

ALASKA LEGISLATURE

HOUSE and SENATE FINANCE COMMITTEE FILES, 2005-2006 2853

Failed (3-7)

AMENDMENT |

OFFERED IN THE HOUSE

BY REPRESENTATIVE

TO: CSHB 130(RES)

1 Page ~~8~~⁶, line ~~2~~¹⁰:

2 Delete "and"

3
4 Page ~~8~~⁶, line ~~3~~¹¹, following "Bay":

5 Insert "; and

6 (10) ~~(8)~~ Parcel Number MA.MC.1001, McCarthy-Nizina"

4/12/05
Failed 2-8

24-GH1034\L.2
Bullock
4/12/05

AMENDMENT 2

OFFERED IN THE HOUSE

BY REPRESENTATIVE CROFT

TO: CSHB 130(), Draft Version "L"

1 Page 1, line 2:

2 Delete "establishing the university research forest;"

3

4 Page 3, lines 6 - 23:

5 Delete all material and insert:

6 "Sec. 14.40.365. University state-grant land. (a) The commissioner of
7 natural resources shall convey to the Board of Regents in trust for the University of
8 Alaska, by quitclaim deed, the state land identified by the Department of Natural
9 Resources as the Point Thompson Unit."

10

11 Reletter the following subsections accordingly.

12

13 Page 4, line 11:

14 Delete "(e)"

15 Insert "(c)"

16

17 Page 5, line 2:

18 Delete "(g)(2)"

19 Insert "(e)(2)"

20

21 Page 5, line 31, through page 6, line 30:

22 Delete all material and insert:

23 "(l) The Board of Regents shall deposit payments received as a result of the

1 conveyance under (a) of this section on behalf of the state as required under
2 AS 37.13.010 and on behalf of the commissioner of revenue under AS 37.14.150."

3

4 Page 8, line 16, through page 9, line 23:

5 Delete all material.

6

7 Renumber the following bill sections accordingly.

8

9 Page 9, following line 30:

10 Insert a new bill section to read:

11 "* Sec. 7. The uncodified law of the State of Alaska is amended by adding a new section to
12 read:

13 TRANSITION. For the first five years after the conveyance under AS 14.40.365(a),
14 enacted in sec. 3 of this Act, the Department of Natural Resources shall manage the land on
15 behalf of the Board of Regents of the University of Alaska. After the five-year period
16 described in this section, the land may be managed by the Department of Natural Resources
17 under contract with the Board of Regents or by the Board of Regents."

Allocation Summary - FY 2005 Operating Budget - Conf Comm Structure

Numbers & Language
Fund Group: General Funds

Agency: University of Alaska

Page	Appropriation/ Allocation	03Actual	04HgtPln	04SupKPI	Gov And	House	Senate	Enacted	Bills	OpInCap	05Budget	04HgtPln to 05Budget
University of Alaska												
1	System Reductions/Additions	0.0	2.1	1.0	1.0	1.0	228,316.2	0.0	0.0	15,551.0	15,551.0	15,548.9 >999 %
2	Statewide Services	8,353.0	11,261.1	0.0	11,261.1	0.0	0.0	0.0	0.0	11,261.1	11,261.1	0.0
3	System Reduction	15.9	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
4	Statewide Networks (ITS)	6,872.1	6,973.3	0.0	6,973.3	0.0	0.0	0.0	0.0	6,973.3	6,973.3	0.0
5	Anchorage Campus	63,760.7	64,151.3	0.0	64,151.3	200.8	200.8	200.8	0.0	63,950.5	64,151.3	0.0
6	Kenai Peninsula College	3,930.9	3,980.1	0.0	3,980.1	0.0	0.0	0.0	0.0	3,980.1	3,980.1	0.0
7	Kotlik College	1,957.5	1,977.0	0.0	1,977.0	0.0	0.0	0.0	0.0	1,977.0	1,977.0	0.0
8	Metanuska-Susitna College	2,892.6	2,948.2	0.0	2,948.2	0.0	0.0	0.0	0.0	2,948.2	2,948.2	0.0
9	Prince Wm Sound Comm College	1,786.4	1,819.1	0.0	1,819.1	0.0	0.0	0.0	0.0	1,819.1	1,819.1	0.0
10	Cooperative Extension Service	3,060.7	3,221.6	0.0	3,221.6	0.0	0.0	0.0	0.0	3,221.6	3,221.6	0.0
11	Bristol Bay Campus	872.6	877.4	0.0	877.4	0.0	0.0	0.0	0.0	877.4	877.4	0.0
12	Chukchi Campus	617.4	617.4	0.0	617.4	0.0	0.0	0.0	0.0	617.4	617.4	0.0
13	Fairbanks Campus	70,354.8	70,450.2	0.0	70,450.2	0.0	0.0	0.0	0.0	70,450.2	70,450.2	0.0
14	Fairbanks Organized Research	12,640.9	14,908.4	0.0	14,908.4	0.0	0.0	0.0	0.0	14,908.4	14,908.4	0.0
15	Interior-Aleutians Campus	1,096.9	1,141.5	0.0	1,141.5	0.0	0.0	0.0	0.0	1,141.5	1,141.5	0.0
16	Kuskokwim Campus	2,022.0	2,149.9	0.0	2,149.9	0.0	0.0	0.0	0.0	2,149.9	2,149.9	0.0

Allocation Summary - FY 2005 Operating Budget - Conf Comm Structure

Numbers & Language
Fund Group: General Funds

Agency: University of Alaska

Page	Appropriation/ Allocation	03Actual	04HgtPln	04SupRPL	Gov Bud	House	Senate	Enacted	Bills	04InCap	05Budget	04HgtPln to 05Budget
	University of Alaska											
17	Northwest Campus	1,184.7	1,377.4	0.0	1,377.4	0.0	0.0	0.0	0.0	1,377.4	1,377.4	0.0
18	Rural College	3,390.1	3,512.8	0.0	3,512.8	0.0	0.0	0.0	0.0	3,512.8	3,512.8	0.0
19	Tanana Valley Campus	3,210.1	3,090.5	0.0	3,090.5	0.0	0.0	0.0	0.0	3,090.5	3,090.5	0.0
20	Juneau Campus	14,339.6	14,484.5	0.0	14,484.5	0.0	0.0	0.0	0.0	14,484.5	14,484.5	0.0
21	Ketchikan Campus	1,746.5	1,762.4	0.0	1,762.4	0.0	0.0	0.0	0.0	1,762.4	1,762.4	0.0
22	Sitka Campus	1,995.5	2,015.1	0.0	2,015.1	0.0	0.0	0.0	0.0	2,015.1	2,015.1	0.0
	* Appropriation Total	206,080.9	212,717.1	1.0	212,716.0	201.8	228,517.0	200.8	0.0	228,065.2	228,266.0	15,548.9 7.3 %
	*** Totals for Agency	206,080.9	212,717.1	1.0	212,716.0	201.8	228,517.0	200.8	0.0	228,065.2	228,266.0	15,548.9 7.3 %

15 year Forecast of Point Thomson Unit Royalty Revenues

Assumptions:

75,000 barrels of condensate production per day @ \$20/bbl netback

1.5 billion cubic feet of gas production per day @ \$2/MCF netback

15% State Royalty

<u>Year</u>	<u>Oil Revenue (\$/yr)</u>	<u>Gas Revenue (\$/yr)</u>	<u>Total Revenue (\$/yr)</u>
1	\$82,125,000	\$164,250,000	\$246,375,000
2	\$82,125,000	\$164,250,000	\$246,375,000
3	\$82,125,000	\$164,250,000	\$246,375,000
4	\$82,125,000	\$164,250,000	\$246,375,000
5	\$82,125,000	\$164,250,000	\$246,375,000
6	\$82,125,000	\$164,250,000	\$246,375,000
7	\$82,125,000	\$164,250,000	\$246,375,000
8	\$82,125,000	\$164,250,000	\$246,375,000
9	\$82,125,000	\$164,250,000	\$246,375,000
10	\$82,125,000	\$164,250,000	\$246,375,000
11	\$82,125,000	\$164,250,000	\$246,375,000
12	\$82,125,000	\$164,250,000	\$246,375,000
13	\$82,125,000	\$164,250,000	\$246,375,000
14	\$82,125,000	\$164,250,000	\$246,375,000
15	\$82,125,000	\$164,250,000	\$246,375,000
15 year Total:	\$1,231,875,000	\$2,463,750,000	\$3,695,625,000
Daily Revenue	\$225,000	\$450,000	\$675,000

kwg: DOG-DNR
4/11/2005

4-12-05

15 year Forecast of Point Thomson Unit Royalty Revenues
Including Permanent Fund and Public School Trust Fund Deposits

