 504 of the Rehabilitation Act of 1973, and Title II of the Americans with Disabilities Act. Local policies and procedures can be based on these federal laws to ensure that students with asthma can take their medicines as needed. (*Am J Public Health*. 2004;94:1102–1108)

MORE THAN 6 MILLION AMERICAN children aged younger than 18 years have asthma, making it one of the most common chronic diseases among children.[1] In 2001, more than 4 million children younger than 18 years had an asthma episode in the previous year (a rate of 57/1000), suggesting that many young people with asthma may not have their asthma under control.[1] As many as an estimated 1.4% of all American children experience some level of limitation owing to asthma, such as an inability (or limited ability) to engage in school or play activities.[2] Young people with asthma miss an estimated

14 million days of school each year because of the disease,[1] and some children's school performance consequently suffers.[4]

Provided parents or guardians and a health care provider, preferably with input from the child's school and especially the school nurse, deem it appropriate for a student to self-medicate and have granted authorization, it is beneficial to students with asthma to have unobstructed access to their medication before, during, and after school.[5,6] Students who self-administer their asthma medications can prevent or reduce the severity of asthma episodes.[7] However, some schools perhaps as part of a drug use prevention program or in hopes of minimizing liability claims, do not allow students to carry their inhalers in school.[8,9] In 2000, students were allowed to self-medicate with prescription inhalers in 68% of all schools nationwide (79% of middle/junior and senior high schools).[10]

Restrictions on students carrying their inhalers may preclude the immediate use of medication at the onset of symptoms. For example, the room in which the medication is kept may be too far from the student's classroom or playing field, some students may believe it is too disruptive to go to another part of the school building to take their medication,[11] and many students are embarrassed about needing to take medications.[12] Restrictions on the use of inhalers may ultimately compromise medication adherence, increase the risk of a full-blown asthma episode, and cause unnecessary suffering, emergency treatment, and asthma-related school absences.[2,8,13]

In 2000, approximately 223 children aged 0 through 17 years died as a result of asthma (a rate of 0.3/100 000).[1] Furthermore, asthma results in substantial increased use of the health care system. In 2000, children aged 0 through 17 years had an estimated 4.6 million asthma-related outpatient visits to doctors' offices and hospital outpatient departments (a rate of 649/10 000), approximately 728 000 asthma-related emergency department visits (a rate of 104/10 000), and approximately 21 000 asthma-related hospitalizations (a rate of 30/10 000).[1] Asthma-related missed school days among children aged 5 through 17 years resulted in an estimated cost of $726.1 million in caretakers' time lost from work.[14]

By knowing the rights of students with asthma, school administrators, educators, physicians, and other health care providers can help ensure that students have appropriate access to medications. This article explores state laws and policies that allow students to carry and self-administer asthma inhalers in school and federal statutes that may, under certain circumstances, require schools to allow students to do so.

STATE LAWS AND POLICIES ALLOWING INHALERS

As of April 2004, 38 states allow self-medication among students at school. Twenty-three states (Alabama,[15] Delaware,[16] Florida,[17] Georgia,[18] Illinois,[19] Kentucky,[20] Maine,[21] Massachusetts,[22] Michigan,[23] Minnesota,[24] Mississippi,[25] Missouri,[26] New Hampshire,[27] New Jersey,[28] New York,[29] Ohio,[30] Oklahoma,[31] Rhode Island,[32] Tennessee,[33] Texas,[34] Utah,[35] Virginia,[36] and Wisconsin[37]) have enacted legislation specifically to allow students with asthma to possess and self-administer inhaled asthma medications while at school. These laws require parental consent and permission from a physician or other health care provider. Also, the School Health Policies and Programs Study 2000 found that an additional 10 states (Kansas, Louisiana, Maryland, Nebraska, New Mexico, North Dakota, South Carolina, South Dakota, Vermont, and Washington) have adopted policies allowing students to self-medicate at school with prescription inhalers.[38] Five other states (California,[39] Connecticut,[40] Indiana,[41] Iowa,[42] and Oregon[43]) have laws broadly providing for the self-administration of medications. Because state laws are often changing, interested readers can access the National Conference of State Legislatures Web site to monitor legislative action related to asthma, including self-medication laws (http://www.ncsl.org/programs/esnr/asthmamain.htm).

ASTHMA AS A DISABILITY: FEDERAL STATUTES

In the absence of a state or local law or policy allowing students to possess inhalers and self-medicate, health care providers and parents might be able to use 1 of 3 federal statutes that, under certain circumstances, will provide the legal justification requiring schools to allow students with asthma to do so. Those laws are the Individuals With Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act of 1973 (Section 504), and Title II of the Americans With Disabilities Act (Title II of ADA).

INDIVIDUALS WITH DISABILITIES EDUCATION ACT

The purpose of IDEA is to partially fund states to develop special education programs "to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living."[44]

IDEA applies only to children who meet the definition of a *child with a disability*, that is, a child with "mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance (hereinafter referred to as emotional disturbance), orthopedic impairments, autism, traumatic brain injury, *other health impairments*, or specific learning disabilities; and who, by reason thereof, needs special education and related services" (italic added).[45]

The implementing regulations further define *other health impairment* as "having limited strength, vitality or alertness, in-

cluding a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that—(i) *Is due to chronic or acute health problems such as asthma* . . . and (ii) Adversely affects a child's educational performance (italic added)."[46]

To be classified as disabled under IDEA, a child with asthma must fall under the *other health impairment* category and require special education because of the asthma or have some other disabling condition under IDEA and require special education because of that disability. In either case, modifications must be made for that student that are determined necessary by the child's individual education program team and allow the student to receive a "free appropriate public education" (defined as education and related services provided at the public's expense, which meet the standards of the state educational agency, include an appropriate preschool, elementary, or secondary school education in the state involved, and are consistent with the student's individual education plan[47]), including "related services" designed to meet the child's unique needs.[44,46,50] Such related services might include allowing a student to carry an asthma inhaler.

SECTION 504 OF THE REHABILITATION ACT OF 1973

The purpose of Section 504 is to eliminate discrimination on the basis of a disability: "No otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . ."[51] Under this law, *disability* is more broadly defined than under IDEA and, consequently, covers a large number of youths with disabilities who attend federally funded programs not covered under IDEA. The federal regulations promulgated under Section 504 define a disabled person as one who "(i) has a physical or mental impairment which substantially limits one or more major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment."[52] The term *physical impairment* encompasses respiratory disorders or conditions. *Major life activities* refers to functions such as caring for oneself, breathing, and learning.[52] Section 504 is broader than IDEA because it applies to not only the education program, but also to other nonacademic and extracurricular activities.[53,54]

As with IDEA, the regulations promulgated under Section 504 require school districts to provide a "free appropriate public education" to children with disabilities.[55] In the context of Section 504, this requirement means that "the provision of regular or special education and related aids and services . . . designed to meet individual educational needs of handicapped persons [must be as adequate as those designed to meet] the needs of nonhandicapped persons . . ."[56] Of note, some case law is in conflict with the Section 504 regulations requiring a free appropriate education. Some courts, including the US Supreme Court, have held that Section 504 "does not impose an obligation . . . a free appropriate public education despite federal regulations to the contrary."[57] What this conflict means for future lawsuits is unclear. In accordance with the language of Section 504, courts consistently hold, however, that Section 504 requires that schools make reasonable accommodations to allow disabled students to gain equal access to educational opportunities provided at that school.[57]

TITLE II OF THE AMERICANS WITH DISABILITIES ACT

ADA extends Section 504 to public accommodations in the private sector and state and local public agencies that do not receive federal funding (the discussion of which is beyond the scope of this article).[58] In the context of disabled students attending public schools, Section 504 and Title II of ADA are similar. Title II of ADA prohibits any public entity (e.g., public schools) from discriminating on the basis of a disability.[59,60] Congress intended Title II of ADA and its implementing regulations to be consistent with Section 504,[54,61–63] although the federal regulations and the US Department of Education, Office for Civil Rights have interpreted Section 504 more broadly than Title II of ADA.[57] Under both Section 504 and Title II of ADA, recipients of federal funds and public entities must address the disability-related needs of disabled students so they can participate in services or programs to the extent necessary to avoid discrimination.[54] The definition of *disability* under Title II of ADA is identical to that of Section 504. Under the regulations of Title II of ADA, a school must "make reasonable modifications in policies."[54] A school that refuses to administer medication because of a student's disability would be in violation of Title II of ADA.[48]

HOW THESE FEDERAL STATUTES HAVE BEEN APPLIED

A clear demarcation indicating at what point a child's asthma rises to the level of a disabling condition is not available. Presumably, when a child's asthma significantly interferes with breathing, the child would be considered to have a disability.[58] Parents and the child's health care provider, along with teachers, the school nurse, and other school officials, are in the best position to evaluate the effect a child's asthma has on a child's health and academic performance. Gelfman and Schwab recommend that health professionals document the following: "(1) how the disability interferes with 1 or more life functions [e.g., breathing, learning], (2) how the disability affects the student's functioning (e.g., energy level, exercise needs, medication effects, etc); and (3) what individualized

supports or accommodations in school the student requires in order to access an appropriate education."[58(p337)]

When a child's asthma is disabling to the extent that the child needs "special education and related services,"[45,46] under IDEA a school is obligated to offer that student sufficient specialized services (e.g., allowing a student to carry an asthma inhaler) so that the student may benefit from his or her education.[50,64] During 2000–2001, the US Department of Education estimated that 292 000 children aged 3 to 21 years were served under IDEA as a result of a disability categorized as "other health impairment."[65] The US Supreme Court, in *Cedar Rapids Community School District v Garret F.* established that under IDEA, those services may go as far as providing a full-time, one-on-one nurse or health assistant.[66] If a student has no other disability and the student's asthma does not affect his or her educational performance, IDEA does not apply.[67] However, students who need access to an asthma inhaler because their asthma places a substantial limitation on major life activities (i.e., the child is disabled because of his or her medical condition) but do not need special education remain qualified under Section 504 and Title II of ADA[68,69] and may avoid being labeled as children who need special education.

To succeed in a Section 504 or Title II of ADA claim alleging that an accommodation was not granted, the claimant must show that the accommodation was denied because of the student's disability (i.e., was discriminatory).[54,70,71] In *East Helena (MT) Elementary School District # 9*, the school district refused to either administer or ensure that the student took asthma medication prescribed and filled by a naturopathic physician.[70] Instead, the school offered to allow a family member to administer the child's medication. In refusing to administer the medication, the school district was following a state law that prohibited the administration of medication unless the prescription was filled by a pharmacist. In that case, the court upheld the policy because the refusal applied to all students regardless of disability status.

Similarly, in *DeBord v Board of Education of the Ferguson-Florissant School District*[54] and *Davis v Francis Howell School District*,[71] schools refused to administer a prescription medication (methylphenidate [Ritalin] for attention deficit hyperactivity disorder) because the doses exceeded that recommended by the *Physicians' Desk Reference*. Both school districts had policies prohibiting schools from administering such prescriptions, although both were willing to let a parent or designee come to the school to administer the medication. The schools argued that the policies were to protect students' health and minimize potential liability. Courts in both cases found that because the school policies were neutral and applied to all students regardless of disability status, no discrimination had taken place. *DeBord*, *Davis*, *and East Helena* are examples of situations in which the claimant could not show that the school district's refusal to accommodate the child was based solely on a disability; therefore, no violations of Section 504 or Title II of ADA were found.[54,70,71]

Although some school policies that forbid staff to administer medications to students have been upheld by courts if uniformly applied, it is unlikely that a "no medications" policy (i.e., a policy that denies the administration of any and all medications at school) applied to all students would stand up in court because those policies have the effect of denying children with disabilities the free appropriate public education to which they are entitled under IDEA and perhaps Section 504, or reasonable accommodations under Section 504 and Title II of ADA.[57,72,73] A free appropriate public education must be specifically designed to meet the unique needs of the child,[74] and consequently, related services, including medications, must accompany that design.[53,56,60] Likewise, under Section 504, health services provided as part of related services must be individually evaluated and prescribed.[58]

INDIVIDUAL EDUCATION PROGRAMS

Under IDEA, a "child with a disability" must be provided with an appropriate individualized educational program (IEP).[49,75] Federal regulations promulgated under Section 504 indicate that schools may use IEPs or other plans as a means of meeting free appropriate public education requirements included in those regulations[55] (whether Section 504 includes such requirements is less clear[57]). An IEP is a written statement designed to identify a child's educational needs and other programs and related services the child requires to progress in the general curriculum.[49] IEPs are developed by an IEP team that typically includes the disabled child's parents, regular and special education teachers, and other representatives from the local education agency who are best suited to assist the child in meeting his or her educational needs.[49] A school nurse may be part of the IEP team when school health services (e.g., administration of medications) are necessary.[76] This team, created specifically for each individual child, ensures that all aspects of the child's educational and related services needs are tailored to that child. This team, along with consultation from the child's health care provider, is best equipped to determine on a case-by-case basis whether self-medication using asthma inhalers is appropriate.

For students with asthma, an *asthma management plan* (Table 1) is an appropriate part of an IEP.[5] Health care providers give instructions on how best to manage the child's asthma during the school day. For a student with asthma, it is helpful if part of the IEP (or 504 plan or individual health service plan or asthma management plan) includes specific information about where, when, and how each asthma medication is to be taken, including when medication possession

TABLE 1—Elements of Typical Asthma Management Plan

- Student's asthma history
- Student's asthma symptoms
- How to contact student's health care provider and parent or guardian
- Signatures of physician and parent or guardian permitting use of medications in school
- List of factors that make student's asthma worse
- Student's best peak flow reading (if student uses peak flow monitoring)
- List of student's asthma medications
- Student's treatment plan, including actions school personnel can take to help handle asthma episodes

Source. NIH Publication 95-3651.[5]

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

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January 13, 2005

Dear sir or madam:

The Alaska Chapter of the American Academy of Pediatrics wishes to provide support to the Alaska Asthma Coalition's efforts to encourage Alaska legislation this year allowing elementary and secondary school students to self administer medication for asthma or anaphylaxis under specified conditions.

The ability for students to use safe and effective medication for these conditions in school, as they do out of school, has been a recommendation for years of the American Academy of Pediatrics (Committee on School Health, Guidelines for the Administration of Medication in School, *Pediatrics;* 112 (3): 697-699, September, 2003) and the American Academy of Allergy, Asthma, and Immunology (Policy Statement, Anaphylaxis in schools and other child-care settings, *Journal of Allergy and Clinical Immunology;* 102 (2): 173-176, August, 1998). Now with financial encouragement of the federal government through the Asthmatic Schoolchildren's Treatment and Health Management Act of 2004, which provides preference for certain grants to states with this legislation, the time has come in Alaska for action. Furthermore 35 states already have these laws in place.

Warm regards,

Thomas J. Porter, MD, FAAP
President
American Academy of Pediatrics, Alaska Chapter

Allergy & Asthma Network
Mothers of Asthmatics

February 1, 2005

The Honorable Kevin Meyer
Alaska House of Representatives
State Capitol, Room 515
Juneau, AK 99801

Dear Representative Meyer:

Founded in 1985, Allergy & Asthma Network Mothers of Asthmatics (AANMA) strives to eliminate suffering and death due to asthma and allergies through education, advocacy, community outreach, and research. For the last decade, the organization assisted state and federal lawmakers to secure students' rights to carry and self-administer prescribed lifesaving asthma and anaphylaxis medications while at school and school-sponsored activities. Today, we thank you for your leadership in sponsoring HB 85, potentially lifesaving legislation for Alaska students living with asthma and anaphylaxis.