Assumptions:

- 75,000 barrels of condensate production per day @ \$20/bbl netback
- 1.5 billion cubic feet of gas production per day @ \$2/MCF netback
- 15% State Royalty

<u>Year</u>	<u>Revenue from oil (\$/yr)</u>	<u>Revenue from gas (\$/yr)</u>	<u>Total Revenue before PF deposits (\$/yr)</u>	<u>Permanent Fund and Public School Trust Fund Deposits (\$/yr)</u>	<u>Total University Revenue after PF and Public School Trust Fund deposits (\$/yr)</u>	<u>Unrestricted University Revenue after required 25% deposit to University Trust Fund</u>	<u>University Trust Fund Balance (8% return, no withdrawals)</u>
1	\$82,125,000	\$164,250,000	\$246,375,000	62,825,625	\$183,549,375	\$137,662,031	\$45,887,344
2	\$82,125,000	\$164,250,000	\$246,375,000	62,825,625	\$183,549,375	\$137,662,031	\$85,445,676
3	\$82,125,000	\$164,250,000	\$246,375,000	62,825,625	\$183,549,375	\$137,662,031	\$148,968,673
4	\$82,125,000	\$164,250,000	\$246,375,000	62,825,625	\$183,549,375	\$137,662,031	\$208,773,510
5	\$82,125,000	\$164,250,000	\$246,375,000	62,825,625	\$183,549,375	\$137,662,031	\$269,202,735
6	\$82,125,000	\$164,250,000	\$246,375,000	62,825,625	,549,375	\$137,662,031	\$336,626,297
7	\$82,125,000	\$164,250,000	\$246,375,000	62,825,625	3,549,375	\$137,662,031	\$409,443,745
8	\$82,125,000	\$164,250,000	\$246,375,000	62,825,625	\$183,549,375	\$137,662,031	\$488,086,588
9	\$82,125,000	\$164,250,000	\$246,375,000	62,825,625	\$183,549,375	\$137,662,031	\$573,020,859
10	\$82,125,000	\$164,250,000	\$246,375,000	62,825,625	\$183,549,375	\$137,662,031	\$664,749,872
11	\$82,125,000	\$164,250,000	\$246,375,000	62,825,625	\$183,549,375	\$137,662,031	\$763,817,205
12	\$82,125,000	\$164,250,000	\$246,375,000	62,825,625	\$183,549,375	\$137,662,031	\$870,809,925
13	\$82,125,000	\$164,250,000	\$246,375,000	62,825,625	\$183,549,375	\$137,662,031	\$986,362,063
14	\$82,125,000	\$164,250,000	\$246,375,000	62,825,625	\$183,549,375	\$137,662,031	\$1,111,158,372
15	\$82,125,000	\$164,250,000	\$246,375,000	62,825,625	\$183,549,375	\$137,662,031	\$1,245,938,385
15 year Total:	\$1,231,875,000	\$2,463,750,000	\$3,695,625,000	942,384,375	\$2,753,240,625	\$2,064,930,469	\$8,216,291,249

Revenue forecasts exclude severance and corporate taxes not collected by the University

FISCAL NOTE

STATE OF ALASKA
2005 LEGISLATIVE SESSION

Replaced

Fiscal Note Number: 1
 Bill Version: CSHB 109(L&C)
 (H) Publish Date: 2/9/05

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	*	*	*	*	*
Miscellaneous						
TOTAL OPERATING	0.0	*	*	*	*	*

CAPITAL EXPENDITURES						
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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	*	*	*	*	*

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)
 Ser. 47.20.230 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 2/1/05 2:18 PM
 Approved by: Karen Rehfeld, Deputy Commissioner Date 2/1/2005
 Agency: Education & Early Development

FISCAL NOTE

STATE OF ALASKA
2005 LEGISLATIVE SESSION

Fiscal Note Number: _____
Bill Version: HB109-DHSS-DPH-02-04-05
() Publish Date: _____

Revision Date/Time (Note if correction): 02/04/05 8:00 AM Dept. Affected: Health & Social Services

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

Sponsor: RAMRAS
Requester: HOUSE (L&C) 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 current year (FY2005) cost: _____
Mark this box if funding for this bill is included in the Governor's FY 2006 budget proposal:

POSITIONS

Full-time						
Part-time						
Temporary						

(SIS: *(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 02/02/2005
Approved by: Joel S. Gilbertson, Commissioner Date 02/04/2005
Agency: Department of Health and Social Services

FISCAL NOTE
FN #

STATE OF ALASKA
2005 LEGISLATIVE SESSION

BILL NO. HB109-DHSS-DPH-02-04-05

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. 5) The department is proposing elimination of Sec. 47.20.310 (g). It is not possible on this short notice to determine the increased cost to the department of the mandate included in (g), and therefore this fiscal note assumes that subsection (g) is deleted.

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 FY 08 if awarded.

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).

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 in FY 09, assumes a 3.5 percent annual merit increase thereafter):

- 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.

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.

Representative Jay Ramras
Co-Chair, House Resources
V-Chair, Economic Develop.
Tourism & Trade

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Alaska State Legislature



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House District 10

House of Representatives

Sponsor Statement

HB 109

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 a 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.

Documents Attached to HB 109

1. Why is Mandatory Newborn Hearing and Screening and Reporting So Important? - This is a two-page document describes why newborn hearing screening is important.
2. Alaska Early Hearing Detection & Intervention Program Overview – A flow-chart explaining EHDI.
3. Goal of Alaska Early Hearing Detection & Intervention Program (EHDI) – Overview. – Hearing Impairment is the most common disability in newborns. Explanation of Alaska EHDI Program.
 - Ensure babies born in Alaska have newborn hearing screening prior to hospital discharge or within 30 days of birth.
 - 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.
4. Locations of Newborn Hearing and Screening Hospitals in Alaska.
5. March of Dimes Resource Center - Hearing Loss.
 - What causes hearing loss in babies and children?
 - Are there different types of hearing loss?
 - How are newborns screened for hearing loss?
 - What happens if a baby does not pass the hearing screening?
 - How are babies and children tested for hearing loss?
 - What are signs of hearing loss in infants and children?
 - How is hearing loss treated?
6. March of Dimes Resource Center – Newborn Screening Tests.
 - Which newborn screening tests are most likely to be given?
 - What other disorders can newborn screening tests detect?
 - How are the tests for inborn errors of body chemistry and hearing loss done?
 - How soon after birth should screening tests be done?
 - What does an abnormal test result mean?
 - What should you do if your child is diagnosed with one of the conditions for which they were tested?
 - If one of my children has a disorder will my other children have it?

7. March of Dimes Resource Center – Birth Defects.

- What causes birth defects?
- What are some common types of birth defects?
- Can birth defects be prevented?
- Can some birth defects be diagnosed before birth?
- Can birth defects be treated before birth?

8. The Governor's Council on Disabilities and Special Education – FY06 Legislative Priorities. – A legislative recommendation is made for Universal Newborn Hearing Screening.

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 1/10th 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 its 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 Alaska 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:

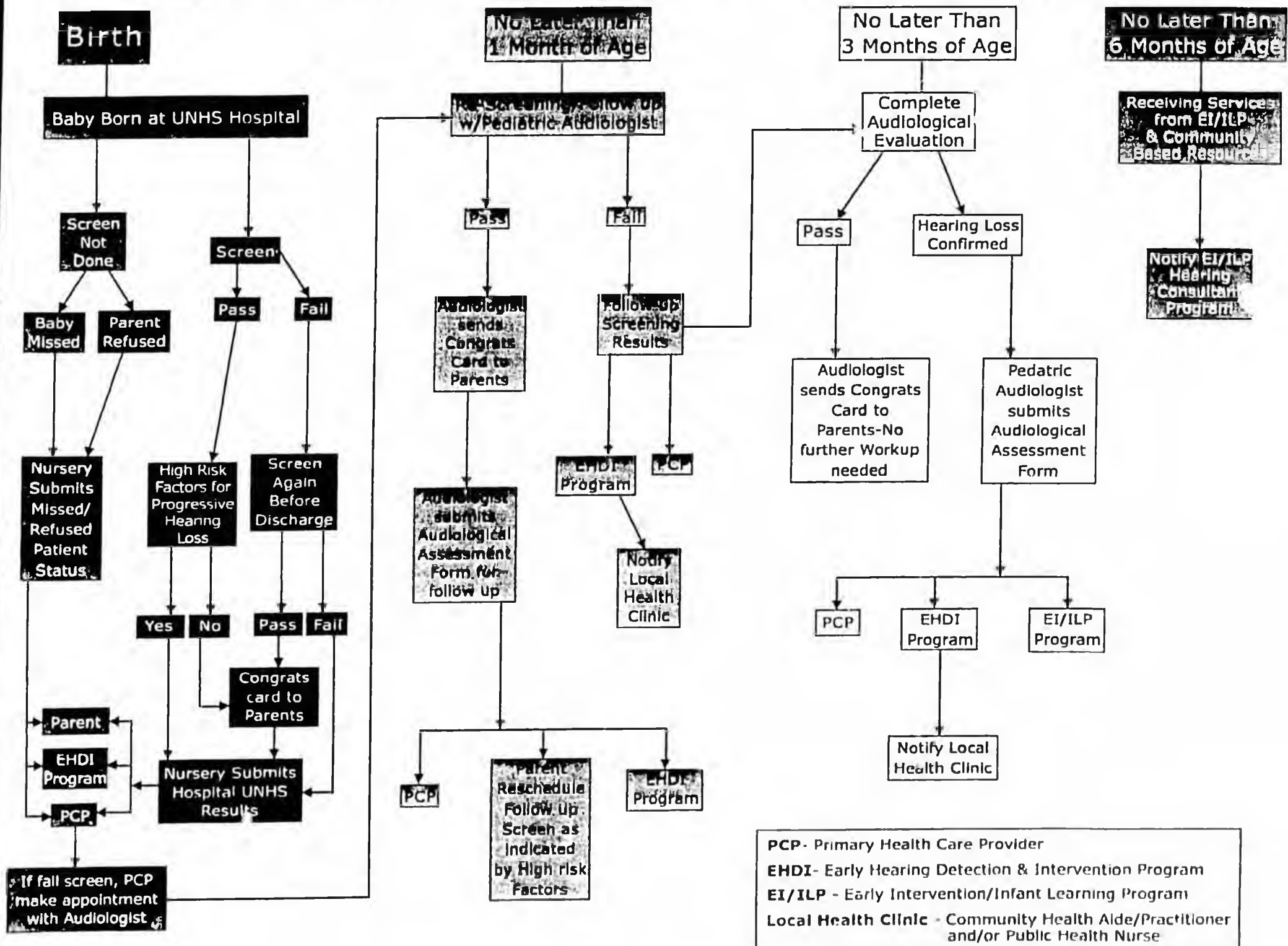
Margaret Lanier Kossler
4501 Business Park Blvd. Suite 24
Anchorage, AK 99503-7167
Margaret.lanier@health.state.ak.us e-mail

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

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

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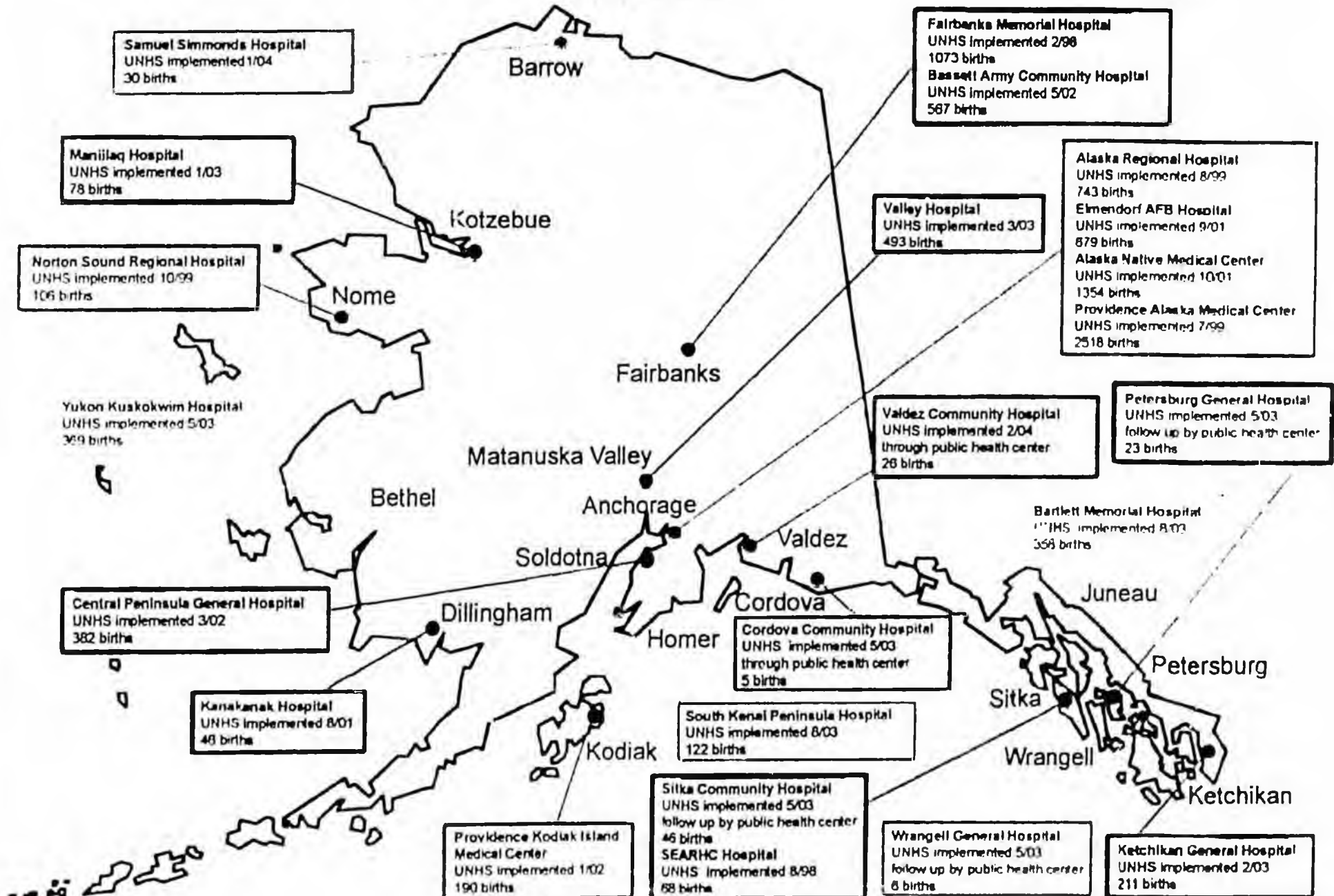
Goal Alaska Early Hearing Detection & Intervention Program (EHDl)



PCP - Primary Health Care Provider
EHDl - Early Hearing Detection & Intervention Program
EI/ILP - Early Intervention/Infant Learning Program
Local Health Clinic - Community Health Aide/Practitioner and/or Public Health Nurse

Locations of Newborn Hearing Screening Hospitals

2003 births





GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION

P.O. Box 240249 • Anchorage, Alaska 99524-0249 • Phone: 907-269-8990 • Fax: 907-269-8995 • Toll Free 888-269-8990

*Disability & Special Ed.
Benarzi Ltd.*

FY06 Legislative Priorities

Fiscal Plan

Home and community-based services funded by Medicaid and state grants enable Alaskans with severe disabilities to live independently and become productive, gainful members of their communities. In an economy where the source of revenues is unpredictable, Alaskans with severe disabilities, whose independence and productivity is linked to government supports, are at risk for negative, unpredictable life changes.

Recommendation: The Council urges the Legislature to meet the needs of Alaskans with disabilities by developing a consistent revenue stream for supports and services as a part of a long range fiscal plan.

Dental Services

Governor Murkowski will introduce legislation to expand Medicaid coverage for adult recipients that will include preventive and restorative dental services. Proposed coverage will be capped at \$1,150 annually. The Alaska Mental Health Trust Authority has agreed to contribute \$5.4 million over five years toward the costs of dental services for Trust beneficiaries. In FY03, costs of emergency dental care totaled \$2.2 million. Over time, the State's investment, coupled with the Trust funded donated dental and dental training programs, will significantly reduce the cost for emergency dental services.

Recommendation: The Council urges adoption of the Governor's legislation to include adult preventive dental coverage under Medicaid.

Bring the Kids Home

At any given time approximately 400 children are served in costly out-of-state placements. Governor Murkowski's initiative will develop a support system within the state to allow Alaskan children to receive services near their homes and families. State expenditures will decrease as children are moved home and supported in their communities. The Council recommends that all cost savings realized in this initiative be reinvested in Keeping Kids Home.

Recommendation: The Council urges the legislature to support the Governor's Bring the Kids Home Initiative.

2000-01-15 special meeting
Petersen, J. et al.