Breathing is a right, not a privilege. Physicians prescribe lifesaving medications to patients, and with parental support, train students how to use these medications in a life-threatening emergency. However, not all schools protect students' rights to carry and self-administer emergency medications. Tragically, inconsistent school policies have led to student deaths across the country. In many cases, it has taken a student's death and subsequent lawsuit to prompt statewide legislation protecting students' rights.

On October 30, 2004, President signed HR 2023, the Asthmatic Schoolchildren's Treatment and Health Management Act of 2004, into law. States with laws protecting students will receive asthma-related funding preference from the federal government.

Bill HB 85 will qualify the state for this preference, create a uniform self-administration policy for all Alaska schools, and enable students to focus on learning. Alaska will join the nearly 20 states currently protecting these vital student rights. We commend you for your leadership and support of Alaska students living with asthma and anaphylaxis.

On behalf of students who just want to breathe, thank you!

With warm regards,

Marissa Magnetti
Advocacy Network Coordinator

Sandra Fusco-Walker
Patient Advocate

School Boards United

The 52 member districts of the [redacted] met in district forums during the AASB Legislative Fly-In on February 13, 2005 and considered the following bills pending before the Alaska Legislature:

Bill/Topic	REAA/Rural Districts	Municipalities	Large Districts
Education Funding HB 1 - Base Student Allocation increase	$4,995 minimum level in FY06, but not adequate	$4,995 minimum, but not adequate	$4,995 minimum, but not adequate
PERS/TRS funding (inside foundation)	Support	Support	Support
Early Funding HB 20, SB 13, SB 23	Support, but need option of supplemental	Support March 15, but need option of supplemental	Support, but need option of supplemental
Limit administrative expenses SB 57	Oppose	Oppose	Oppose
School Construction Debt HB 13	Support	Support	Support
School Safety HB 41 Min. 60 days for assault	Support	Support	Support
HB 88, SB 65 Waive minors into adult court	Monitor	Support	Monitor
SB 10 Remove cap on damage awards for vandalism	Monitor	Support	Support
Student Health HB 3 - Scoliosis tests	Oppose	Oppose	Oppose
HB 85 Self-administer drugs	Support	Support	Support
SB4 SB 35 First aid classes	Oppose	Oppose	Oppose
SB 48 Psychotropic Drugs	Oppose	Oppose	Oppose
HB 128 Physical fitness task force	Monitor	Monitor	Oppose
Teacher Recruitment SB 24, SB 31, SB 61	Support	Support	Support

Talking Points on Education Bills

Education Funding HB 1	$4,995 minimum needed to provide education mandated by NCLB and higher costs Continue the positive investment trend line established in 2004 Districts already hurting from years of under-funding Many districts already at local funding cap Federal education cuts and under-funding will impact schools
PERS/TRS funding	Appreciate governor's initiative to fund at 100 percent; keep inside formula
Early Funding HB 20, SB 13, SB 23	Good idea to help district planning, but when revenues are available late in session, education should be at the table
Limit Administrative Expenses SB 57	30 percent ceiling is already unrealistic; 32 districts secured waivers this year
School Construction Debt HB 13	Districts have identified $580 million in construction needs; governor requesting only $30 million in FY 06 school repairs
School Safety HB 41, HB 88, HB 65, SB 10	School employees must be protected and our schools must be safe from violent acts. But legislature should be careful about removing discretion from the hands of school officials and the courts.
Student Health HB 85, HB 3, SB 4, SB 35, SB 48, HB 128	Districts are skittish about more unfunded mandates from the state and federal government. It makes sense to allow students to carry and self-administer allergy and asthma drugs (HB 85). We will monitor other bills as they move through the process.
Teacher Recruitment SB 24, SB 31, SB 61	Retire-rehire law has helped many districts cope with personnel emergencies & teacher shortages. Cost to the retirement program has been minimal. It's a local option that should be extended.

Alaska Nurses Association

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Testimony of Patricia Senner MS, RN, ANP
Chair Legislative Committee
Alaska Nurses Association
HB 85
February 15, 2005

The Alaska Nurses Association would like to express their support of HB 85, "an Act relating to self-administration and documentation of certain types of medication prescribed to a child attending school"

The Nurses Association emailed a copy of this Bill to nurses throughout the state. The responses we received back were all supportive of the legislation

This legislation mandates a practice that has already been in place in the Anchorage School District, so there has been practical experience with implementation of the Bill's mandates. The school nurses we consulted on both the elementary and high school level stated that they had not encountered any serious problems with student's carrying their own medication.

We did receive numerous comments that some student's, with more serious disease, should be required to also have an inhaler left with the school nurse. As you might imagine, student's frequently forget to bring their inhalers to school, or the inhalers run out of medication and the student forgets to tell their parents. There must be some corollary to Murphy's law that when the student forgets their inhaler is when they need it most.

It might be advisable that a section be added to the bill that would allow the school district to require a student to provide a back-up inhaler to be left in the office. Most school's already have back up epi pens on hand because they can never tell which student might have an anaphylactic reaction to something in the environment.

Thank you for this opportunity to respond to this bill.

National Association of School Nurses

POSITION STATEMENT

Epinephrine Use in Life-Threatening Emergencies

HISTORY:

An increasing number of students and school staff have life-threatening allergies. Exposure to the affecting allergen can trigger anaphylaxis. Anaphylaxis requires prompt medical intervention with an injection of epinephrine.

DESCRIPTION OF ISSUE:

Avoidance, early recognition, and prompt treatment are essential to the management of life-threatening allergies. There are students and school staff who have known life-threatening allergies, as well as those who have not been identified. Prompt intervention with epinephrine is vital to saving lives.

RATIONALE:

Medication and emergency policies in school districts must be developed with the safety of all students and staff in mind. Easy access to and correct use of epinephrine are necessary to avoid life-threatening complications.

CONCLUSION:

It is the position of the National Association of School Nurses that school nurses supervise the management and treatment of life-threatening allergies. The self-managed administration of epinephrine should be evaluated on a case-by-case basis by the school nurse, the parent, the health care provider, and the student. Written permission from the parent and health care provider must be obtained for students with known life-threatening allergies who will self-medicate.

An individual health care plan that includes continuous monitoring, emergency plans, and evaluation should be written by the school nurse and maintained for every student with prescribed epinephrine. The school nurse should provide training for school staff in the recognition of life-threatening allergic reactions and, if appropriate, in the administration of pre-filled, single dose epinephrine prescribed for these students.

School districts must establish direction for handling episodes of anaphylaxis in students and staff with no previous history of life-threatening allergies. State laws

pertaining to nursing practice will impact the need for protocols or standing orders.

References/Resources:

Gold, M.S. and Sainsburg, R. "First Aid Anaphylaxis Management in Children Who Were Prescribed an Epinephrine Autoinjection Device (Epi-Pen)", Journal of Allergy and Clinical Immunology, July 2000: 106(1 Pt. 1): 171-6, Cit IDS PM1D: 10887321 UI: 20347070.

Weller, John, "Anaphylaxis in the General Population: A Frequent and Occasionally Fatal Disorder That is Under Recognized", Journal of Allergy and Clinical Immunology, August 1999, part 1, vol. 104, No. 2, p271-273.

Dibs, S. D. and Baker, M.D., "Anaphylaxis in Children: A Five Year Experience", Pediatrics 1997, 99.e7.

Masoud, Froudi, Alshedri, Mohammed, Hummel, David, and Chaim M. Raifmon. "Anaphylaxis and Epinephrine Auto-Injector Training: Who Will Teach the Teachers?" Journal of Allergy and Clinical Immunology, July 1999, vol. 104, No. 1, p. 190-193.

American Academy of Allergy, Asthma, and Immunology, 611 East Wells Street, Milwaukee, WI 53202

Asthma and Allergy Foundation of America (AAFA), 1233 20th Street, NW, Suite 402, Washington, DC 20036.

www.SchoolAsthma.com

Adopted: November, 2000

National Association of School Nurses

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POSITION STATEMENT

The Use of Asthma Inhalers in the School Setting

HISTORY:

The number of diagnosed cases of asthma is increasing each year. Inhaled Medication is frequently used to manage the condition and treat acute exacerbation.

DESCRIPTION OF ISSUE:

Early recognition and prompt treatment of symptoms are vital to the management of asthma.

RATIONALE:

School district medication policies must be developed with the safety of all students in mind. Easy access to and correct use of asthma inhalers are necessary to avoid serious respiratory complications secondary to acute exacerbation and to improve the quality of life of students with asthma.

CONCLUSION:

It is the position of the National Association of School Nurses to support the self-management of asthma, including the use of prescribed, inhaled medications on a case-by-case basis with parent, physician, school nurse, and if appropriate, student involvement. Self-managed administration of inhaled medication for asthma must be evaluated by the school nurse. Written permission from the parent and physician must be obtained. A written individual health care plan that includes continuous monitoring and evaluation by the school nurse must be maintained for every student who self-administers prescribed inhaled medications.

Adopted: June 1993
Revised: June 1999

Medication Survey

A survey of Alaska school districts shows no consistent policy in allowing students to carry and administer their own medication for asthma and anaphylactic episodes. And while 14 districts indicated support for such a policy allowing self-administration of medication, nine districts expressed opposition.

The survey by AASB was conducted following introduction of House Bill 85 requiring public schools to permit students to administer their own medication for asthma, anaphylaxis (allergic reactions to food or insect bites) and other potentially life-threatening illnesses. Sponsored by Rep. Kevin Meyer, R-Anchorage, the bill requires written authorization from a parent or guardian and a health care provider.

Ten districts that responded to the survey said they currently allow students to carry and use asthma inhalers and/or an auto-injector syringe. Several require parental or physician permission.

Eleven districts reported requiring students to keep any such device in the custody of a school nurse or other trained staff member. Two districts allow inhalers but not syringes, while three allow auto-injectors but not inhalers.

When asked if they would support a measure such as HB 85, nine districts indicated no. One district said they were currently in a dispute with parents demanding that staff administer insulin to their child

Among the 14 districts that indicated support for the bill, one district said it would welcome any law absolving their schools of liability for students treating themselves.

"The inhaler is much easier to administer, and all but the very youngest of students know how to use them and they keep them at their desks or in accessible lockers," the district reported.

HB 85 was referred for the Health, Education and Social Services Committee and the Judiciary Committee.

ASSOCIATION OF ALASKA SCHOOL BOARDS
Advocates for Alaska's Youth

Quick Survey on Self-administration of Medications

DUE DATE: 02/08/05

Legislation (House Bill 85) has been introduced to require public schools to allow students to self-administer medication for the treatment of asthma, anaphylaxis (allergic reactions to insect bites or food) and other potentially life-threatening illnesses. The bill contains various requirements for written authorization from parents and health-care professionals, as well as assurances that schools will not be held liable for any misuse of the medication.

In preparation for public hearings on the bill, AASB is taking a quick survey to answer the following questions:

1. Is it your district policy for students who carry an asthma inhaler or auto-injector syringe to turn those devices into the school office or nursing station?

   Asthma Inhaler Yes_____ No_____

   Auto-injector Syringe Yes_____ No_____

2. If yes to either, who is authorized to dispense such medication?

   School nurse_____ Office aide_____
   Secretary_____ Classroom teacher_____
   Site administrator_____ Other_____

3. Has your district had any recent incidences in which a student had a severe asthma attack or anaphylactic episode? Can you describe the circumstances briefly? _____
   _____
   _____

4. Would your district support a change in state law that allows students to carry and self-administer medication with an asthma inhaler or self-injector syringe?

   Yes_____ No_____

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	Question #1		Question #2					
District	Asthma Inhaler	Auto-Injector Syringe	School Nurse	Secretary	Site Administrator	Office Aide	Classroom Teacher	Other
Aleutians East	N	N						
Anchorage	Y-Parent permission required	Y-Parent permission required	X-Trained annually	X-Trained annually	X-Trained annually	X-Trained annually	X-Trained annually	X-Trained annually
Bering Strait	N	Y						X
Cordova	Y	Y		X	X		X	
Delta/Greely	Y	Y		X				
Denali Borough	Y	Y	X				X	
Dillingham City	Y	Y		X				
Fairbanks	Y-Some HS students may carry their own inhaler	Y-No exceptions	X-Each school nurse trains an alternate (usually the secretary).	X	X			
Galena	N	Y		X			X	
Haines Borough	N	N						
Hydaburg City	N	N						
Iditarod Area	N	N						
Juneau Borough	Y-Elementary	Determined case by case	X					
Kake City	N	N						
Kenai Peninsula	N	Y	X					Trained Staff
Klawock City	Y	Y		X				
Kodiak Island	N- Form must be filled out by parent & doctor if student carries this	Y	X		X			
Kuspuk	N	N						
Lake & Peninsula	Y	Y			X			
Mat-Su Borough	Y	Y	X	X	X	X	X	
Nome City	N	N						
Northwest Arctic	Y	Y			X			
Pribilof	N	N		X				
Sitka Borough	Y	N	X	X	X			
Skagway City	N	N						
Southeast Island	Y	N		X	X			
Southwest Region	Y	Y		X	X			
Tanana	Y	Y		X	X		X	

	Question #1		Question #2					
District	Asthma Inhaler	Auto-Injector Syringe	School Nurse	Secretary	Site Administrator	Office Aide	Classroom Teacher	Other
Unalaska City	N	N						
Valdez City	Y-Items are kept in the office and students come to the office to take their medication	Y-Items are kept in the office and students come to the office to take their medication						Y- Student self medicates in the presence of school office staff or principal.
Wrangell City	Y	Y		X	X			
Yupiit	Y	Y		X	X			
Totals: 32	14 No, 17 Yes, 1 No/Yes	12 No, 18 Yes, 1 No/Yes, 1 Case by Case	8	15	13	2	6	4

	Question #3			Question #4		
District	Yes	No	Description of asthma attack or anaphylactic episodes	Yes	No	N/A Uncertain
Aleutians East		X		X		
Anchorage	X		[illegible] school district wherein asthma-kid no inhaler-paramedics gave meds; student recovered	X		
Bering Strait		X				X
Cordova		X			X	
Delta/Greely		X		X		
Denali Borough		X			X	
Dillingham City		X			X	
Fairbanks	X		An elementary student with asthma used an inhaler but was not getting relief, the child was transported to the hospital. Our district is supplying all schools with pulse-oximeters for the nurse's use.	X-See comment		
Galena		X			X	
Haines Borough				X		
Hydaburg City		X		X		
Iditarod Area		X			X	
Juneau Borough	X		Student did not responds to inhaler. Parent was called and transported student to doctor.		X	
Kake City		X				X
Kenai Peninsula	X		Asthma attacks are not uncommon in our district		X	
Klawock City		X		X		
Kodiak Island		X		X- Needs to address age-appropriateness		
Kuspuk		X		X		
Lake & Peninsula		X		X		
Mat-Su Borough	X		One on the playground, and one on the bus			X
Nome City	X		left their device at home. The parent was contacted and			
Northwest Arctic		X		X		
Pribilof		X		X		
Sitka Borough		X			X- syringe	
Skagway City		X		X		
Southeast Island		X		X		
Southwest Region		X			X	
Tanana		X			X	

	Question #3			Question #4		
District	Yes	No	Description of asthma attack or anaphylactic episodes	Yes	No	N/A Uncertain
Unalaska City		X		X		
Valdez City	X		Students have had attacks, but they have been able to come to the office to take their medication.	X- Soc comment		
Wrangell City		X			X	
Yupiit		X				X- Needs to be based on individual needs
Totals: 32	7	24		16	11	4

Changes to HB 85 in CS HB 85 version 24-LS 0367\Y

HB 85

1.) Page 2, line 19:
"shall be permitted to carry an inhaler.."