Additional Legislative Recommendations

Grant dollars for DD services

Investing general fund dollars in DD community grants will save the state money. Grant-funded services are generally low-cost and if provided at the right time, help keep families together and avert high-cost crisis situations. Although some services were one-time services or did not completely meet people's needs, in FY02 the average cost of grant-funded services was \$6,683 compared to the State's share (\$32,500) of a waiver.

Recommendation: The Council urges that the legislature increase general fund dollars for DD community grants.

Capital Funding for Assistive Technology and Home Modifications

The Governor's budget includes \$300,000 for assistive technology and home modifications that will enable the Division of Vocational Rehabilitation to get more Alaskans to work.

Recommendation: The Council urges that this capital request be funded.

→ Universal Newborn Hearing Screening

Using national incidence rates, the Department of Health & Social Services estimates that congenital hearing loss is likely to be present in 30 of the 10,000 babies born annually. Thirty-eight (38) states have passed UNHS legislation. The average lifetime costs in present dollars for persons with hearing loss are estimated to be \$417,000 (CDC 2004). With appropriate early intervention, children with hearing loss can learn and progress at a rate similar to children with normal hearing, underscoring the importance of early diagnosis and intervention (Yoshinaga-Itano, 2003). In addition, early intervention for children with hearing loss has been associated with higher language development scores and newborn hearing screening is projected to be cost-effective because of anticipated gains in lifetime earnings. (CDC, 2004)

Recommendation: The Council urges passage of UNHS legislation.

Increase in Formula Funding and Two-Year Funding Cycle for Education

This initiative will allow school districts to know how much funding they can rely on, which will help them retain staff. The increase in formula funding will allow them to better address student needs throughout Alaska.

Recommendation: The Council urges that school formula funding be increased and that education be funded on a two-year cycle.

Sec. 08.11.120. Audiology exemptions.

(a) This chapter does not apply to an individual who practices audiology consistent with the accepted standards and code of ethics of the individual's profession as part of the individual's duties as

(1) a physician licensed under AS 08.64;

(2) an employee of the federal government who is required to practice audiology during the employment, if

(A) the employer maintains appropriate supervision of the individual's practice of audiology;

(B) the individual practices audiology as part of the duties for which the individual is employed;

(C) the individual practices audiology in the facility where the individual is employed or under the supervision of the federal governmental unit where the individual is employed; and

(D) the individual does not render or offer to render audiology services to the public for compensation in addition to the salary the individual receives from the federal governmental unit;

(3) a student, intern, or resident pursuing a course of study in audiology at an accredited college or a clinical training facility approved by the department, if the activities of the student, intern, or resident constitute part of a supervised course of study and the student, intern, or resident is designated as an "audiology intern," "audiology trainee," or other title approved by the department that clearly indicates that the person is training to be an audiologist.

(b) Notwithstanding the provisions of this chapter,

(1) a nurse licensed under AS 08.68 may perform hearing sensitivity evaluations;

(2) an individual licensed as a hearing aid dealer under AS 08.55 may deal in hearing aids;

(3) an individual holding a class A certificate issued by the Conference of Executives of American Schools of the Deaf may teach the hearing impaired;

(4) an individual may engage in the testing of hearing as part of a hearing conservation program that complies with the regulations of the Occupational Safety and Health Administration of the federal government if the individual is certified to do the testing by a state or federal agency acceptable to the Occupational Safety and Health Administration.

(c) An individual who is not an audiologist, but who is exempt under this section, may not use a title or description stating or implying that the person is an audiologist.

(d) An individual exempt under (a)(2) of this section may consult with and disseminate research findings and scientific information to accredited academic institutions or governmental agencies, and offer lectures to the public for a fee, monetary or otherwise, without being licensed under this chapter.

(e) An individual who is not licensed under this chapter but who teaches the practice of audiology in an audiologist training program at a college or university may use the title "audiologist" but may not practice audiology.

Sec. 21.42.347. Coverage for costs of birth.

(a) A health care insurer who provides coverage for the costs of childbirth shall also provide coverage for the costs of hospitalization or medical care following childbirth for a period of not less than

(1) 48 hours after a vaginal birth; and

(2) 96 hours after a caesarean birth.

(b) Except as otherwise required to provide coverage specified under (a) of this section, this section does not affect a payment arrangement entered into between a hospital or health care provider and a health care insurer.

(c) This section may not be construed to require hospitalization or medical care as described under (a)(1) or (2) of this section if the mother giving birth and the mother's health care provider agree that the mother and any newborn child of the mother should be discharged earlier than required under (a)(1) or (2) of this section.

(d) In this section,

(1) "health care insurer" has the meaning given in AS 21.54.500; "health care insurer" includes the Comprehensive Health Insurance Association as described in AS 21.55.010;

(2) "health care provider" means a person licensed in this state to provide health care services.

Sec. 21.42.350. Exemption of proceeds, annuity contracts. [Repealed, Sec. 14 ch 62 SLA 1982. For current law see AS 09.38.025 (a)].

AS 47.20

Sec. 47.20.060

It is the purpose of this chapter to

(1) subject to the availability of funding, provide quality learning and related early intervention family support services to eligible children under the age of three who have developmental delays or disabilities and, on a discretionary basis, to those children under the age of three who are at risk of developmental delays or disabilities;

(2) bring together and make optimal use of all available federal, state, local, and private resources for the benefit of children under the age of three with developmental delays or disabilities and their families;

(3) expand and improve existing learning and early intervention services and to provide and arrange for comprehensive services through local agencies and statewide support programs.

Sec. 47.20.070. Establishment of program.

(a) The department, with the assistance of the Governor's Council for the Handicapped and Gifted, shall establish a coordinated, comprehensive, statewide system of multidisciplinary interagency programs that provide appropriate early intervention services to eligible persons under this chapter.

(b) The department is the lead agency for purposes of federal law with respect to the administration of the early intervention services system required under (a) of this section. The department shall establish and administer the system required under (a) of this section so that the state is eligible for the maximum available funding from public and private sources.

(c) in connection with the system established under (a) of this section, the department shall

(1) develop a state plan that identifies the best methods of providing services to children under the age of three with developmental delays or disabilities and their families and report to the governor on the extent to which that plan is being implemented in the state;

(2) develop and implement an educational program concerning the nature and effects of developmental delays and disabilities;

(3) serve as a clearinghouse for educational materials and information about developmental delays and disabilities;

(4) organize and encourage training programs for persons who provide services to children under the age of three with developmental delays and disabilities and their families;

(5) establish a training program for paraprofessionals who provide services to children under the age of three with developmental delays and disabilities and their families;

(6) cooperate with other public and private agencies and individuals to facilitate the transition of children served in the early intervention system to the formal education system;

(7) identify and use all public and private resources available to the state; and

(8) monitor and evaluate the services provided to ensure the demonstrable effectiveness of the services and compliance with state and federal law and department policy regarding the provision of early intervention services.

Sec. 47.20.075. Grant authority.

The department may award grants for covered services to children and their families who are eligible under this chapter.

Sec. 47.20.080. Program eligibility.

(a) A child and the child's family are eligible for core early intervention services and additional early intervention services under this chapter if the child is under the age of three and

(1) experiencing developmental delay or disability; or

(2) at risk of experiencing developmental delay or disability if early intervention services are not provided.

(b) If the department estimates that funding available for services under this chapter will be insufficient to provide services to all persons who are eligible under (a) of this section, the department shall eliminate coverage for services in the following order:

(1) additional early intervention services for persons eligible under (a)(2) of this section;

(2) additional early intervention services for persons eligible under (a)(1) of this section;

(3) core early intervention services for persons eligible under (a)(2) of this section; and

(4) core early intervention services for persons eligible under (a)(1) of this section.

Sec. 47.20.090. Finding and evaluating eligible participants.

(a) The department shall establish a comprehensive system for finding children and their families who are eligible for services under this chapter. This child find system must

(1) include a public awareness program focusing on early identification of developmentally delayed and disabled children under three years of age;

(2) provide for participation by primary referral sources; and

(3) include procedures with timelines for referral of eligible participants to service providers.

(b) The department shall, within 45 days after a child's referral for services under (a) of this section, ensure that all affected public agencies and service providers

(1) provide for a comprehensive multi-disciplinary evaluation of the functioning of the child and the needs of the child's family so that the family can appropriately assist in the development of the child;

(2) in consultation with the child's parents, develop a written individualized service plan that identifies how the needs of the child and the family could be met.

Sec. 47.20.100. Individualized family service plan.

The individualized family service plan developed under AS 47.20.090(b)(2) shall be based on the evaluation conducted under AS 47.20.090(b)(1) and must include, subject to AS 47.20.080 (b),

(1) provisions for case management services to implement the plan, including the name of the case manager from the profession most immediately

relevant to the child's or family's needs who will be responsible for the implementation of the plan and coordination with other agencies and persons;

(2) a statement of the child's present levels of physical development, cognitive development, language and speech development, psychosocial development, and self-help skills, based on appropriate objective criteria;

(3) a description of the family's concerns, priorities, and resources as they relate to the future enhancement of the child's development;

(4) a description of the specific early intervention services that will help meet the unique needs of the child and the family, including the frequency, intensity, and method with which the services should be delivered;

(5) the projected dates for initiation of services and the anticipated duration of the services;

(6) an outline of the major outcomes expected to be achieved for the child and the family along with the criteria, procedures, and timelines that will be used to determine the degree to which progress toward achieving the outcomes are being made and whether modifications or revisions of the outcomes or services are necessary; and

(7) a statement of the steps that will be taken to support the transition of the child and the family to the use of services available under other appropriate programs, including programs for children who are three years of age or older.

Sec. 47.20.110. Other duties of the department.

(a) The department shall adopt regulations necessary to implement this chapter, including regulations

(1) for personnel development, including preservice and in-service training programs for providers of early intervention services;

(2) to govern resolution of intra-agency and interagency disputes about the provision of services under this chapter and the financial responsibility of the respective parties for those services;

(3) that ensure that services are provided to children and their families in a timely manner pending the resolution of disputes among public agencies or service providers;

(4) providing for due process with respect to the rights of children and parents who are eligible for services under this chapter; the regulations must provide that during the pendency of a complaint about a change in services, the child and family shall continue to receive the prior services unless the state and the family otherwise agree, or, if the complaint relates to an application for initial services, the child and family shall receive the services that are not in dispute; and

(5) for the award of grants under this chapter.

(b) The department shall establish a system for compiling data on the numbers of children and their families in the state who need early intervention services, the numbers being served, the types of services provided, and other information as required under federal law. Personally identifiable information obtained under this chapter is confidential for purposes of AS 40.25.110 - 40.25.120.

Sec. 47.20.290. Definitions.

In this chapter,

(1) "additional early intervention services" means

(A) family training and counseling;

(B) speech pathology and audiology;

(C) occupational therapy;

(D) physical therapy;

(E) psychological services;

(F) medical services only for diagnostic or evaluation purposes; and

(G) health services for the child that are necessary to enable the child to benefit from the other early intervention services;

(2) "core early intervention services" means

(A) case management services;

(B) special instruction; and

(C) early identification, screening, and assessment;

(3) "department" means the Department of Health and Social Services;

(4) "developmentally delayed" means functioning at least 15 percent below a chronological or corrected age or 1.5 standard deviations below age appropriate norms in one or more of the following areas: cognitive development, gross motor development, sensory development, speech or language development, or psychosocial development, including self-help skills and behavior, as measured and verified by appropriate diagnostic instruments and procedures or through systematic observation of functional abilities in a daily routine by two professionals and a parent, developmental history, and appropriate assessment procedures;

(5) "disability" means having an identifiable physical, mental, sensory, or psychosocial condition that has a probability of resulting in developmental delay even though a developmental delay may not be exhibited at the time the condition is identified, including

(A) chromosomal abnormalities associated with delays in development, such as Down's syndrome, Turner's syndrome, Cornelia de Lange syndrome, or fragile X syndrome;

(B) other syndromes and conditions associated with delays in development, such as fetal alcohol syndrome, cocaine and other drug-related syndromes, metabolic disorders, cleft lip, or cleft palate;

(C) neurological disorders associated with delays in development, such as cerebral palsy, microcephaly, hydrocephaly, spina bifida, or periventricular leukomalacia;

(D) sensory impairment, such as hearing loss or deafness, visual loss or blindness, or a combination of hearing and visual loss, that interferes with the child's ability to respond effectively to environmental stimulus;

(E) congenital infections, such as rubella, cytomegalovirus, toxoplasmosis, or acquired immune deficiency syndrome;

(F) chronic illness or conditions that may limit learning or development, such as cystic fibrosis, bronchopulmonary dysplasia, tracheostomies, amputations, arthritis, or muscular dystrophy;

(G) psychosocial disorders, such as reactive attachment disorder, infant autism, or childhood schizophrenia; or

(H) atypical growth patterns consistent with a prognosis of developmental delay based upon parental and professional judgment, such as failure to thrive;

(6) "early intervention services" or "services" means services that are designed to help meet the developmental needs of a child under the age of three who is developmentally delayed or disabled or at risk of developmental delay or disability or the needs of the child's family so that the family can support the child's development.



February 3, 2005

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

RE: HB 10J (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

Marie Darlin, Coordinator
AARP Capital City Task Force
415 Willoughby Avenue, Apt. 506
Juneau, AK 99801
586-3637 (voice)
463-3580 (fax)

CC: Vice-Chair Pete Kott
Representative Gabrielle LeDoux
Representative Bob Lynn
Representative Norman Rokeberg
Representative Harry Crawford
Representative David Guttenberg
Representative Jay Ramras

Hearing Loss

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.

For resources:

American Speech-Language-Hearing Association. Hearing Treatment and Rehabilitation, Rockville, MD, February 12, 2002. www.asha.org.

Boys Town National Research Hospital. Information on Hearing Loss, Omaha, NE, February 12, 2002. www.boystownhospital.org.

Centers for Disease Control and Prevention. The Early Hearing Detection and Intervention Program, Atlanta, GA, February 7, 2002. www.cdc.gov/nbddd/ehdi.

National Center for Hearing Assessment and Management. Early Hearing Detection and Intervention Programs, Utah State University, Logan, UT, February 7, 2002. www.infanthearing.org/ehdi.

Stenberg, A., Bam, L.J. Hearing loss. In: Barshaw, M.L., ed. When Your Child Has a Disability, Baltimore, MD, Paul H. Brookes Publishing Company, 2001, pages 289-306.

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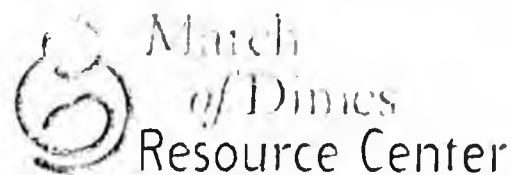
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Newborn Screening Tests



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 website 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

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

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

For more information:

American Academy of Pediatrics, Newborn Hearing Screening and Your Baby, Elk Grove, IL, 2002.

Lloyd-Puryear, M. Newborn screening: a blueprint for the future. *Pediatrics*, volume 106, number 2 (supplement), August 2000, pages 389-422.

National Newborn Screening and Genetics Resource Center. U.S. National Screening Status Report. University of Texas Health Science Center at San Antonio, Austin, TX, 3/11/02, <http://genes-r-us.uthscsa.edu>

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Birth Defects



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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.

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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 chance of the birth defect recurring in another pregnancy. Genetic counselors also can provide referrals to medical experts as well as to appropriate support groups.

References

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

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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 is 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 months 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,

● Page 2

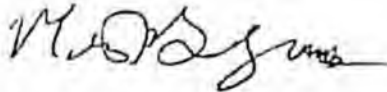
February 1, 2005

Information will be shared with a state program that can make sure that each infant that needs further intervention have this option provided for them. Without a state mandate, this information will have to be shared voluntarily between institutions, which will allow for some institutions to ignore this critical step. Diagnostic intervention involves testing called auditory brainstem response testing (ABR) which is only done by audiologists trained in this procedure.

3. Once diagnosed, in order to receive maximum benefit, parents should be presented with communication options and intervention should begin before 6 months of age. These options may include hearing aids (which are accepted by infants much better if started in early infancy), and various communication options including sign language and other visual cues. The parents and the infant's medical provider must serve as a medical home and have information to make appropriate referrals for subspecialty evaluation and community based resources in accordance with the Individuals with Disabilities Education Act.

Thank you for sponsoring HB 109 which will assure that our youngest Alaskans have the opportunity to have this most common, but invisible, birth defect diagnosed early with appropriate intervention that will offer long term benefits for their future. If I can be of any assistance, please let me know.

Sincerely,



Martin F. Beals, Jr., M. D., FAAP
Alaska AAP Chapter Champion, EHDI program

Quota International of Fairbanks

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Resolution in support of establishing a screening, tracking, and intervention program related to the hearing ability of newborns and infants

Whereas thirty to forty babies born annually in Alaska are likely to have some type of congenital hearing loss; and

Whereas approximately 50% of newborns with hearing loss are not identified and will not be identified until 18 mos. to 3 years of age; and


Whereas undetected hearing loss can result in lifelong delays in language, cognitive, socio-emotional and academic development; and

Whereas over the educational lifetime of a child, substantial amounts of money would be saved if, as a result of early identification and intervention, the most appropriate educational setting for the child is a regular mainstream classroom instead of a self-contained classroom or a self-contained program; and

Whereas the prevalence of congenital hearing loss at 3 per 1000 births nation wide is substantially higher than the prevalence of phenylketonuria (PKU), hyperthyroidism, or sickle cell anemia, which are required for screening in every state;

Now therefore be it resolved that Quota International of Fairbanks, a service organization focused on the speech and hearing impaired, wholeheartedly supports HB 109 "an act to establish a screening, tracking, and intervention program related to the hearing ability of newborns and infants....."