2.) Page 2, line 20—26: *underlined deleted*
"times as long as the pupil does not endanger any person through the misuse of the inhaler. Misuse of an inhaler includes exceeding the prescribed dosage of the medication. An inhaler includes metered-dose, breath-activated, and dry powder inhalers, and spacers and holding chambers. (d) The school may confiscate a self-administered medication if a pupil misuses the medication."

3.) To page 2, line 27-28: *replaced*
"advanced nurse practitioner.....public health nurse."

4.) Not included in HB85

CSHB 85

1.) To page 2, line 19: *inserted*
"shall be permitted to carry **and store with the school nurse** an inhaler..."

2.) Page 2, lines 20-24: *replaced with*
"times. (d) If a student uses the student's prescribed medication in a manner other than as prescribed, disciplinary action according to school codes may be imposed upon the student. The imposed disciplinary action may not limit or restrict the student's immediate access to the student's prescribed medication."

3.) Page 2, lines 25-26: *replaced with*
"licensed nurse"

4.) Page 2, lines 26: *added*
"pharmacist"

Prepared by Representative Meyer's Office

Changes to HB 85 in CS HB 85 version 24-LS 0367\F

HB 85	CSHB 85
1.) Page 1, line 8 - ",or other potentially life-threatening illness.."	1.) Page 1, line 8 - Deleted - ", or other potentially life threatening illness."
2.) Page 2, line 3 - "is able to self-administer the medication safely."	2.) Page 2, lines 2-4 - Added - "has demonstrated to the health care provider the skill level necessary to administer the medication as prescribed."
3.) Not included in HB 85	3.) Page 2, lines 10-12 - Added: "(5) a written treatment plan for the pupil for managing asthma or anaphylaxis episodes and a list and dosage of medication needed during school hours that is signed by the pupil's health care provider; and"
4.) Not included in HB85	4.) Page 2, lines 13-14 - Added: "(6) any other documentation required by the school that is consistent with this section."

Prepared by Representative Meyer's Office

SENATE COMMITTEE REPORT

DATE: 3/16/05

FURTHER: Judiciary

DATE TURNED IN TO OFFICE: 4.4.05

Health, Education and Social Services Committee considered CS FOR HOUSE BILL NO. 85(JUD)

HB 85 PRESCRIBED MEDICATION FOR STUDENTS

"An Act relating to self-administration and documentation of certain types of medication prescribed to a child attending school."

and recommends:

[ ] be **replaced** with _____ **CS** _____ (_____)

[ ] adopt **previous** _____ **CS** _____ (_____)

[ ] attached amendment(s)

[ ] adopt Letter of Intent by _____ _____ Committee

[ ] further referral to _____ Committee

Senate Bill:
[ ] Same Title
[ ] New Title

House Bill:
[ ] Same Title
[ ] Technical Title Change
[ ] New Title w/ SCR #_____

NEW FISCAL NOTE(S):

Department	Date	Fiscal	Indet.	Zero	FN#

PREVIOUS FISCAL NOTE(S):

Department	Date	Fiscal	Indet.	Zero	FN#
EED	2/22			X	2

[ ] **APPROPRIATION - no fiscal note**

SIGNATURES AND RECOMMENDATIONS:	DO PASS	DO NOT PASS	NO REC	AMEND
			✓	
Lyda Green	✓			
Tony Willett	✓			
	✓			
CHAIR:	—			

REPRESENTATIVE KEVIN MEYER

HOUSE DISTRICT 30

MEMORANDUM

DATE: **April 6, 2005**

TO: **Senator Fred Dyson, Chairman**
Senate HESS Committee

CC: **Senator Gary Wilken, Vice-Chair**
Senator Lyda Green
Senator Kim Elton
Senator Donny Olson

FROM: **Michael Pawlowski, Representative Meyer's Office**

RE: **Testimony on House Bill 85 *Prescribed Medication for Students***

Mr. Chairman,

Attached is the opinion from legislative legal regarding the application of HB 85 *Prescribed Medication for Students* to private schools. Your reiteration, and clarification of the testimony I gave was that HB 85 does not apply to private schools, but that if a private school chose to follow the law they could receive the same benefits.

The attached memorandum from legislative legal clarifies that HB 85 does **not** apply to private schools, but that if a private school chose to follow the law they would benefit from the indemnity provisions and not necessarily the law itself. The distinction I failed to make in my testimony to the committee was that a private school benefits not from the passage of HB 85, but from following the prescribed steps in the legislation.

I sincerely apologize for failing to make that distinction and thank the Chairman and committee for their consideration. If I can be of any further service please contact me at extension 2812.

Thank you,

Michael Pawlowski

Email: Representative_Kevin_Meyer@legis.state.ak.us • **Toll Free:** (866) 465-4945
Session: State Capitol, Juneau, Alaska 99801-1182 • Phone: (907) 465-4945 Fax: (907) 465-3476
Interim: 716 W. 4th Ave., Anchorage, Alaska 99501-2133 • Phone: (907) 269-0199 Fax: (907) 269-0197

LEGAL SERVICES

DIVISION OF LEGAL AND RESEARCH SERVICES
LEGISLATIVE AFFAIRS AGENCY
STATE OF ALASKA

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State Capitol
Juneau, Alaska 99801-1182
Deliveries to: 129 6th St., Rm. 329

MEMORANDUM April 6, 2005

SUBJECT: Effect of HB 85 on Private Schools (CSHB 85(JUD)
Work Order No. 24-LS0367\Y)

TO: Representative Kevin Meyer
Attn: Mike Pawlowski

FROM: Jean Mischel
Legislative Counsel

You have asked whether CSHB 85(JUD) applies to private schools, and if not, whether a private school may choose to comply with the Act, should it become law, and receive what is construed as the immunity protections provided in the bill. The bill requires a school to permit self administration of certain prescribed medication by a student under a specified procedure. The procedure includes the provision of a release of liability and a hold harmless agreement to the school.

In my opinion, HB 85 does not expressly apply to private schools and, while a private school is not otherwise precluded from following an identical procedure as contained in HB 85 to allow for self administration of medication by a student at the school, it is inaccurate to say that the bill would voluntarily apply to the school and therefore afford additional protection. However, if the procedures in the bill are followed, the school would have acquired a release and indemnity agreement from the parents of the school that presumably would afford the school protection from civil liability if drafted correctly.

There is a type of exemption for religious and private schools from government regulation under AS 14.45.100. The exemption is quite narrow and reads as follows:

> AS 14.45.100. EXEMPTION. A religious or other private school that complies with AS 14.45.100 - 14.45.130 is exempt from other provisions of law and regulations relating to education except law and regulations relating to physical health, fire safety, sanitation, immunization, and physical examinations.

A "private school" is defined in AS 14.45.200 as a school that accepts no state or federal funds.

The exemption under AS 14.45.100 pertains to laws and regulations relating to education and specifically requires only those private schools that choose to comply with AS 14.45.100-14.45.300 to comply with other laws and regulations relating to health and safety. The exemption walks a fine line between competing constitutional interests including protecting public health, safety and welfare and prohibiting interference with free exercise of religion and establishment issues raised by over regulation. It may be argued under the police powers of the state that all private schools, whether in compliance with AS 14.45.100-14.45.300 or not, may be regulated for the benefit of the health, safety and welfare of the students and staff.

The exemption only requires compliance with a specific list of health and safety laws. The list does not include medication other than immunizations though the term "physical health" may be read broadly to include the administration of a select few prescription medications taken by some students. The question really is one of degree.

HB 85 does not even affect all students - only those who need asthma and anaphylactic medication and whose parents are willing to go through the documentation process required by the bill. Does HB 85 relate so strongly to a need to protect the health and welfare of students that it should be applied to all public and private school students, in the face of a potential First Amendment challenge? The legislature has made this judgment call in other instances.

For example, the legislature expressly extended the Safe School Zone Act to private schools under AS 11.61.210. A principal of a public or private school is required to train students in emergency safety drills under AS 14.03.140. In addition, a provision allowing for the search of school lockers by peace officers and other appropriate persons was cross-referenced for voluntary private school applicability under AS 14.43.190.

HB 85's effect is not expressly applicable to private schools by either a reference to private schools or the addition of a cross-reference in AS 14.45.100-14.45.300 as has been done in the past to make the legislative intent clear. Notably, a federal law encouraging states to allow self-administration of medication by students for preferential receipt of federal funds does not extend to private schools.

Absent an amendment to the bill to expressly apply the self-administration of medication procedure to private schools, it is doubtful that a court would apply the provision to private schools either for voluntary or mandatory compliance. Even if a court found that HB 85's procedure relates to "physical health" under AS 14.45.100, the exemption only requires compliance when the private school elects to meet other standards under AS 14.45.100-14.45.300. If a court found that HB 85's procedures otherwise fall within the police powers of the state, then the procedures could be mandated, a result I think that the private schools wish to avoid.

I can recommend a few changes to this bill to allow for voluntary compliance by a private school if that is the intent of this bill. Without a change, the applicability to a private

school is questionable. A private school could, it seems to me, set up its own procedures allowing self-administration of medication in the school that include a release and indemnity agreement without the passage of HB 85.

If I may be of further assistance, please advise.

JMM:lmb
05-107.lmb

HB

92

Alaska State Legislature

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Representative Mike Kelly

House District 7

MEMORANDUM

To: Senator Dyson, Chair, Health, Education and Social Services Committee
From: Rep. Mike Kelly Mike Kelly by Jm
Date: January 24, 2006
Re: Committee Hearing Request – CSHB 92(JUD)

Attached you will find the bill packet for CSHB 92(JUD) - *"An Act relating to the purchase of interests in corporations, including limited liability companies, by the University of Alaska."* The packet contains the following:

- Current version of the bill
- Sponsor Statement
- Fiscal Note
- Testimony of University of Alaska Associate General Counsel Mary E. Greene
- Questions & Answers, Associate General Counsel Mary E. Greene
- Memorandum by Craig Dorman, Vice President for Research and Academic Affairs
- Background information

In addition, I have provided written testimony from Meg Greene - acting General Counsel for the University of Alaska, written testimony from Dr. Craig Dorman – Vice President of Research for the University of Alaska and reference material.

Thank you for your time and attention to this request. If I can provide any other relevant information or answer any immediate questions you might have, feel free to contact me directly at extension 4976 or my staff, Derek Miller at extension 6890.

Member: House Finance Committee

Alaska State Legislature

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Representative Mike Kelly

House District 7

CSHB 92(JUD)

"An Act relating to the purchase of interests in nonprofit corporations by the University of Alaska."

The University of Alaska has proven to be a valuable tool in Alaska's economic development. In a desire to allow the university to continue and expand its vital role in this area, we propose a much needed change in Alaska's corporate liability laws intended to protect the university from liability arising from "piercing the corporate veil".

"Piercing the corporate veil" is *"a judicial process whereby the court will disregard the usual immunity of corporate entities from liability for wrongful corporate activities perpetrating fraud. The doctrine which holds that the corporate structure with its attendant limited liability of stockholders may be disregarded and personal liability imposed on stockholders, officers, and directors in the case of fraud or other wrongful acts done in the name of the corporation."*[1] Generally, we believe this is a sound policy intended to protect consumers from fraudulent corporate abuses and encourage good corporate citizenship. However, in the university context the application of this theory has the unintended consequence of discouraging university investment in new corporate endeavors resulting from intellectual property generated by faculty research.

The university cannot support various types of economic development initiatives or associate with public groups through nonprofit corporations without the fear of liability arising from "piercing the corporate veil". As described above, the university could become liable for the tort obligations of a corporate entity it may start up, where the entity was not adequately capitalized or insured.

In one such immediate example the university rejected a 501 (c)(3) nonprofit corporation to lead the business enterprise institute because of potential corporate veil liability. Likewise, the university has not been supportive of efforts by faculty members with intellectual property to start up corporations, recognizing that if liability were incurred by such a corporation, there would be substantial risk that such liability could pass on to the university. The most recent version of the bill stipulates that instances of fraud or other malfeasance committed by the university will not protect it under the corporate veil. This is positive change to the original bill that clarifies that while the Legislature wants to encourage responsible university investment intended to advance its research mission, it also wants to guarantee ongoing protections to the general public.

Our intent with HB 92 is to specifically define a university/corporate liability structure intended to encourage new university investment in nonprofit corporations resulting from research-generated intellectual property or companies created and managed on university lands. The University of Alaska is a valuable component to Alaska's economic engine and this bill will go to great lengths to expand its ability to increase economic development in our state.

---

[1] Nolan, J.R., & Nolan-Haley, J. M. (1990) Piercing the corporate veil In *Black's Law Dictionary*. (pp. 1147-1148). St. Paul, MN: West.

FISCAL NOTE

STATE OF ALASKA
2005 LEGISLATIVE SESSION

Fiscal Note Number: 1
Bill Version: CSHB 92(EDU)
(H) Publish Date: 4/18/05

Revision Date/Time (Note if correction):
Dept. Affected: University of Alaska
Title: University of Alaska and Corporations
RDU
Component
Sponsor: Representative Kelly
Requester
Component No.

Expenditures/Revenues (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

OPERATING EXPENDITURES	FY 2006	FY 2007	FY 2008	FY 2009	FY 2010	FY 2011
Personal Services						
Travel						
Contractual						
Supplies						
Equipment						
Land & Structures						
Grants & Claims						
TOTAL OPERATING	0.0	0.0	0.0	0.0	0.0	0.0
CAPITAL EXPENDITURES						
CHANGE IN REVENUES ( )						

FUND SOURCE (Thousands of Dollars)

1002 Federal Receipts						
1003 GF Match						
1004 GF						
1005 GF/Program Receipts						
1037 GF/Mental Health						
Other (Specify Type--Do not abbreviate)						
TOTAL	0.0	0.0	0.0	0.0	0.0	0.0

Estimate of any current year (FY2005) cost: 0.0
Mark this box (X) if funding for this bill is included in the Governor's FY 2006 budget proposal:

POSITIONS

Full-time						
Part-time						
Temporary						

ANALYSIS: *(Attach a separate page if necessary)*

The bill limits the universitys' legal liability to the amount that the university invested into a separate corporation for the purpose of advancing the public purpose of the university. This bill would create no additional cost for the University.

Prepared by: Pat Pitney
Phone 450-8191
Division: University of Alaska
Date/Time 4/15/05 1:53 PM
Approved by: Pat Pitney
Date 4/15/2005CS
Agency: University of Alaska

TESTIMONY OF MARY E. GREENE
ASSOCIATE GENERAL COUNSEL
UNIVERSITY OF ALASKA

I appreciate the opportunity to present a fuller explanation of some of the questions posed by members to me during the meeting held April 5, 2005, at 5:30 p.m.