Resolution #1 Adopted unanimously by the general membership on February 1, 2005, 6 p.m. Regency Hotel, Fairbanks, Alaska.



Amy Richards, President
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2	Babers, Terri	P.O. Box 85261 Fairbanks, AK 99703	474-0721	452-2277			Carla K. Leslie G.	5/3/2003	6-JAN-1963 babers@alaska.net	
3	Birdwell, Melissa	P.O. Box 71559 Fairbanks, AK 99707	488-2178	479-3265	479-5225	322-9872	Cindy Shirley	12/1/1985	29-JUL-1985 mbirdwell@alaska.net	
4	Borgeson, Diane	P.O. Box 74346 Fairbanks, AK 99707	452-8233	461-7767	45-2065		Fairbank Hempstead	2/2/2002	18-AUG-1960 dborgeson@alaska.net	
5	Bunch, Karla	PO Box 63723 Fairbanks, AK 99709	478-5355	457-792	457-0781	322-7859	Buzzy	11/1/2003	30-AUG-1965 karlabunch@alaska.net	
6	Cameron, Randi	1676 Vall View Dr Fairbanks, AK 99712	452-8028	452-3100	452-6505	590-1166	Melissa Bridget	12/22/2003	2-APR-1984	
7	Chapman, Rickie	2006 Car St. Fairbanks, AK 99709	456-7285	N/A				4/23/1984	12-NOV-1984	
8	Chlor, Buzzy	P.O. Box 71045 Fairbanks, AK 99707	479-8772	452-6561	452-6126			12/7/1993	12-APR-1963 buzchlor@alaska.net	
9	Codepage, Terry	450 S. Santa Cruz Ln, North Pole, AK 99705	488-5017	488-7082	488-7143	489-2915		5/5/1997	15-JUL-1960 terrycodepage@alaska.net	
10	Coller, Fay	784 Currier Drive Fairbanks, AK 99712	457-1562	451-7229	451-7223		Rebecca Curwin	3/5/1989	25-APR-1961 faycoller@alaska.net	
11	Giberson, Margaretta	3221 Chebano Dr. Fairbanks, AK 99709	457-3969	451-4455	451-6963	322-1445		2/3/1962	10-JUL-1965 marggiberson@alaska.net	
12	Gustafson, Leslie	10293 Old Valdez Trail, Selkirk, AK 99714	462-2673	488-3004	488-2551	388-4544	Beith Renee	11/25/1978	25-DEC-1960 lesliegustafson@alaska.net	

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A	B	C	D	E	F	G	H	I	J	K
Name	Address	Profession	Phone	Phone	Fax	Cell	Spns.	Entry	B-Day	E-Mail
14 Mel Berle	1E Tinsford Dr. Fairbanks, AK 99709	Guess K Road- Paragon Services- Owner Arctic Office	457-4251	452-8500	452-7015	347-7211	Wendy Halter	6/5/2000	13-09-01	melberle@alaska.net
15 Halter Wendy	P.O. Box 70622 Fairbanks, AK 99707	Products- Commerica Designer K&K Recycling Inc.	457-7442	459-0203	459-0324	556-3812	Charal Vansant	11/9/1976	27-11-91	wendyhalter@alaska.net
16 Eskatin Olga	P.O. Box 10268 Fairbanks, AK 99710	Accounter- Hematech & Evans PC Box	452-2111	498-1009	498-4058		Chris McLean	6/7/1994	6-11-1994	olgaeskatina@alaska.net
17 Hematech Barbara	P.O. Box 81534 Fairbanks, AK 99708	Accountant	475-9212	452-1700	456-5693			1/2/2001	14-01-01	barbarahematech@alaska.net
18 Henda Ann	1550 Tardis Dr Fairbanks, AK 99709	Upperware Store Photography	452-8475				Rita Valencia	10/7/2003	10-Feb-2003	henda@alaska.net
19 Kalar, Cora	P.O. Box 10923 Fairbanks, AK 99707	State of AK DOT	456-7103	474-2518	474-2572	978-0087	Melissa Bisval	4/16/1997	14-03-01	corakalar@alaska.net
20 Kocke, Kaye	P.O. Box 55255 North Pole, AK 99705	M. McKinley Bark Manger Gold Coast	488-1810	474-1770	474-7711	322-4110	Amy Richards	5/1/2001	21-11-01	kayekocke@alaska.net
21 Long, Victoria	PO Box 58179 Fairbanks, AK 99711	Mergis Long Realty	489-0390	451-7375	451-7381	322-0966	2-3 Valencia	10/7/2003	2-11-1994	vlong@alaska.net
22 Hoff, Beck	P.O. Box 70143 Fairbanks, AK 99707	World Traveler Phikas	457-6821			451-6545		2/2/1998	28-Mar-1994	beckhoff@alaska.net
23 Reniew, Selin	4477 Pike's Landing Rd. Fairbanks, AK 99709	Lodge Endicott Merrill Mc McKinley Bank VP Operations	937-322- 0082	455-6022	455-5005	607-441- 1528	Rita Valencia	11/11/1989	30-11-1989	selinreniew@alaska.net
24 Richards, Amy	CI Fairbanks, AK 99709		479-721E	452-3751	456-6982	1978-1558	Beck PMDX	3/12/2001	2-Jan-00	amrichards@alaska.net

M. Mill, Cynthia
99709
4430 Dillard Ave
Assistant
via Aardvark
974 3734
9-7-04 12-16-57
Cynthia@alaska.net

Quota of February's Roster (3-25-04)

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A	B	C	D	E	F	G	H	I	J	K
Name	Address	Profession	Home Phone	iPhone	Fax	Cell	Sponsor	Entry	3-Day	E-Mail
1	Shannon Dr. Fairbanks, AK 99701	Police Fuel Owner	458-8772	451-9355	451-9201	590-3990	Virginia Party W.	2/4/2004	11-Feb	shannon@alaska.net
25	107 Navina St Fairbanks, AK 99709	FBKS Monessor	474-4077	451-8185	452-1672	322-9188		5/8/1997	13-Apr	schroef@arcasales.com
26	P.O. Box 83744 Fairbanks, AK 99705	Schneefer & Shelby CPA	474-1631	474-1631	474-1632			4/2/1995	10-Sep	schneefer@arcasales.com
27	1140 Chena Ridge Rd. Fairbanks, AK 99708	Foundations Dev. Sales Coordinator	457-9240	459-6117	451-3378	378-3827	Malisa Devi	12/1/2001	3-Jan	malisa@arcasales.com
28	2551 Gold Street Naila Park, AK 99705	Owner Corporation	450-5825	450-5825	450-5825	322-7821	Mal Sally	12/5/2000	28-Oct	malisa@arcasales.com
29	2005 Rensselaer Hwy. VerA Pala, AK 99705	M. Rensselaer Dymer	453-4125	488-9407	483-5584	398-3522	Malisa Virginia	5/21/99	23-Jun	malisa@arcasales.com
30	3111 Penguin Lane Fairbanks, AK 99712	Jack Rencil Scale Farm Maintenance	493-2325	452-881	451-5029	347-899	Tennis Coburn	12/1/2003	20-Apr	malisa@arcasales.com
31	2871 Perimeter Dr. North Pole, AK 99705	Avis Rent-A- Car Manager General	488-7738	474-0500	474-2043	322-3820		2/1/1998	28-Jul	malisa@arcasales.com
32	1104 Cat Ave. Fairbanks, AK 99703	Manager "Pikes On The River"	475-7289	458-5200	456-5214	378-6065		3/2/1994	5-May	malisa@arcasales.com
33	PO Box 75012 Fairbanks, AK 99707	President/Direc- tor - Diamond Fence Co.	452-2570	458-0087	453-2229	322-3244	Becky Ft.pa	1/14/2005	29-Sep	malisa@arcasales.com
34	596 1/2 Ill Ave. #502 Fairbanks, AK 99701	Rethel Nurse	479-4255	479-7432	322-0111	479-7432	Wendy Helen	5/8/1997	5-Oct	malisa@arcasales.com

Susan Walker
P.O. Box 770658
Eagle River, Alaska
Ph. 907-696-1995 Email:jsjk@mtaonline.net

February 3, 2005

Representative Jay Ramras
State Capitol
Juneau, Alaska 99801-1182

Subject: Letter in Support of House Bill 109
"An Act relating to establishing a screening, tracking, and intervention program related to the hearing ability of newborns and infants..."