One of the questions raised concerned why the University of Alaska should be treated differently than other corporations. There are several reasons. First, unlike most corporations, the University is a constitutional corporation created in Article VII, section 2 of the Alaska Constitution. That makes the University a part of the state unlike other corporations. The property of the State and the University is owned by the people of Alaska, not by a few shareholders. The University's mission is to serve the public interest, not provide dividends to investors like other corporations. Public money and public assets would be tapped if a plaintiff was able to pierce the corporate veil and reach University assets in addition to the money the University invested as a shareholder.

The effort of the University to avoid potential liability beyond those funds it voluntarily invests in a corporation is very much like the state's actions when it creates a state corporation or authority and refuses to pledge the credit of the state. That says to creditors of the authority or state corporation that they can only look to the assets the legislature has placed in the authority or corporation to pay the debts of the authority or corporation. The legislature has frequently used this tool to protect state assets while at the same time promote economic development or create a service that serves the public interest. For example, the legislature refused to pledge the credit of the state in the creation of the Alaska Railroad Corporation (AS 42.40.690), the Alaska Housing Finance Corporation (AS 18.56.170), corporations organized under the Business and Industrial Development Corporation Act (AS 10.10.190), the Alaska Student Loan Corporation (AS 14.42.260), the Alaska Medical Facility Authority (AS 18.26.150), Regional Electrical Authorities (AS 18.57.110), the Knik Arm Bridge and Toll Authority (bonds) (AS 19.75.241), state and municipal port authorities (AS 29.35.640), Regional Resource Development Authorities (bonds) (AS 30.13.090), Adak Reuse Authority (bonds) (AS 30.17.240), the Alaska Natural Gas Development Authority (AS 41.41.400), Alaska Energy Authority (bonds) (AS 44.83.130), the Alaska Municipal Bond Bank Authority (bonds and notes) (AS 44.85.130), and the Alaska Industrial Development and Export Authority (bonds) (AS 44.88.120). HB 92, if enacted, would do no more for University investments than the legislature has done is these instances. It would allow the University to voluntarily invest funds where the Board of Regents authorizes the investment AND the investment advances a public purpose. Those voluntarily invested funds would, of course, not be protected. They would be available for the payment of the corporation's debts. But a clever plaintiff would not be able to go beyond that corporation's assets to the other assets of the University. That is, the University would not have to pledge its credit by investing in a project that advances a public purpose.

If granted this protection, the University could help its faculty develop their research ideas into marketable goods and promote the economic development of Alaska. It could participate in worthwhile non-profit corporations that meet a public purpose. It could do so without risking the public's money that is invested in the University.

Thank you.
Mary E. Greene
Associate General Counsel

QUESTIONS & ANSWERS
ASSOCIATE GENERAL COUNSEL MARY E. GREENE

5 examples of UA or any university's investment in a corporation that worked well.

THE UNIVERSITY GENERALLY DOES NOT INVEST IN CORPORATIONS. ONE OF THE REASONS IT DOES NOT, IS THAT, AS A DEEP POCKET, IT IS VERY CONCERNED ABOUT LIABILITY IF THE CORPORATE VEIL IS PIERCED.

5 reasons why UA would invest in a corporation, and what the benefits of UA investment would be to UA and to the venture.

START-UP CORPORATIONS WITH FACULTY MEMBER:

1. PROMOTE ECONOMIC DEVELOPMENT BY TURNING A RESEARCH PRODUCT INTO A MARKETABLE PRODUCT;
2. FOSTER BETTER RELATIONSHIPS WITH RESEARCH FACULTY;
3. ENHANCE REPUTATION OF UNIVERSITY THROUGH MARKETABLE PRODUCT (LIKE UNIV. OF FL WITH GATORADE) OR INVENTIVE PRODUCT (LIKE SOME OF THE MAPPING PROGRAMMING THAT IS GOING ON HERE)

NON-PROFIT COOPERTIVE CORPORATION WITH OTHER UNIVERSITIES OR RESEARCHERS:

1. CHANCE TO WORK WITH OTHERS TO SOLVE LARGE IMPORTANT ISSUES
2. ASSIST OTHERS IN ADDRESSING ISSUES OF PUBLIC CONCERN

Is there in-kind investment that results in equity? How would that be structured?

THERE ARE IN START-UPS. NORMALLY WHAT UNIVERSITIES DO IS TO CONTRIBUTE THEIR INTEREST IN PATENTS OR OTHER INTELLECTUAL PROPERTY TO THE CORPORATION. OTHERS ARE MORE WILLING TO LEND MONEY TO A START-UP IF THE WHOLE IP IS PORPERTY OF THE CORPORATION. IT DOES NO HARM, NO MONEY IS INVESTED, BUT IT HELPS THE START-UP.
I CANNOT GIVE SPECIFICS, BUT IT IS COMMON IN RESEARCH UNIVERSITIES TO DO SOMETHING LIKE THIS. MOST DO NOT MAKE MONEY FOR THE CORPORATION, BUT DO GET THINGS TO MARKET. I SPOKE WITH ONE OF THE ATTORNEYS FROM THE UIVERSITY OF CHICAGO ABOUT THEIR PROGRAM AT A CONFERENCE A WHILE AGO. THEY HAD SEVERAL START-UPS. NONE HAD EVER PAID OFF IN DOLLARS, BUT ALL THOUGHT IT STILL TO BE A GOOD IDEA.

3 examples of lost opportunities for UA under current liability law.

1. BUSINESS ENTERPRISE INSTITUTE WANTED TO ORGANIZE AS A NON-PROFIT WITH UNIVESITY PARTICIPATION INSTEAD OF AS A DEPARTMENT OF THE UNIVERSITY. GENERAL COUNSEL WOULD NOT ALLOW BECAUSE OF THE DEEP POCKET/CORP. VEIL ISSUE.
2. WE HAVE HAD OFFERS TO PARTICIPATE IN START-UPS WITH FACULTY MEMBERS, BUT I DO NOT KNOW THE SPECIFICS.

Arguments for eliminating lawsuit options against UA, in the face of the loss of protection the current law may give non-UA stockholders of the spin-off company, or any member of the public that may be harmed by the spin-off.

1. THE CREDITORS OF THE CORP AND OTHER PARTICIPANTS WOULD BE TREATED JUST THE SAME AS THE LAW NORMALLY WOULD TREAT THEM. EVERY INVESTOR WOULD LOSE ITS SHARE OF THE MONEY INVESTED. THE CREDITORS OF A CORPORATION CAN NORMALLY NOT COLLECT MONEY OWED BY THE CORPORATION FROM AN INVESTOR. THAT IS THE WHOLE REASON TO INCORPORATE IN MANY INSTANCES. AN INVESTOR CAN PROTECT HIS OR HER ASSETS WHILE STILL INVESTING IN THE BUSINESS.

2. THE ONLY THING THAT WOULD BE LOST TO CREDITORS/OTHER INVESTORS IS THE POSSIBILITY OF GOING AFTER THE DEEP POCKET OF THE UNIVERSITY BY ATTEMPTING TO PIERCE THE CORPORATE VEIL. THERE ARE PRECAUTIONS THAT THE UNIVERSITY CAN TAKE, BUT THE TEST IN ALASKA IS NOT BLACK/WHITE. IT IS A BALANCING TEST. IF THE PLAINTIFF WAS SYMPATHETIC, THERE IS ENOUGH WIGGLE ROOM IN THE LAW FOR A JURY THAT WAS SO INCLINED TO HELP OUT THE SYMPATHECTIC PARTY BY ZAPPING THE UNIVERSITY. THE UNIVERSITY CANNOT RISK THE PUBLIC'S ASSETS BY RISKING A DETERMINATION THAT WE WERE TOO INVOLVED TO KEEP CORPORATE PROTECTIONS GIVEN TO ALL, AND THUS ARE LIABLE FOR THE CORPORATION'S DEBTS.

Would UA investments typically be temporary?

I DOUBT IT. HOWEVER, IF A START-UP IN FACT TOOK OFF AND A LARGER CORPORATION WANTED TO BUY IT, THE UNIVERSITY WOULD LIKELY SELL SO AS NOT TO BLOCK THE DEAL. WITH NON-PROFITS, NORMALLY THERE IS LITTLE OR NO WAY OUT ONCE YOU INVEST FROM A PRACTICAL PERSPECTIVE. I AM GOING TO FORWARD THIS TO DIANNE MCLEAN WHO DOES IP FOR THE UNIVERSITY. SHE MAY HAVE SOME KNOWLEDGE ABOUT START-UP OR OTHER OPPORTUNITIES THE UNIVERSITY HAS MISSED.

MEMORANDUM

DATE: 6 April 2005
TO: House Education Committee, Chair Mark Neuman
FROM: Craig Dorman, Vice President for Research and Academic Affairs, University of Alaska Statewide System
RE: Comments re HB92 from

Thank you for the opportunity to testify briefly last evening on the proposed change to AS 14.40.458, University Corporate Relations. Per your request, I will briefly reiterate my points:

The authorization requested is limited to ownership of stock, or membership in a corporation, that would "advance the mission of the University of Alaska, pursuant to the policies of the Board of Regents". Thus, such ownership or membership would be undertaken only to advance the instructional and research responsibilities of the university, and not principally as a money-making enterprise.

The motivation for participation in ownership of a corporation derives ba ically from PL- 96-517 of 1980 (and amendments in PL 98-620 of 1984), commonly referred to as the Bayh-Dole Act. This Act permits universities to elect ownership of inventions made under federal funding, and to become directly involved in the commercialization process. In the quarter century since its enactment, this Act has fundamentally changed university-industrial relationships, and has resulted in the introduction of many new technologies into public use. While there are a variety of ways that universities can transfer their technology to industry, the incubation of new small businesses has proven very successful in enhancing local, state and national economic development, particularly in the vicinity of university campuses. As part of that incubation process, universities may encourage and even assist their faculty to take an equity interest in bringing one of their inventions or ideas into public use; and since under Bayh-Dole the ownership of the invention accures to the university (with sharing rights as detailed in the testimony of Judge Greene), universities may (and many do) elect to invest their non-general fund resources to encourage such activity. All such arrangements are conducted as business arrangements with full review by University General Counsel, and the proposed provision in AS 14.40 seeks to limit the University's liability to the obligations specified in those agreements.

The university is seeking this provision at this time because of recently enhanced emphasis on support of state needs, and in particular our interest in supporting diversified economic development in the state. As I have stated in earlier testimony to the House and Senate Finance Committees, nationally, industry conducts 70% of R&D, and universities conduct 14%. In Alaska, UA conducts

55% of R&D, and industries only 10%. This disparity suggests the need for even greater diligence on the part of UA than is typical for universities, in taking an active role in the development and incubation of new business. Recent actions to this end include both external and internal reviews of our technology transfer procedures, the formation of the Business Enterprise Institute (BEI) at the College of Business and Public Policy at UAA, the establishment of the Office of Electronic Miniaturization and search for a Vice Chancellor for Research and Economic Development at UAF, and UAF collaboration with local groups in Fairbanks in the establishment of the "NanookTech Technology Accelerator".

BEI and NanookTech are examples of entities that may evolve into non-profit corporations in which the university may wish to participate. As with stock ownership, the intent of the proposed change to AS 14.40 is to limit the university's liability to those obligations to which it explicitly agrees as a condition of its membership. Another example, which I briefly mentioned during my oral testimony, is the Alaska Ocean Observing System (AOOS), one of a number of such regional systems around the U.S., as recommended by the U.S. Commission on Ocean Policy. AOOS is designed to support safety of life at sea, improved weather forecasting, fisheries, and safety of marine transportation, and the University has played a leading role in its establishment and development. As AOOS and the associated national associations and federal funding mechanisms mature, it will likely become a 501(c)(3) corporation, and again the University would like to be able to continue to participate without the fear of liability reaching beyond its explicit obligations as a member.

SPIN-OFF COMPANY MODELS FOR UNIVERSITIES: *Hands Off, Hands On, or Up-to-Your-Neck*

Prepared by:
K. Diane McLean
Director, Intellectual Property & Licensing
Deputy Director, Office of Sponsored Programs
University of Alaska Fairbanks

Universities that are able to accept equity in start-up businesses, usually accept the equity in lieu of up-front licensing fees. Most universities have policies dictating whether or not the university will accept a seat on the start-up's board and define triggers are for stock divestiture. Many universities try to hold the stock for as short a time as is reasonable. The desired technology is licensed to the start-up for reasonable commercial terms. Sometimes the inventing faculty member is given a leave of absence during the new business' startup phase. Agreements are often made that allow the start-up access to university facilities.

There are typically three approaches used by universities to spin-off companies: Hands Off (U. of Washington uses this one.), Hands On, or the Up-to-Your-Neck approach. The Hands off Approach requires the faculty member to develop his/her own business plan, find venture funding and pay all other start-up costs. The university negotiates with a representative of the company (not the faculty member to avoid conflict of interest) for the technology license. Typically, the deal has a low or no up-front fee that is balanced by higher than usual royalties down the road and the university receiving equity in lieu of the up-front money. In that case, the university's costs are the patenting and maintenance fee payments while waiting on a royalty stream to begin.

With the Hands on Approach the university may review the faculty member's business plan, go with them to help acquire venture capital, and maybe provide a little funding. Otherwise it would be the same as the Hands Off Approach.

With the Up-to-Your-Neck approach the university puts together the business management team or provides a business incubator. The university provides substantial funding and other start-up support for the business.

Typically universities that regularly enter into start-ups or have ownership in other corporations use a research foundation/corporation as the intermediary. These foundations come in all sorts of flavors. Some universities run all their research awards through the foundation. Others use the foundation to handle IP, development and entrepreneurial activities, etc.

Universities that handle start-ups thoughtfully and well attract high energy, innovative faculty who, in turn, attract top-notch students. (Students often tend to settle near communities where they attended school.) Start-ups can provide training grounds for students and valuable collaborators for university faculty, as well as economic development opportunities. There are a number of successful models for handling start-ups.

Health, Education, and Social Services Committee
Alaska State Senate

MEMORANDUM

To: Senator Ben Stevens, President
Alaska State Senate

From: Senator Fred Dyson, Chair
Senate H.E.S.S. Committee

Date: February 3, 2006

Re: HB 92—" An Act relating to the purchase of interests in nonprofit corporations by the University of Alaska."

The Senate Health, Education, and Social Services Committee respectfully requests that HB 92 be waived from the H.E.S.S. Committee and instead, be referred to the Labor & Commerce or Judiciary Committee for consideration.

Respectfully,

Senator Fred Dyson, Chair

Senator Donny Olson

Senator Lyda Green

Senator Kim Elton

Senator Gary Wilken

•Alaska State Capitol • Juneau, Alaska 99801 • Butrovich Room 205 • Monday, Wednesday, Friday 1:30 p.m. •
• Committee Aide Jason M. Hooley • (907) 465-3762 phone • (907) 465-4587 fax •

HB

109

Representative Jay Ramras
Co-Chair, House Resources
V-Chair, Economic Develop.
Tourism & Trade
House State Affairs
119 N. Cushman St. Suite 207
Fairbanks, Alaska 99701
Phone: (907) 452-1088
Fax: (907) 452-1146

Alaska State Legislature

While in Session
State Capitol, Room 104
Juneau, Alaska 99801-1182
(907) 465- 3004
Fax: 465-2070
Toll Free: (877) 465-3004

House District 10

House of Representatives

Sponsor Statement

CSHB 109(FIN)

Hearing impairment has been shown to be the most common disability in newborns, affecting about 3 in every 1,000 babies. House Bill 109 will protect newborns in the State of Alaska by mandating that newborns receive hearing screening at birth, or within thirty days of birth, if not born in a hospital. Once at risk infants have been identified, this bill will then serve to assist parents of at risk children with appropriate, available follow-up care. Finally, the Department of Health and Social Services shall prepare an annual report to the Governor detailing the program's needs and success.