Dear Representative Jay Ramras:

I am writing to thank you for your sponsorship of HB 109. I am a parent of two children with hearing loss. I serve as a parent representative on the State's Early Hearing Detection and Intervention (EHDI) Programs' advisory group and am on the March of Dimes steering committee to introduce newborn and infant screening legislation.

My son Jack has a bilateral profound loss and my daughter Kate has a unilateral mild/moderate loss. Their hearing loss was not identified until six months of age and four years respectively. Identification of my son's loss at 6 months, appropriate intervention from highly skilled professionals, and technology have all been instrumental in providing him access to sound – a critical element in his language, social, and emotional development. Our family goal for Jack was that he will be oral and just prior to his second birthday he received a cochlear implant. His language and speech skills are on par with hearing children his age. Jack is now 5 years old, a phenomenal reader, and mainstreamed in kindergarten at his local elementary school. He receives support services but does not require an interpreter or full-time assistance. The degree of Kate's hearing loss is minor compared with her brother but a unilateral loss can still affect a child's ability to receive clear information. And it is harder to detect because they are obviously hearing.

HB 109 is one of two bills before the Legislature relating to newborn hearing screening. The other is SB 68. HB 109 contains the elements that are needed to successfully implement a screening, tracking, and intervention program for newborns and infants in the State of Alaska. Hearing loss is invisible – it cannot be seen at birth. For many toddlers, the possibility that there may be a problem only begins to emerge when they should be talking but seem to be delayed. By then, it is very hard to make up lost time. Early detection is the first critical step, but the other elements are extremely important and part of the process that will allow newborns and infants with hearing loss to maximize the critical brain development window (0 to 3 years) for language acquisition.

I have testified for previous versions of this bill at an earlier time and stage in my son's speech and language development when we (the family) were still hoping it was all going to work. Now we have no doubts – he is cruising! I make no attempt to quantify or reduce his progress to a dollar value or to predict what he will be when he moves on into the world of work. But I know

Susan Walker
P.O. Box 770658
Eagle River, Alaska
Ph. 907-696-1995 Email:jsjk@mtaonline.net

one thing for certain - he will not be limited by his hearing loss. At 5 years old he can have telephone conversations with family and friends, communicate with them directly when visiting, advocate for himself in the classroom and in the recreational and cultural activities in which he participates.

How often do you think about the importance of good language and writing skills to your success and effectiveness as a legislator? Communication is key to your job. Early detection and intervention works. Early detection and intervention opens doors that have been closed to many: children with hearing loss deserve that key to open up their world to language and sound.

Sincerely,

Susan Walker

Distribution:

Sponsor and Co-Sponsors

Representative Jay Ramras
Representative Les Gara
Representative Jim Elkins
Representative Peggy Wilson
Representative Max Gruenberg
Representative Lesil McGuire

Labor and Commerce Committee

Representative Pete Kott
Representative Gabrielle LeDoux
Representative Bob Lynn
Representative Norman Rokeberg
Representative Harry Crawford
Representative David Guttenberg

House Leaders

Representative Ethan Berkowitz
Representative John Coghill

Hello my name is Pam Mueller-Guy. I work for Southeast Alaska Independent Living as the Deaf Services & Interpreter Referral Coordinator. I am representing for SAIL in support for the Newborn Hearing Screening test, House Bill 109 and Senate Bill 68.

I was born as a hearing child. However, I had to have a blood transfusion from a stranger when I was five days old, due to my rare blood type. Due to this blood transfusion, I became deaf, but no one realized it till I was about 2 years old.

Even as a toddler, I could speak a little bit and mimicked by brother while playing with toys. My grandmother finally figured out that I could not hear, realizing I never responded when they called my name. Only when a loud noise occurred, such as a stomp on the floor, did I look their way.

They finally took me to have a hearing test and I was diagnosed with severe profound nerve deafness. They were in shock and wept for me because they didn't know what to do. They asked, "How can she can hear music?" My whole family is musical! They had grief until they realized I could experience music.

I started speech classes at 2 1/2 years old then started wearing hearing aids at 3 1/2 years old and started half days till four years old to stay at boarding parents house during the week because deaf school was 25 miles away from my home.

I was held back in school twice due to my hearing disability. One time, just because they wanted to keep all the students who were deaf together in one grade. I had to make friends all over again.

If this bill is passed, it will also allow parents of newborn babies with hearing loss to get information immediately and begin preparing for life with a child who is deaf. It is difficult for organizations like SAIL to identify and assist persons who have hearing loss; a much better way to do this is to catch the baby and family at the beginning of life. I do not want to see people with hearing loss have to go the hard way like me.

I hope for the new generation that they can be diagnosed early and begin to learn early so they may be capable of writing English easy instead of the hard way. I see most deaf and hard of hearing have a hard time in Alaska for jobs. Schools also should have programs specifically for children who are deaf so they won't be isolated. I am hopeful children who are deaf will be able to communicate in both the hearing world and the deaf world.

The newborn hearing screen would be best for all needs so the parents of the baby can start early to learn to cope with the child and their lives would be easier! This bill will

save a lot of money for the government, schools, and insurance, including Medicaid, in the long run. Thank you for taking your time to listen to me. Keep passing those bills for better lives in Alaska!



3225 Hospital Drive Juneau, Alaska 99801
Phone (907) 586-4920 Fax (907) 586-4980 TTY (907) 523-5285
Toll Free IRL Pager 1-877-950-8286

Interpreter Referral Line Policies

TO SCHEDULE INTERPRETER SERVICES

- Call SAIL at least 1 week before the interpreter is needed. 2 weeks notice is preferred.
- We try to fill all requests, but generally require at least one week's notice

The service provider and not the deaf person is responsible for the expense of the interpreter. If you are scheduling an interpreter, please be sure the business or agency that will be paying for the interpreter is aware of the cost.

FEEES

2-hour minimum for all interpreting services

- Regular interpreting services (excluding legal/medical)
\$70.00 minimum for the first 2 hours + \$35.00 for each additional hour
- Legal or medical interpreting services
\$80.00 minimum for the first 2 hours + \$40.00 for each additional hour
- After hours or emergency interpreting services (outside 8am-5pm Mon-Fri)
\$100.00 minimum for the first 2 hours plus \$50.00 an hour for each additional hour
This rate applies to all interpreting services requested less than 48 hours in advance.
- Any assignments lasting more than 2 hours will be billed in 15-minute increments.

NO SHOWS AND SHORT NOTICE CANCELLATIONS (LESS THAN 24 HOUR NOTICE)

For cancellations with less than 24-hour notice or for which the party fails to appear, a fee will be charged according to the following schedule:

- \$35 for regular interpreting
- \$40 for legal/medical interpreting
- One-half the scheduled time at \$35/hour for all interpreting services scheduled to last over two hours

HOW TO CONTACT US

- Call SAIL office voice/TTY 586-4920
- Call Pam Mueller-Guy (Interpreter Referral Coordinator) TTY 523-5285
- Call Toll Free in Alaska 1-800-478-7245
- Call Alaska Relay at 711. Information about Alaska Relay is in the front of the telephone directory.
- For services after regular business hours (8-5 M-F) call the toll free pager at 1-877-950-8286. Enter the telephone number the interpreter needs to call to schedule services.

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, 1996, 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

DEDICATED TO THE HEALTH OF ALL CHILDREN™



February 4, 2005

Alaska Chapter

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3600 Madnews Drive
Anchorage, AK 99516
907/346-5911

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907/346-8028
Fax: 907/346-8028
E-mail: jtower@alaska.com

Representatives: Tom Anderson, Chair, House Labor and Commerce
Pete Kott, Vice-Chair
Gabrielle LeDoux
Bob Lynn
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

Suzanne Rust
7930 Ingram Street
Anchorage, Alaska 99502
907-243-3160

February 1, 2005

Representative Tom Anderson
Special Assistant Health and Human Services
State Capitol
Juneau, Alaska 99801-1182

Dear Representative Anderson:

I want to take this opportunity to tell you about Lauren, my 12-month-old daughter. Besides being a marvelous girl, she happens to be hard of hearing. Providence Hospital's New-Born Screening identified Lauren's condition at birth. Although it took us 13 weeks of hard work to verify that she has a hearing loss, the screening was essential. Since she is hard of hearing, we may not have detected her loss until her language was affected. We would have lost the opportunity for laying a solid foundation of speech and language development.