Statistics show that in Alaska, 30 to 40 babies are born each year with some type of congenital hearing defect. Further studies have shown that children with hearing impairment not detected at birth, will not be detected, until 2-3 years of age, and that the most critical period for speech and language development is from birth to three years of age. When children are not identified and served early, special education for a child with a hearing loss may cost an additional $420,000, and deafness has an estimated lifetime cost of approximately $1 million per individual. These savings in special education costs will pay for universal newborn hearing screening many times over.

As of December 2003, 80% of newborns in Alaska have been screened for hearing impairment. Even though 80% sounds like a large number, because newborn hearing screening is not mandated and the screening, reporting, and follow-up is not institutional in facilities across the state, Alaska remains in the "unsatisfactory" category when rated nationally.

Representative_Jay_Ramras@legis.state.ak.us

LEGAL SERVICES

DIVISION OF LEGAL AND RESEARCH SERVICES
LEGISLATIVE AFFAIRS AGENCY
STATE OF ALASKA

(907) 465-3867 or 465-2450
FAX (907) 465-2029
Mail Stop 3101

State Capitol
Juneau, Alaska 99801-1182
Deliveries to: 129 6th St., Rm. 329

MEMORANDUM February 4, 2005

SUBJECT: CSHB 109( ), Infant Hearing Screening
(Work Order No. 24-LS0450\G)

TO: Representative Jay Ramras
Attn: Jane Pierson

FROM: Jean M. Mischel
Legislative Counsel

You have requested a sectional summary of the above-described bill.

As a preliminary matter, note that a sectional summary of a bill should not be considered an authoritative interpretation of the bill and the bill itself is the best statement of its contents. If you would like an interpretation of the bill as it may apply to a particular set of circumstances, please advise.

Section 1. Describes legislative findings with respect to newborn and infant hearing loss, the value of early intervention and the relationship to language ability.

Section 2. Describes legislative intent to cover 100 percent of newborns and infants under the hearing screening and intervention program established by the act by January 1, 2008.

Section 3. Adds certain individuals who have been authorized by the Department of Health and Social Services to the list of individuals who may perform hearing screening tests without an audiology license.

Section 4. Requires the state Bureau of Vital Statistics to forward names and addresses of parents of newborns born outside of a hospital to the Department of Health and Social Services for notification of the merits of hearing screening.

Section 5. Requires certain minimum insurance coverage for newborn and infant screening.

Section 6. Establishes a newborn and infant hearing screening, tracking, and intervention program within the Department of Health and Social Services.

Section 7. Authorizes the Department of Health and Social Services to promulgate regulations required to implement the act before the effective date of the act.

Section 8. Adds a revisor's instruction to make conforming amendments.

Section 9. Provides an immediate effective date for secs. 6 through 8 of the act.

Section 10. Provides a January 1, 2006 effective date except as stated in sec. 9.

JMM:lmb
05-031.lmb

FISCAL NOTE

STATE OF ALASKA
2005 LEGISLATIVE SESSION

Fiscal Note Number:
Bill Version: HB109CS(FIN)-DHSS-DPH-04-15-05
( ) Publish Date:

Revision Date/Time (Note if correction): corrected 4/15/05
Dept. Affected: Health & Social Services

Title: RELATING TO NEWBORN HEARING SCREENING
RDU: Public Health
Component: Women, Children and Family Health

Sponsor: RAMRAS
Requester: HOUSE (FIN)
Component No.: 2788

Expenditures/Revenues (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

OPERATING EXPENDITURES	FY 2006	FY 2007	FY 2008	FY 2009	FY 2010	FY 2011
Personal Services						
Travel						
Contractual						
Supplies						
Equipment						
Land & Structures						
Grants & Claims	31.9	39.4	47.4	55.8	64.6	64.6
Miscellaneous						
TOTAL OPERATING	**31.9**	**39.4**	**47.4**	**55.8**	**64.6**	**64.6**
CAPITAL EXPENDITURES						
CHANGE IN REVENUES (0)						

FUND SOURCE (Thousands of Dollars)

1002 Federal Receipts			(29.7)	(111.6)	(115.9)	(119.8)
1003 GF Match						
1004 GF	31.9	39.4	77.1	167.4	180.5	184.4
1037 GF/Mental Health						
Other(Specify Type-do not abbreviate)						
Other(Specify Type-do not abbreviate)						
TOTAL	**31.9**	**39.4**	**47.4**	**55.8**	**64.6**	**64.6**

Estimate of any current year (FY2005) cost:
Mark this box (X) if funding for this bill is included in the Governor's FY 2006 budget proposal:

POSITIONS

Full-time						
Part-time						
Temporary						

ANALYSIS: *(Attach a separate page if necessary)*

The intent of this bill is to ensure all newborns are provided with hearing screening within 30 days of their birth, and that those identified with a positive screen or high risk factors receive a second screen or diagnostic work-up, are enrolled in early intervention and receive treatment as needed. Projected costs associated with maintenance of the Early Hearing Detection and Intervention program (EHDI) are based on the following assumptions: 1) The number of newborns screened is based on the average number of births currently at 10,000 per year. 2) The diagnostic rate of hearing loss is estimated to be at 0.3% of the 10,000 births=30 newly diagnosed infants per year, however, not all newborns with hearing loss will be immediately identified. 3) 90% of newborns would be screened by FY 06; 95% by FY 07; and 100% by FY 08 and beyond. (Continued on P.2)

Prepared by: Richard Mandsager, M.D. Phone 465-3090
Division: Public Health Date/Time 04/13/2005
Approved by: Joel S. Gilbertson, Commissioner Date 04/15/2005
Agency: Department of Health and Social Services

STATE OF ALASKA
2005 LEGISLATIVE SESSION

BILL NO HB109CS(FIN)-DHSS-DPH-04-15-05

ANALYSIS CONTINUATION

4) There is a need to follow an additional 10% of all newborns each year who are at high risk for later onset hearing loss during their first three years of life. Thus, the program requires a reporting and surveillance system for tracking all newborns and assisting them with ongoing hearing screening, diagnostic and intervention services.

At present the Division of Health Care Services is receiving two federal grants to support the development of this program. One grant, scheduled to be completed in March of FY 05, covers the expenses associated with development of the newborn hearing program, including assisting hospitals with implementation and education, and professional and public educational information. The second grant will end in August of 2005 and covers start up costs associated with the statewide early detection/intervention surveillance and tracking system. Both grants have been submitted for continuation funding for three additional years. This would provide funds for infrastructure costs through March 2008 if awarded. General Funds are also being requested in FY08 to fund the fourth quarter activities after the expiration of the continuation grant. This portion is shown as a switch fund from Federal to GF.

The increased line item expenditures shown on page 1 will be utilized for:
GRANTS AND CLAIMS ($31.9 in FY 06): Additional funds for special hearing resources would be needed for the existing Early Prevention/ILP programs to work with the anticipated increased volume as children are identified earlier and thus require services during the 0-3 period. The additional grant funds would be awarded incrementally over the next five fiscal years to allow for increased capacity-building to support special hearing services for children identified with hearing loss in preparation for school readiness and learning. The dollar figure is based on:

1) An average FY 05 cost of $3,100 per newly enrolled infant, with a 3% inflation factor built in annually. 2) Only assumes about 50% of the newly diagnosed infants would enroll in the early intervention hearing resources program (10 new infants in FY 06; 12 in FY 07; 14 in FY 08; 16 in FY 09; and 18 in FY 10 and FY 11).

The General Funds replacing Federal Funds (and so not shown as line item expenditures on page 1) will be allocated by cost category as follows:

PERSONAL SERVICES ($72.0 covers all of these personnel expenses in FY 09 and assumes a 3.5 percent annual merit increase):
a) 0.5 FTE - EHDI Health Program Manager II (R/19). This position oversees the maintenance of the reporting and surveillance activities of the program, assures early intervention referrals, tracks high-risk infants through the age of 3, provides outreach education to providers, and technical assistance to health care facilities throughout the state.
b) 0.5 FTE - Administrative Clerk III (R/10). This position provides administrative support and data entry for the activities required for maintenance of a statewide newborn hearing screening program.

TRAVEL ($1.0 in FY 08): Travel costs are included for the EHDI manager to visit screening sites for TA and program compliance. Additional travel funds would be required in FY 09 with the termination of federal funding.

(Continued on P. 3)

STATE OF ALASKA
2005 LEGISLATIVE SESSION

BILL NO. HB109CS(FIN)-DHSS-DPH-04-15-05

ANALYSIS CONTINUATION

SUPPLIES ($1.0 in FY 08): This includes the cost of postage to mail brochures and technical assistance resources.

CONTRACTUAL ($27.7 in FY 08): Includes the actual cost of supporting web-based data and surveillance system. Cost averages at $3.00 per newborn. Costs also include those needed for the reprinting of educational materials for parents and providers. Slight increases in contractual costs are included in FY09 and beyond.

FISCAL NOTE

STATE OF ALASKA
2005 LEGISLATIVE SESSION

Fiscal Note Number: 3
Bill Version: CSHB 109(FIN)
(H) Publish Date: 4/14/05

Revision Date/Time (Note if correction):
Dept. Affected: Education & Early Development
Title: "An Act relating to establishing a screening, tracking, and intervention program related to the hearing of newborns"
RDU: TLS
Component: Special & Supplemental Services
Sponsor: Representative Ramras
Requester: Labor and Commerce
Component No.: 166

Expenditures/Revenues (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

OPERATING EXPENDITURES	FY 2006	FY 2007	FY 2008	FY 2009	FY 2010	FY 2011
Personal Services						
Travel						
Contractual						
Supplies						
Equipment						
Land & Structures						
Grants & Claims	0.0	0.0	0.0	0.0	0.0	0.0
Miscellaneous						
TOTAL OPERATING	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**
CAPITAL EXPENDITURES						
CHANGE IN REVENUES ( )						

FUND SOURCE (Thousands of Dollars)

1002 Federal Receipts						
1003 GF Match						
1004 GF	0.0					
1005 GF/Program Receipts						
1037 GF/Mental Health						
Other (Specify Type--Do not abbreviate)						
TOTAL	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**

Estimate of any current year (FY2005) cost: 0.0
Mark this box (X) if funding for this bill is included in the Governor's FY 2006 budget proposal:

POSITIONS

Full-time						
Part-time						
Temporary						

ANALYSIS: *(Attach a separate page if necessary)*

Sec. 47.20.330 relates to the establishment of guidelines for the provision of follow-up care for newborn and infant children in the state who have been identified as having or being at risk of developing a hearing loss. The Department of Education & Early Development identifies no costs at this time.

Prepared by: Barbara Thompson, Director
Phone: 465-8727
Division: Teaching & Learning Support
Date/Time: 4/12/05 10 08 AM
Approved by: Karen Rehfeld, Deputy Comissioner
Date: 04/12/2005
Agency: Education & Early Development

FISCAL NOTE

STATE OF ALASKA
2005 LEGISLATIVE SESSION

Fiscal Note Number: 2
Bill Version: CSHB 109(FIN)
(H) Publish Date: 4/14/05

Revision Date/Time (Note if correction):
Dept. Affected: Commerce
Title: Screening Newborns for Hearing Ability
RDU: Occupational Licensing (117)
Component: Occupational Licensing
Sponsor: Ramras, et al
Requester: House Finance
Component No.: 2360

Expenditures/Revenues (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

OPERATING EXPENDITURES	FY 2006	FY 2007	FY 2008	FY 2009	FY 2010	FY 2011
Personal Services						
Travel						
Contractual						
Supplies						
Equipment						
Land & Structures						
Grants & Claims						
Miscellaneous						
TOTAL OPERATING	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**
CAPITAL EXPENDITURES						
CHANGE IN REVENUES ( )						

FUND SOURCE (Thousands of Dollars)

1002 Federal Receipts						
1003 GF Match						
1004 GF						
1005 GF/Program Receipts						
1037 GF/Mental Health						
Other 1156 - Receipt Supported Services						
TOTAL	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**

Estimate of any current year (FY2005) cost: 0 0
Mark this box (X) if funding for this bill is included in the Governor's FY 2006 budget proposal:

POSITIONS

Full-time						
Part-time						
Temporary						

ANALYSIS: *(Attach a separate page if necessary)*

The amendment made to the Audiology statute in Section 3 of this bill does not require new funding to be implemented.

Prepared by: Jennifer Strickler, Administrative Manager
Phone: (907) 465-2144
Division: Occupational Licensing
Date/Time: 4/11/05 6:24 PM
Approved by: Edgar Blatchford, Commissioner
Date: 4/11/2005
Agency: Commerce, Community, and Economic Development

(Revised 9/23/2004 OMB)

Why Is Mandatory Newborn Hearing Screening and Reporting So Important?

1. Every day, 33 babies (or 12,000 each year) are born in the United States with permanent hearing loss, or 3 in every 1,000 births (1). In Alaska, approximately 10,000 babies are born each year and according to statistics 30-40 will likely have some type of congenital hearing loss.

2. The evidence for the benefits, practicability, and cost-efficiency of universal newborn hearing screening is so compelling that 38 other states have passed legislative mandates requiring that newborns be screened for hearing loss (2).

3. Hearing impairment is the most common disability in newborns, with a higher incidence than cerebral palsy, Down Syndrome, and severe mental retardation (3).

4. Hearing impairment is approximately 30 times more prevalent than PKU and hypothyroidism, screened through the metabolic disorder screening programs, and mandated by law in all 50 states. (4).

5. The cost of identifying a newborn with hearing loss is less than $1/10^{th}$ the cost of identifying newborns with metabolic disorders such as PKU and hypothyroidism, for which screenings are required in every state (5). For most birthing hospitals, the cost for newborn hearing screening per child is between $20 - $60 and continues to decrease (6). Many birthing facilities in Alaska, implementing newborn hearing screening voluntarily, include the cost in the total labor and delivery package cost.

6. Children not detected at birth or soon after, will not be detected, on average, until 2-3 years of age, and the most critical period for speech and language development is from birth to three years of age (7).

7. When children are not identified and served early, special education for a child with hearing loss may cost an additional $420,000, and deafness has an estimated lifetime cost of approximately $ 1 million per individual (8). These savings in special education costs will pay for universal newborn hearing screening many times over.

8. If left undetected, hearing loss can impair a child's language, speech, psycho-social and cognitive development. Recent research has compared children with hearing loss who receive early intervention and amplification (i.e. hearing aids) before 6 months of age versus after 6 months of age. By the time they enter first grade, children identified earlier (prior to 6 months of age) are 1-2 years ahead of their later-identified peers in language, cognitive, and social skills (9, 10, 11).

9. If it remains undetected, even mild hearing loss or hearing loss in only one ear has substantial detrimental consequences. For example, research shows that children

with hearing loss in one ear are ten times as likely to be held back at least one grade compared to a matched group of children with normal hearing (12).

10. The American Academy of Pediatrics, the National Institutes of Health, the American Academy of Audiology, the Joint Committee on Infant Hearing, and the National Association of the Deaf have recommended that all babies be screened for hearing loss before they leave the hospital (13).

11. To date, 23 of 23 communities in Alaska with birthing hospitals have voluntarily implemented universal newborn hearing screening programs. The majority of the screenings are performed in hospitals by nurses prior to discharge. However, in some smaller communities, public health nurses perform the screenings during home visits after hospital discharge. As of December 2003, the total number of newborns in Alaska that received hearing screening was approximately 80% (14).

12. Even though 80% sounds like a large number of Alaska's newborns, because newborn hearing screening is not mandated and the screening, reporting and follow-up is not institutionalized in facilities across the state, Alaska remains in the "unsatisfactory" category when rated nationally.

13. Due to Alaska's large geographic size, high staff turnover occurs as well as difficulty recruiting and keeping healthcare providers in many of it's more rural communities. And because the screening and reporting is not mandated, it is often times not a priority at birthing facilities and among providers. As a result, it is increasingly difficult to keep nurses and other providers with the knowledge necessary to maintain a newborn hearing screening program. Gaps in screening occur in hospitals, thus babies miss their screening and are not followed for high risk factors.

Alaska Early Hearing Detection & Intervention Program Overview

January 2005

In Alaska each year, approximately 10,000 babies are born and according to national statistics, about 30 of them will have some type of congenital hearing loss.

Hearing impairment is the most common disability in newborns, with a higher incidence than cerebral palsy, Down Syndrome and severe mental retardation.

Early Identification is important because:

- The most important period of speech and language development is from birth to age three.
- Delay in diagnosis can impair a child's language, speech, psycho-social and cognitive development.
- The average age of identification of a hearing impairment in the absence of newborn hearing screening is 2-3 years of age.
- Through early identification, children identified at birth with a hearing loss can learn and progress at a rate comparable to those with normal hearing.

Alaska EHDI Program

The Alaska Early Hearing Detection & Intervention (EHDI) Program began in April 2000. the EHDI Program is funded by two federal grants from: the Health Resources & Services Administration (HRSA) and Centers for Disease Control & Prevention (CDC).

Key program include the following:

- Ensure that babies born in Alaska have newborn hearing screening prior to hospital discharge
- Ensure that all newborns who fail hearing screening receive an audiological evaluation by three months of age.
- Ensure that infants diagnosed with hearing loss are referred to and enrolled in appropriate early intervention and other needed services by six months of age.

Screening

To date, 23 of 23 communities within Alaska have implemented universal newborn hearing screening programs. The majority of screenings are performed in hospitals by nurses prior to discharge. However, in some smaller communities, public health nurses perform the screen during home visits after hospital discharge.

Legislation

Nationwide, 38 states have enacted legislation requiring hospitals to implement newborn hearing screening programs. In Alaska, newborn hearing screening was introduced and worked on during the 2001, 2002, 2003, and 2004 legislative sessions.

Data & Evaluation

A primary role of the Alaska EHDI Program is to support hospitals, audiologists and other health care providers, and assist early intervention programs (Infant Learning Program) in their tracking and follow-up efforts. The EHDI Program received a grant from the Centers for Disease Control & Prevention (CDC) to develop an electronic data tracking and surveillance system to facilitate the follow-up process and ensure smooth transition occurs through services. The EHDI Program is purchasing the web-based database, Oz, and will begin implementing in communities in 2005.

Loaner Program

The EHDI Loaner Program provides assistive hearing devices (i.e. hearing aids) for children (0-3 years) whose families cannot otherwise afford them. For example, these families are not eligible for Denali Kid Care and/or do not have private insurance that covers hearing aids and/or cannot afford to purchase hearing aids themselves. The Loaner Program allows these families to "borrow" money to purchase hearing aids for 6 12 months. The Loaner Program is made possible through a grant from the Mental Health Trust Authority.

Education & Outreach

The EHDI Program travels to communities introducing the Alaska EHDI Program. Presentations target primary health care providers in those communities (i.e. pediatricians, public health nurses, community health aide/practitioners) regarding newborn hearing screening and early hearing detection and intervention.

To assist with this effort, educational materials were developed by EHDI Program with assistance by many dedicated providers and parents. The following materials are available from the EHDI Program: 1) general brochure regarding: universal newborn hearing screening for parents and prospective parents, 2) brochure outlining the protocol for parents to follow if their newborn does not pass the newborn hearing screening, 3) basic hearing loss information for parents and the general public, 4) parent resource manual for families of children diagnosed with hearing loss, 5) provider guide for health care providers, 6) hospital orientation manual regarding implementation of universal newborn hearing screening, and 7) video/DVD for community health aide/practitioners (CHA/Ps) in rural Alaskan communities.

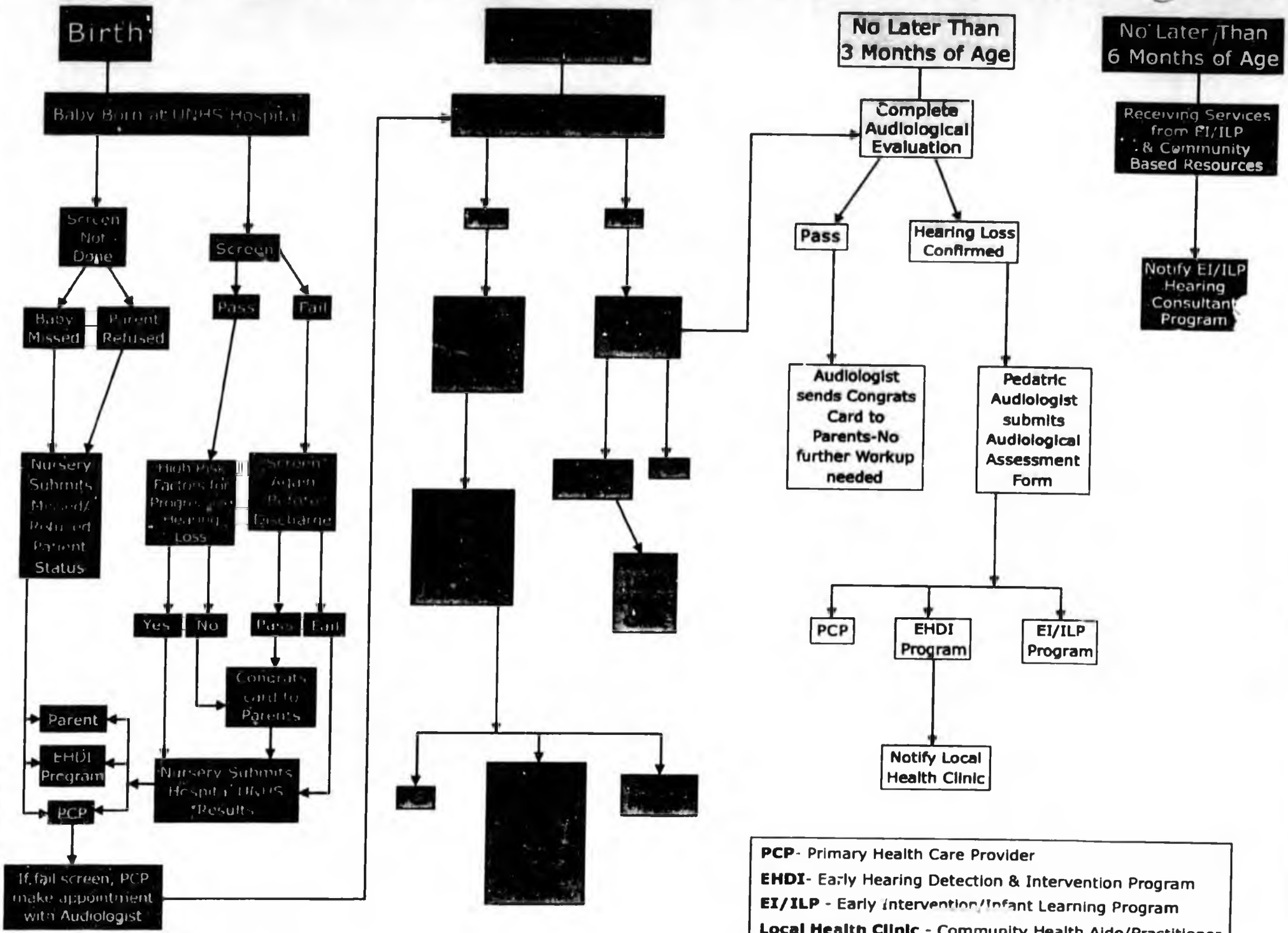
For copies of the materials and/or information regarding the EHDI Program, contact:

Margaret Lanier Kossler
4501 Business Park Blvd. Suite 24
Anchorage, AK 99503-7167
Margaret_lanier@health.state.ak.us e-mail

(907) 269-3466 – telephone
(907) 269-3465 – fax

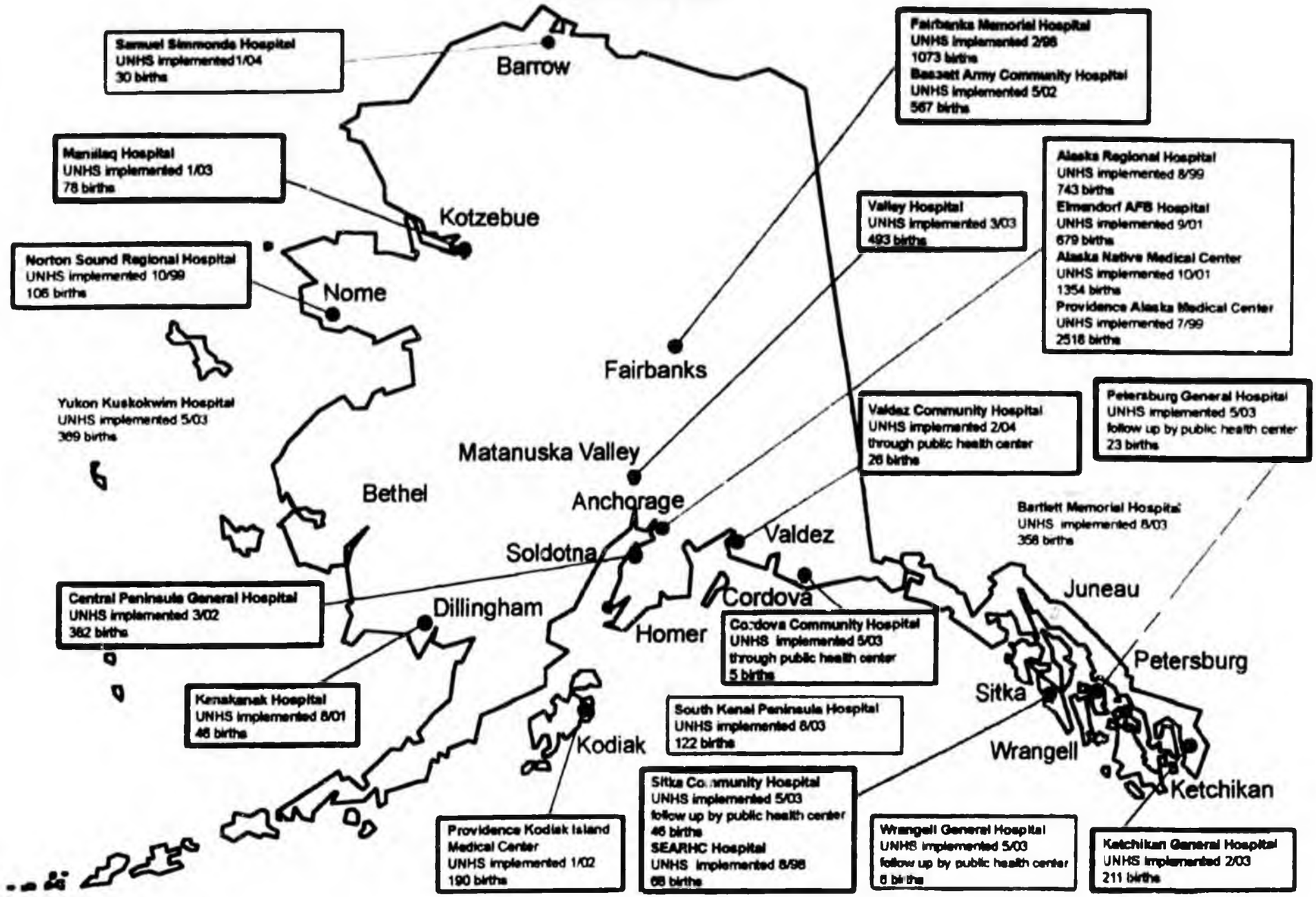
http://hss.state.ak.us/dhcs/newborn

Goal: Alaska Early Hearing Detection & Intervention Program (EHDI)



Locations of Newborn Hearing Screening Hospitals

2003 births



Hearing Loss

March of Dimes Resource Center

Hearing loss is one of the most common birth defects, affecting about 3 in 1,000 babies. Hearing loss that is present at birth is called congenital hearing loss. Hearing loss also can develop later in childhood or during adulthood.

Hearing loss can have a major impact on the life of a child and his family. Because language and communication develop so rapidly during the first 3 years of life, an undetected hearing loss is likely to interfere with a child's speech, language and communication with others. Hearing loss also can result in learning problems that affect a child's performance at school. The goal of early screening, diagnosis and treatment is to help children with hearing loss to develop language and academic skills equal to their hearing peers.

Because hearing loss in infancy is hard to recognize, most hospitals screen all newborns before they are discharged. Most states have an Early Hearing Detection and Intervention program to help ensure that infants who don't pass the screening receive follow-up care. The March of Dimes, the American Academy of Pediatrics, the Maternal and Child Health Bureau, the Centers for Disease Control and Prevention (CDC) and others strongly support these programs.

What causes hearing loss in babies and children?

Hearing loss can be inherited (genetic) or can be caused by illness or injury. In some cases, the cause of hearing loss is not known. About 90 percent of babies with congenital hearing loss are born to hearing parents.

Genetic factors are believed to cause about 50 percent of cases of congenital hearing loss. About 25 genes that play a role in hearing loss have been identified.

About 30 percent of children with hearing loss also have other birth defects. In such cases, hearing loss is part of a syndrome (group of birth defects that occur together).

Illnesses that can cause congenital hearing loss include infections during pregnancy, such as rubella (German measles), cytomegalovirus, toxoplasmosis, herpes or syphilis. Babies born preterm also are at increased risk.

After birth, head injuries or childhood infections, such as meningitis, measles or chickenpox, can cause permanent hearing loss. Certain medications, such as the antibiotic streptomycin and related drugs, also can cause hearing loss. Ear infections (otitis media) may cause temporary hearing loss.

Are there different types of hearing loss?

Hearing loss is the decreased ability to hear sounds. When sound enters the outer ear (auricle or pinna), it moves through the ear canal to the eardrum (tympanic membrane). Incoming sound causes the eardrum to vibrate which moves three small bones (ossicles) in the middle ear. In this way, the ear canal, the eardrum and the middle ear transmit sound from the outside world to the inner ear (cochlea). Within the inner ear, thousands of tiny hair cells detect the incoming vibrations and convert them into signals that are relayed to the auditory nerves, which send neural impulses to the hearing center in the brain.

Hearing loss is often discussed in terms of where the loss occurs in the hearing pathway.

- Conductive hearing loss occurs when something interferes with sound passing through the outer or middle ear. A blockage in the ear canal, damage to the eardrum, or fluid or an infection in the middle ear (called otitis media) are examples of conditions that can cause a conductive hearing loss. This type of hearing loss is usually temporary and can often be corrected with medication or surgery.
- Sensorineural hearing loss usually occurs when the hair cells in the inner ear cannot detect all incoming vibrations or when neural impulses are not transmitted to the brain. Prenatal infections, lack of oxygen at birth, or genetic factors can cause this type of hearing loss, which is generally permanent. However, many children can be aided with devices that amplify sound. Sensorineural hearing loss also can result from damage to the brain's auditory center.
- Mixed hearing loss occurs when a child who has a sensorineural hearing loss also has a conductive loss (such as fluid in the middle ear). It is very important that children with permanent hearing loss be monitored and treated for middle ear problems so hearing is not further reduced.

How are newborns screened for hearing loss?

Newborns are screened with one of two tests, both of which measure how a baby responds to sound. Both tests take 5 to 10 minutes, are painless, and can be done when the baby is resting.

In the otoacoustic emissions (OAE) test, a small microphone is placed in the baby's ear. The microphone, connected to a computer, sends soft clicking sounds into the ear and records the inner ear's response to sound.

In the automated auditory brainstem response (AABR) test, soft clicking sounds are presented to the ear through small earphones. Sensors placed on the head and connected to a computer measure brain wave activity in response to sound.

What happens if a baby doesn't pass the hearing screening?

If a baby does not pass the OAE or the AABR, the test should be repeated or the baby should be referred to a hearing specialist (audiologist) or an ear, nose and throat specialist (ENT or otolaryngologist)for more extensive tests to determine if the baby has a hearing loss. It is important for babies to be assessed by specialists who have experience testing very young children. Diagnostic testing should be completed by 3 months of age.

Parents must keep in mind that the screening tests cannot diagnose hearing loss. Up to 5 percent of babies will have abnormal results on their hearing screening test. However, additional tests show that only about 1 in 10 of these babies actually have hearing loss.

How are babies and children tested for hearing loss?

The most common hearing test for infants under 6 months of age is the diagnostic auditory brainstem response test. It is similar to the automated screening test, but it provides more information and must be administered by a specialist.

Children between 6 months and 2 years of age often are tested with visual reinforcement audiometry (VRA).

During VRA testing, a series of sounds is presented to the child through earphones or speakers. The child is trained to turn toward any sound, and is then rewarded with an entertaining visual image for responding.

Children between 2 and 4 years of age are tested with conditioned play audiometry (CPA). They are asked to perform a simple play activity (like placing a ring on a peg) when they hear a sound. This is similar to the test for older children and adults, who are asked to press a button or raise their hand when they hear a sound.

These tests also may be recommended if a child was not screened as a newborn; if he has had persistent ear infections, meningitis or other illness that can cause hearing loss; has been diagnosed with a syndrome that can include hearing loss; or if a parent suspects the child is not responding normally to sounds.

What are some signs of hearing loss in infants and young children?

Parents should be alert to any signs of hearing loss and discuss them with their child's pediatrician. Some signs include: failure to startle at loud sounds; not turning toward the sound of a voice or imitating sounds after about 6 months of age; lack of babbling at 9 months; not using single words by 18 months; or using gestures instead of words to express needs. Parents should be concerned about hearing loss in older children if they develop vocabulary more slowly than their peers; have speech that is difficult to understand or that is too loud or too soft; often ask you to repeat what was said; turn the TV too loud. At school age, children with hearing loss often appear inattentive and have difficulties learning to read or perform simple mathematics, and fall behind at school.

How is hearing loss treated?

A child with a congenital hearing loss should begin receiving treatment before 6 months of age. Studies suggest that children treated this early are usually able to develop communication skills (using spoken or sign language) that are as good as those of hearing peers. Because of a federal law (the Individuals with Disabilities Education Act), children with a hearing loss between birth and 3 years of age have the right to receive interdisciplinary assessment and early intervention services at little or no cost. After age 3, early intervention and special education programs are provided through the public school system.

There are a number of treatment options available, and parents will need to decide which are most appropriate for their child. They will need to consider the child's age, developmental level and personality, the severity of the hearing loss, as well as their own preferences. Ideally a team of experts including the child's primary care provider, an otolaryngologist, a speech-language pathologist, audiologist and an educator will work closely with the parents to create an Individualized Family Service Plan. Treatment plans can be changed as the child gets older.

Children as young as 4 weeks of age can benefit from a hearing aid. These devices amplify sound, making it possible for many children to hear spoken words and develop language. However, some children with hearing loss are helped more than others by hearing aids. Some children with severe to profound hearing loss may not be able to hear enough sound, even with a hearing aid, to make speech audible. A behind-the-ear hearing aid is often recommended for young children because it is safer and more easily fitted and adjusted as the child grows as compared to one that fits within the ear.

Parents also will need to decide how their family and child are going to communicate. If the child is going to communicate orally (speech), he may need assistance learning listening skills and lip reading skills to help him understand what others are saying. Many children with hearing loss also need speech or language therapy.

A child also can learn to communicate using a form of sign language. The type preferred by most deaf adults is American Sign Language (ASL), which has rules and grammar that is distinct from English. There are also several variations of sign language that can be used along with spoken English.

Surgery may be recommended if a child has a permanent conductive hearing loss caused by malformations of the outer or middle ear, or by repeated ear infections. Although fluid in the middle ear usually results in only temporary hearing loss, chronic ear infection can cause a child to fall behind in language skills. In some cases, a doctor may suggest inserting a tube through the eardrum to allow the middle ear to drain. This procedure generally does not require an overnight hospital stay.

Surgery also may be an option for some children with severe to profound sensorineural hearing loss. A device called a cochlear implant can be surgically inserted in the inner ear of children as young as 12 months of age to stimulate hearing. The surgery requires a hospital stay of one to several days. With additional language and speech therapy, children with cochlear implants may learn to understand speech and speak reasonably well, but the amount of improvement is variable.

Does the March of Dimes support research on hearing loss?

Several March of Dimes grantees are exploring the role that specific genes play in causing hearing loss, with the goal of developing treatments for hereditary hearing loss. Others are seeking to prevent hearing loss by preventing infections that can cause it and to improve treatment of individuals with hearing loss. One is developing improved hearing aids that amplify speech more clearly.

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Newborn Screening Tests

March of Dimes Resource Center

Every state and U.S. territory now screens newborns for certain disorders of body chemistry. These birth defects have no immediate visible effects on a baby but, unless detected and treated early, can cause physical problems, mental retardation and, in some cases, death. A number of states are also screening babies for hearing loss.

Fortunately, most babies are given a clean bill of health when tested. But when test results are abnormal, early diagnosis and proper treatment can make the difference between lifelong impairment and healthy development.

Here are the answers to some common questions parents ask about newborn screening tests.

Which newborn screening tests are most likely to be given to my baby?

All states and U.S. territories screen newborns for phenylketonuria (PKU). This was the nation's first newborn screening test. Developed with the help of the March of Dimes, it has been routinely administered since the 1960s. PKU affects about 1 baby in 12,000. Babies with the disorder cannot process a part of protein called phenylalanine, which is found in nearly all foods. Without treatment, phenylalanine builds up in the bloodstream and causes brain damage and mental retardation.

When PKU is detected early, mental retardation can be prevented by feeding the baby a special formula that is low in phenylalanine. This low-phenylalanine diet will need to be followed throughout adolescence and, generally, for life.

Women of childbearing age with PKU need to remain on this special diet prior to and during pregnancy. This will prevent mental retardation in their children by avoiding fetal exposure to high maternal phenylalanine levels.

Along with PKU testing, all states and U.S. territories test newborns for hypothyroidism, and most test for galactosemia. Congenital hypothyroidism is the most common disorder identified by routine screening. It affects about 1 baby in 4,000. Congenital hypothyroidism is a thyroid hormone deficiency that retards growth and brain development. If it is detected in time, a baby can be treated with oral doses of thyroid hormone to permit normal development.

Galactosemia, which affects about 1 baby in 50,000, can cause death in infancy, or blindness and mental retardation. A baby with galactosemia is unable to convert galactose, a sugar present in milk, into glucose, a sugar the body uses as an energy source. The treatment for galactosemia is to eliminate milk and all other dairy products from the baby's diet; this dietary restriction is lifelong.

You can find out which tests are routinely done in your state by asking your health care provider or state health department. You can also visit the web site of the National Newborn Screening and Genetics Resource Center at http://genes-r-us.uthscsa.edu/resources/newborn/state.htm.

What other disorders can newborn screening tests detect?

Currently, tests are available for over 30 inborn errors of body chemistry. Babies are not tested for all of these disorders for a number of reasons, including the fact that not all of these disorders are treatable. The March of Dimes would like to see all babies, in all states, screened for at least nine specific inborn errors of body chemistry including: PKU, congenital hypothyroidism, congenital adrenal hyperplasia (CAH), biotinidase deficiency, maple syrup urine disease, galactosemia, homocystinuria, sickle cell anemia, medium chain acyl-CoA dehydrogenase deficiency (MCAD), as well as hearing screening.

All of these disorders can be accurately diagnosed in newborns, and treatment is likely to improve the health of these children.

More than 40 states screen newborns for sickle cell anemia, an inherited blood disease that can cause bouts of pain, damage to vital organs such as the lungs and kidneys and, sometimes, death in childhood. Sickle cell anemia affects about 1 in 400 African-American babies and also occurs at a lower frequency among people of Hispanic, Mediterranean, Middle Eastern and South Asian descent.

Early treatment can prevent some of the complications of sickle cell anemia. Young children with the disease are especially prone to certain dangerous bacterial infections, such as pneumonia and meningitis. Studies in recent years have shown that treatment with penicillin, beginning by 2 months of age and continuing to about 5 years, dramatically reduces the risk of these infections and the deaths that result from them. Newborn screening alerts the physician to begin antibiotic treatment before infections begin.

More than 25 states test for CAH. This group of disorders, in which there is a deficiency of certain hormones, affects genital development and, in severe cases, can disturb kidney function and cause death. Lifelong treatment with the missing hormones suppresses this disease, which occurs in about 1 in 5,000 babies.

One newborn screening test, developed by a March of Dimes grantee, detects biotinidase deficiency. About 20 states screen for this disorder. Biotinidase is an enzyme that recycles biotin, one of the B vitamins, in the body. A deficiency of this enzyme, which occurs in about 1 in 70,000 babies, may cause frequent infections, hearing loss, mental retardation and even death. If the deficiency is detected in time, problems can be prevented by giving the baby extra biotin.

Maple syrup urine disease and homocystinuria are rare life-threatening disorders that affect fewer than 1 baby in 250,000. About 20 states screen for maple syrup urine disease, and 15 for homocystinuria.

At least eight states are now testing for MCAD, a disorder that can cause sudden death in infancy and serious disabilities in survivors, such as mental retardation. MCAD affects about 1 baby in 15,000. Normally the body burns fat for energy when it runs out of stored sugar (glucose). Babies with MCAD cannot make this switch, so they may suddenly develop seizures, respiratory failure, cardiac arrest or go into a coma or get infections or other illnesses if they do not eat regularly. When diagnosed early, the disorder can be successfully treated with a steady food intake and avoidance of fasting.

About half of all states now screen newborns for hearing loss. Approximately 1 to 3 in 1,000 babies in well-baby nurseries and 2 to 4 in 100 in intensive care nurseries have significant hearing loss. Without testing, most babies with hearing loss are not

diagnosed until 2 to 3 years of age. By this time, they often have delayed speech and language development. Detection of hearing loss in the neonatal period allows the baby to be fitted with hearing aids before 6 months of age. Recent studies show that this early intervention helps prevent serious speech and language problems.

How are the tests for inborn errors of body chemistry and hearing loss done?

Inborn errors of body chemistry are detected by a blood test. The baby's heel is pricked to obtain a few drops of blood for laboratory analysis. The same blood sample can be used to screen for a number of disorders. Usually, the baby's blood specimen is sent to a state public health laboratory for testing, and findings are sent to the health care professional responsible for the infant's care.

Babies are tested for hearing loss with one of two tests that measure how the baby responds to sounds. The tests use either a tiny soft earphone or microphone that is placed in the baby's ear. If either of these tests shows abnormal results, the baby may need more extensive hearing testing to see if he or she does have hearing loss.

How soon after birth should screening tests be done?

A blood specimen should be taken from every newborn prior to hospital release. Some of the tests (such as the one for PKU) may not give accurate results, however, if they are done too soon after birth. Because of early hospital discharge, some babies are tested within the first 24 hours of life. Because some cases of PKU can be missed when the test is performed this early, the American Academy of Pediatrics recommends that a repeat specimen be taken 1 to 2 weeks later from infants whose initial test was taken within the first 24 hours of life. Hearing tests are also usually performed before the baby is discharged from the hospital. Babies born outside the hospital should have newborn screening tests done before the 7th day of life.

What does an abnormal test result mean?

Parents should not be overly alarmed by abnormal test results, as the initial screening tests give only preliminary information that must be followed up by more precise testing. Most babies with abnormal thyroid screening test results, for example, prove normal in further testing, as do many with abnormal hearing test results.

What should I do if my child is diagnosed with one of the conditions for which he was tested?

Your child may need follow-up treatment at a pediatric center that specializes in children with inborn errors of body chemistry. It is essential for your child's healthy development that you follow the recommendations of his or her doctor. As your child grows, he or she will need careful, continued evaluations and monitoring.

If one of my children has a disorder, will my other children also have it?

When one child in a family has PKU, galactosemia, biotinidase deficiency, sickle cell anemia, CAH or MCAD, the chance of the same birth defect occurring in a sibling is 1 in 4. The chances remain the same with each pregnancy. Parents who have a baby with one of these disorders can discuss their risk of having another affected child with their health care provider or a genetic counselor.

These disorders are inherited when both parents have the same abnormal gene and pass it on to their baby. A parent who has the abnormal gene, but not the disease, is called a carrier. The health of a carrier is rarely affected.

Congenital hypothyroidism usually is not passed on through parents' genes. The siblings of those who have this disorder are seldom affected.

Hearing loss can be passed on through parents' genes. However, other causes of hearing loss, such as infections that are passed on to the baby during pregnancy or birth, are unlikely to recur in another pregnancy.

You also may wish to read these other March of Dimes Fact Sheets:

Hearing Loss
PKU
Sickle Cell Disease

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Stay healthy together!

Birth Defects

March *of* Dimes Resource Center

About 150,000 babies are born each year with birth defects. The parents of one out of every 28 babies receive the frightening news that their baby has a birth defect.

A birth defect is an abnormality of structure, function or metabolism (body chemistry) present at birth that results in physical or mental disability, or is fatal. Several thousand different birth defects have been identified. Birth defects are the leading cause of death in the first year of life.

What causes birth defects?

Both genetic and environmental factors can cause birth defects. However, the causes of about 60 to 70 percent of birth defects currently are unknown.

A single abnormal gene can cause birth defects. Every human being has at least 30,000 to 35,000 genes that determine traits like eye and hair color, as well as direct the growth and development of every part of our physical and biochemical systems. Genes are packaged into each of the 46 chromosomes inside our cells.

Each child gets half its genes from each parent. A person can inherit a genetic disease when one parent (who may or may not have the disease) passes along a single faulty gene. This is called dominant inheritance. Examples include achondroplasia (a form of dwarfism) and Marfan syndrome (a connective tissue disease). Many other genetic diseases are inherited only when both parents (who do not have those diseases) happen to carry the same abnormal gene and pass it on to a child. This is called recessive inheritance. Examples include Tay-Sachs disease (a fatal disorder seen mainly in people of European Jewish heritage) and cystic fibrosis (a fatal disorder of lungs and other organs, affecting mainly Caucasians). There also is a form of inheritance (X-linked) where sons can inherit a genetic disease from a mother who carries the gene (usually with no effect on her own health). Examples include hemophilia (a blood-clotting disorder) and Duchenne muscular dystrophy (progressive muscle weakness).

Abnormalities in the number or structure of chromosomes can cause numerous birth defects. Due to an error that occurred when an egg or sperm cell was developing, a baby can be born with too many or too few chromosomes, or with one or more chromosomes that are broken or rearranged. Down syndrome, in which a baby is born with an extra chromosome 21, is one of the most common chromosomal abnormalities. Affected children have varying degrees of mental retardation, characteristic facial features and, often, heart defects and other problems. Babies born with extra copies of chromosome 18 or 13 have multiple birth defects and usually die in the first months of life.

Missing or extra sex chromosomes (X and Y) affect sexual development and may cause infertility, growth abnormalities, and behavioral and learning problems. However, most affected individuals have essentially normal lives.

Birth defects also may result from environmental factors such as drug or alcohol abuse, infections, or exposure to certain medications (such as the acne drug Accutane) or other chemicals. Many birth defects appear to be caused by a combination of one or more genes and environmental factors (called multifactorial inheritance). Some examples include cleft lip/palate, clubfoot and some heart defects

What are some common types of birth defects?

Birth defects generally are grouped into three major categories: structural/metabolic, congenital infections, and other conditions.

- *Structural/metabolic abnormalities*

When a baby has a structural birth defect, some part of the body (internal or external) is missing or malformed. Heart defects are the most common type of structural birth defect, affecting one baby in 125. While advances in surgery have dramatically improved the outlook for affected babies, these remain the leading cause of birth defect-related infant deaths. Doctors usually do not know what causes a baby's heart to form abnormally, although genetic and environmental factors are believed to play a role.

Spina bifida (open spine, in which the backbone never completely closes and the spinal cord is usually malformed) affects one in 2,000 babies. Affected babies suffer varying degrees of paralysis, and bladder and bowel problems. Both genetic and nutritional factors appear to play a role.

About one baby in 135 has a structural defect involving the genitals or urinary tract. These vary greatly in severity, ranging from abnormal placement of the urinary opening in males (hypospadias) to absence of both kidneys. The cause of hypospadias, which is surgically correctable, is unknown. Babies who lack both kidneys die in the first hours or days of life. This tragic defect is sometimes inherited.

Metabolic disorders affect one in 3,500 babies. These disorders are not visible, but can be harmful or even fatal. Most are recessive genetic diseases. These diseases result from the inability of cells to produce an enzyme (protein) needed to change certain chemicals into others, or to carry substances from one place to another. An example is Tay-Sachs disease. Affected babies lack an enzyme needed to break down certain fatty substances in brain cells. These substances build up and destroy brain cells, resulting in blindness, paralysis and death by age five. Phenylketonuria (PKU) is another metabolic disorder, in which affected babies cannot process a part of protein, which builds up in blood and causes brain damage. PKU is routinely detected with newborn screening tests, so affected babies can be placed on a special diet that prevents mental retardation.

- *Congenital infections*

Rubella (German measles) probably is the best known congenital infection that can cause birth defects. If a pregnant woman is infected in the first trimester, her baby has a one-in-four chance of being born with one or more features of congenital rubella syndrome (deafness, mental retardation, heart defects, blindness). Fortunately, with widespread vaccination, this syndrome is now rare in this country.

The most common congenital viral infection is cytomegalovirus (CMV). About 1 percent (40,000 babies a year) of all newborns in this country are infected, although only about 10 percent of them (3,000-4,000) have serious consequences, including mental retardation, and loss of vision and hearing. Pregnant women often acquire CMV from young children, who usually have few or no symptoms.

Sexually transmitted infections in the mother also can endanger the fetus and newborn. For example, untreated syphilis can result in stillbirth, newborn death, or bone defects. About one baby in 2,000 is affected.

• *Other causes*

Other causes of birth defects include fetal alcohol syndrome, which affects one baby in 1,000. This pattern of mental and physical birth defects is common in babies of mothers who drink heavily during pregnancy. Even moderate or light drinking during pregnancy can pose a risk to the baby.

Rh disease of the newborn, which is caused by an incompatibility between the blood of a mother and her fetus, affects about 4,000 infants a year. It can result in jaundice (yellowing of the skin), anemia, brain damage and death. Rh disease usually can be prevented by giving an Rh-negative woman an injection of a blood product called immunoglobulin at 28 weeks of pregnancy and after the delivery of an Rh-positive baby.

Babies of mothers who use cocaine early in pregnancy may be at increased risk of birth defects. A large study has suggested that these babies are five times more likely to be born with urinary tract defects than babies of women who don't use cocaine.

Can birth defects be prevented?

While the causes of most birth defects are not known, there are a number of steps a woman can take to reduce her risk of having a baby with a birth defect. One important step is a pre-pregnancy visit with her health care provider. During this visit, the provider can obtain valuable information about a woman or couple's family history, which may help identify risk factors for birth defects or inherited genetic conditions. This information allows for appropriate testing and screening to be offered prior to or during pregnancy. During a pre-pregnancy visit, providers also can take a good look at a woman's health and lifestyle, and guide her in any changes that could improve her chances of having a healthy baby.

A pre-pregnancy visit is especially crucial for women with medical problems like diabetes, high blood pressure, and epilepsy, which can affect pregnancy. For example, women with poorly controlled diabetes are several times more likely than women without diabetes to have a baby with a serious birth defect. However, if their blood sugar levels are well controlled starting before pregnancy, they are almost as likely to have a healthy baby as women without diabetes.

If a woman has never had chickenpox (and has not been vaccinated), a pre-pregnancy visit is a good time to check whether she should be vaccinated prior to pregnancy. Like rubella, chickenpox can cause birth defects when contracted by the pregnant woman, although the risk is low. If she has not been vaccinated against rubella since childhood, she should ask her doctor about the rubella vaccine or a combination vaccine such as measles-mumps-rubella (MMR). She should avoid pregnancy for one month after chickenpox, rubella or MMR vaccination.

All women who could become pregnant should take a daily multivitamin containing 400 micrograms of the B-vitamin folic acid. Studies show that taking this vitamin prior to and in the early weeks of pregnancy reduces the risk of having a baby with certain birth defects of the brain and spine, including spina bifida. If a woman already has had a baby with one of these birth defects, she should consult her doctor prior to pregnancy about how much folic acid to take. Generally, a higher dose, 4 milligrams, is recommended.

A woman who is pregnant or planning pregnancy should avoid alcohol, smoking, and street drugs — these can cause birth defects and other pregnancy complications. She should not take any medication — prescription, over-the-counter, or herbal — without first checking with her health care provider.

Can some birth defects be diagnosed before birth?

Some birth defects can be diagnosed before birth, using one or more prenatal tests including ultrasound, amniocentesis and chorionic villus sampling (CVS). Ultrasound can help diagnose structural birth defects, such as spina bifida, heart and urinary tract defects. Amniocentesis and CVS are used to diagnose chromosomal abnormalities, such as Down syndrome. They also can detect, or rule out, numerous genetic birth defects that may be suspected because of family history or ethnic background.

Can birth defects be treated before birth?

A small percentage of couples will learn through prenatal diagnosis that their baby has a birth defect. While this news can be devastating, prenatal diagnosis sometimes can improve the outlook for the baby. Advances in prenatal therapy now make it possible to treat some birth defects before birth. For example, biotin dependence and methylmalonic acidemia — two life-threatening inherited disorders of body chemistry — have been diagnosed by amniocentesis and treated in the womb, resulting in the births of healthy babies.

Prenatal surgery has saved babies with urinary-tract blockages, rare tumors of the lung, and congenital diaphragmatic hernia (a hole in the muscle that separates the chest from the abdomen). More than 100 babies have undergone experimental prenatal surgery to repair spina bifida before birth. Preliminary results appear promising: fewer babies who have had surgery for spina bifida require shunts to drain fluid from their brain. However, it is too soon to know how well most of these babies will walk, and the procedure leads to preterm birth. Prenatal blood transfusions have saved numerous babies with severe Rh disease, and heart medications given to the pregnant woman have saved babies with serious heart rhythm disturbances. However, even when a fetus has a condition for which prenatal treatment is not yet possible, prenatal diagnosis permits parents to prepare themselves emotionally, and to plan with their provider the safest timing, location and method of delivery.

Couples who have had a baby with a birth defect, or who have a family history of birth defects, should consider consulting a genetic counselor. These health professionals help families understand what is known about the causes of a birth defect, and the chances of the birth defect recurring in another pregnancy. Genetic counselors also can provide referrals to medical experts as well as to appropriate support groups.

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March of Dimes Perinatal Data Center. Maternal, Infant, and Child Health in the United States, 2001.

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Saving babies, together

Reed Stoops

Mandated Benefits Added by the Legislature in the Last Ten Years

- 42.345 Coverage of newly born children (federal requirement) (1975, amended in 1992, 1995, 1996, 1997)
- 42.347 Postpartum hospital stay coverage (federal requirement) (1996, amended in 1997)
- 42.353 Acupuncture coverage (offer only, does not mandate coverage) (1990, amended in 1995, 1196, 1997)
- 42.355 Coverage for services of midwives (1981, amended in 1995, 1996, 1997)
- 42.365 Substance abuse treatment coverage (1988, amended in 1996, 1997, 2002)
- 42.375 Mammography coverage (1991, amended in 1995, 1996, 1997)
- 42.380 Phenylketonuria (1992, amended in 1995, 1996, 1997)
- 42.385 Dental, Vision, Health coverage (offer only, does not mandate coverage) (1992, amended in 1996, 1997)
- 42.390 Coverage for diabetes treatment (2000, amended in 2002)
- 42.395 Prostate and cervical cancer screening (1996, amended in 1997, 2000)
- 42.400 Reconstructive surgery following mastectomies (federal requirement) (2000)

American Academy of Pediatrics

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February 4, 2005

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Norm Rokeberg
Harry Crawford
David Guttenberg

Dear Representative Anderson and Members of the House L&C Committee:

On behalf of the pediatricians of the Alaska Chapter of the American Academy of Pediatrics I am writing to encourage your support of HB 109: Newborn Hearing Screening, Tracking and Intervention. We recommend that all babies be screened for hearing loss before they leave the hospital.

The cost of identifying a newborn with hearing loss is less than 1/10th the cost of identifying newborns with metabolic disorders such as PKU and hypothyroidism, for which screenings are required in every state. For most birthing hospitals, the cost for newborn hearing screening per child is between $20 and $60 and continues to decrease. The evidence for the benefits, practicability and cost-efficiency of universal newborn hearing screening is so compelling that 37 states have passed legislation requiring that newborns be screened for hearing loss. Most importantly, children not detected at birth or soon after, will on average not be detected until 2-3 years of age. The most critical period for speech and language development is from birth to three years of age.

Thank you for supporting HB 109.

Sincerely,

Thomas J. Porter, MD FAAP
President
American Academy of Pediatrics, Alaska Chapter

AARP Alaska

February 3, 2005

The Honorable Tom Anderson, Chair
House Labor and Commerce Committee
Alaska State Capitol, Room 408
Juneau, AK 99801-1182

RE: HB 109 (Ramras)--Support

Dear Chair Anderson:

On behalf of the members of AARP in Alaska, we encourage you and your colleagues on the House Labor and Commerce Committee to support HB 109, authored by Representative Jay Ramras and co-sponsored by Representatives Gara, Elkins, Wilson, Gruenberg and McGuire.

AARP is not only a "senior organization." We are also an organization of grandparents concerned about the quality of health of all Alaskans of all ages.

The goal of HB 109 is to have all children born in Alaska screened for hearing problems soon after birth. If screening is not done early, very often hearing losses or problems will not be detected until a child is two or three years of age. The most important period for speech and language development is from birth to three. Most of our newborns are offered this screening. AARP hopes you will enable us to have 100% of them screened at birth. We are pleased to join the March of Dimes in support of this bill.

We urge an "AYE" vote on HB 109.

Should you have any questions about our position, please feel free to contact me (586-3637) or Patrick Luby, AARP Advocacy Director (907-762-3314).

Thank you for your consideration.

Sincerely,

Marie Darlin

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Representative Jay Ramras
10th House District

Fax: (907) 465-2070

Re: House Bill 109

February 1, 2005

Dear Representative Ramras:

I am writing in support of House Bill 109 ("related to screening Newborns for Hearing Ability"), which you have agreed to sponsor. I am a pediatrician in private practice in Anchorage with 26 years of experience. I also serve as the Alaska Chapter Champion for the Early Hearing Detection and Intervention Program for the American Academy of Pediatrics. The American Academy of Pediatrics supports the development of programs in each state for universal screening of all infants for hearing deficits at or soon after birth in order to allow for early identification and intervention of hearing impaired children in order to maximize their potential. There are several reasons that this program is important:

1. Hearing loss if one of the most common birth defects. One in 3000 infants are born in Alaska with permanent congenital hearing loss. Without universal newborn hearing programs, the average age of detection of even severe hearing loss is 2-3 years old
2. Hearing loss has a significant negative effect on children. This would seem obvious but many studies indicate the negative impact of hearing loss on a child's emotional and social development as well as language delays that do not seem to progress even after diagnosis, in some children, when that diagnosis is delayed. Even mild and unilateral hearing loss – problems that often defy detection much longer without an objective early hearing screen- may have long lasting negative effects to the child.
3. Early detection and intervention of hearing deficits significantly helps children. Numerous studies show that when children are diagnosed with hearing loss and appropriate intervention to augment hearing and provide appropriate communication options are started early in life, preferably before 6 months of age, significant and long lasting benefits are achieved by the children in language skills, emotional development, social and familial adjustment.

In order to achieve these benefits for children and their families, there are several steps that must occur that are benchmarks for a successful early hearing detection and intervention program and each of these can be greatly aided by HB 109 as written:

1. Universal hearing screen for all newborns – This first step is already nearly achieved in Alaska. Due to new advancement in screening technology almost all birthing hospitals either are or soon will be screening newborns for hearing loss. By allowing non-audiologists to administer the screen and bill appropriately for this service, and asking insurance companies to cover this "standard of care" evaluation, all infants in the state can have this evaluation before they leave the hospital or birthing facility.
2. When a hearing screen is failed, they are referred for evaluation – This step may have one or two parts. A child who fails the initial screen is referred for re-screen and if still abnormal, diagnostic intervention is performed by 3 month of age. Each institution and/or the infant's medical provider are responsible for this step. The failure to return for re-screening or for diagnostic testing markedly reduces the effectiveness of the entire program. With the tracking provision of your bill,