I am contacting you today because I would like you to support House Bill 109 which requires universal hearing screening for new-born infants and mandatory reporting by birthing facilities of the hearing screening results to the State of Alaska's Early Hearing Detection and Intervention Program. This will ensure that children with possible hearing loss receive a timely diagnostic evaluation and, if necessary, are enrolled in early intervention services at the earliest possible time. The reasons I believe this bill should be whole-heartedly supported are many but I will list a few:

- Hearing impairment is the most common disability in newborns
- The low cost of screening is minimal when compared to the additional hundreds of thousands of dollars the state may have to spend in special education.
- The most important period of speech and language development is from birth to age three. The average age of identification in the absence of the newborn hearing screening is 2-3 years.
- Children with hearing loss can develop and progress like those without hearing loss if they are identified early.

Because Lauren was identified in the screening process, she has had hearing aids since she was three months old. Her language and speech seem to be on track and, thankfully, she has been able to hear my voice. Please join me in assuring that everyone's child gets the same chance for success Lauren received. Thank you in advance for your support.

Sincerely,

Suzanne Rust

Douglas Owen

From: Lisa Owens [lowens@tetongravity.com]

Sent: Thursday, January 27, 2005 11:23 PM

To: Rep. Jay Ramras

Dear Rep. Ramras,

I want to thank you and give my support for HB 109. As an audiologist and speech pathologist working with children with hearing loss I feel that it is critical that children with hearing loss are found early. Research and personal experience show that children who are identified with a hearing loss early and receive appropriate intervention, do better academically. They are provided more choices in communication options and develop better speech and language skills. Please let me know if there is anything I can do to help support the passage of this bill.

Sincerely,

Lisa Owens, M.A., CCC-SLP/A



Alaska State Legislature

Please enter into the record my testimony to the House HESS Committee
 Committee name

Committee on HB 109 dated 17 February 2005
 Bill/Subject

I would like to write in support of HB 109. The Grange, the organization I belong to, has supported mandatory infant hearing screening since 1999. I have 2 children of my own and know firsthand how important the first years of life are in language development. Early identification and intervention of hearing loss is so very important. I consulted the National Center for Hearing Assessment and Management website, infanthearing.org, and learned that 2-4 babies per 1000 screened at birth had permanent congenital hearing loss. Alaska's babies deserve early identification and care. Please help Alaska join the 32 other states that have enacted legislation for New born Hearing Screening.

Signed: Lois Biele
 Testifier

Northland Pioneer Grange No. 1
 Representing (Optional)

Po Box 2304 Palmer
 Address

746-4900
 Phone number

Rep. Ramoas - Thanks for sponsoring HB 109! Marie



ALASKA PUBLIC HEALTH ASSOCIATION

Committed To Advancing Alaska's Public Health Since 1978



February 17, 2005
(H) HESS HB 109

IN SUPPORT OF HB 109 "SCREENING NEWBORNS FOR HEARING ABILITY"

Dear members of the (H)HESS Committee:

On behalf of the Alaska Public Health Association, representing two hundred and twenty public health professionals who are deeply committed to developing sound public health policy to improve the health of all Alaskans, we encourage you to vote yes on HB 109 and move it out of Committee today.

Recognizing the importance of universal hearing screening of newborns as a critical public health intervention, the Alaska Public Health Association encourages you to support HB 109. Hearing impairment is the most common disability in newborns, impacting 2-3 children out of every thousand. Identified early, these children will not be left behind during the most critical period for speech and language development: birth to 3 years.

Late identification of infant hearing loss presents a significant public health problem. Without screening, children with hearing loss are usually not identified until two years of age or later, which results in significant delays in speech, language, social, cognitive, and emotional development – and a greater cost for services.

Research has shown that children identified at birth with mild-to-severe hearing loss who receive intervention before they are 6 months of age fall within a normal range of language comprehension and expression as well as social development by the time they are ready to begin school. By contrast, children with hearing loss diagnosed after six months of age experience significant delays in both language and social development. The cost savings of early intervention is significant.

HB 109 offers an important first step in providing newborn hearing loss screening. Yet we urge you to not stop at the hospital or birth center, as what happens after screening is also important. Families need to receive appropriate information and services following newborn hearing screening and to have their children begin receiving intervention services by six months of age. It is also critical the team working with the child measure the impact of early identification of hearing loss on development, tracking gains made and areas to develop. The public health surveillance system must be in place for the Early Hearing Detection Program to be effective.

To quote from Dr. Marlon Downs, the world-renowned pioneer in pediatric audiology, "If a child can be identified at birth and receive immediate intervention, we have done our jobs," she said. "On the other hand, if we don't detect the hearing loss until the child reaches 2 years of age or later, that child has, in most cases, lost the opportunity to catch up with others his or her own age. *Why, with all the tools we have, would we not speed the time to establish a model for screening and early intervention in our nation's hospitals?*" That is the challenge before us in Alaska.

HB 109 takes an important step in bringing forth universal hearing, building on the success of Alaska's hospitals and birthing centers who are already voluntarily screening, to assure all newborns will be screened. With appropriate screening and follow up services, HB 109 will assure our children who are deaf or hearing impaired receive the early intervention services they need to develop their fullest potential. Thank you.

Marie J. Lavigne, Executive Director Alaska Public Health Association

adn.com

Anchorage Daily News

Print Page

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Job's Daughters help kids take a HIKE toward hearing**GRANTS: Girls ages 10-20 raise money for fund, other projects.**By ASTA CORLEY
Anchorage Daily News*(Published: January 26, 2005)*

Lauren Rust, 11-month-old daughter of Suzanne and Todd Rust and unofficial "granddaughter" of former Alaska Rep. Cheryl Heinze, failed her newborn hearing screening at birth. When she was 3 months old, doctors confirmed she had mild to moderate hearing loss at low frequencies, and moderate to severe hearing loss at high frequencies.

Doctors counseled Suzanne to speak clearly while allowing Lauren to see her face during interaction. She was urged to find opportune, quiet times to be expressive and vocal while Lauren absorbed her environment. With the help of hearing aids, Lauren's hearing has significantly improved.

"The minute I knew she could hear me, I was so much more relaxed," Suzanne said.

Lauren's family has applied for help from the Hearing Impaired Kids Endowment, or HIKE, the global charity of the International Order of Job's Daughters.

The HIKE fund was established to provide grants to assist hearing-impaired children and raise public awareness for Job's Daughters, a nonprofit organization for girls ages 10 to 20 who are descendants of Master Masons, a community service organization for men.

Founded in 1920 by Ethel T. Wead Mick in Omaha, Neb., the group gets its name from the 15th verse of the 42nd chapter of the Book of Job: "In all the land were no women found so fair as the daughters of Job; and their fathers gave them inheritance among their brethren." The group promotes citizenship, patriotism, leadership, organization, teamwork, self-reliance and community service.

"This organization is near and dear to me," said adult adviser Susan Anderson of Anchorage. "There's a basis behind everything we do to bring these young girls into womanhood."

Last year, Anchorage Job's Daughters raised \$675 for HIKE. Funds from the national organization allowed them to distribute \$20,000 in HIKE grants to Alaska children, and they hope to award a similar amount this year.



Local members of Job's Daughters participate in a blanket party in December at the Masonic Temple. Pictured from left: Ti'eri Lino, Becky Boggs, Danya Eskridge, Kaylynn St. John, Damesha Shine and Jocelyn Moore. *(Photo courtesy of Job's Daughters)*



Jeanne Hineman, left, the international head of Job's Daughters, attended an October luncheon at the Masonic Temple in Anchorage and visited with Suzanne Rust and her daughter Lauren. The group's Hearing Impaired Kids Endowment project helps children like Lauren, who experiences hearing loss. *(Photos courtesy of Job's Daughters)*

[Click on photo to enlarge](#)

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

In the United States, three children in every 1,000 -- about 12,000 a year -- are born with hearing loss, according to EDHI figures. Of the 10,000 babies born in Alaska annually, 30 to 40 experience some type of congenital hearing loss.

Any child, newborn to age 20, with hearing difficulties is eligible for a HIKE grant. Besides hearing aids, grants may also be used for other hearing devices such as closed-caption converters for television, computers and training. Actual funds disbursed depend on a need assessment by a doctor but can go as high as \$4,000. It's also possible to reapply for funds.

Suzanne and Todd Rust are owners of Rust's Flying Service in Anchorage and K2 Aviation in Talkeetna. Testing for Lauren during her first three months cost about \$5,500. The Rusts estimate they will pay \$8,000 for Lauren's hearing aids, which are accompanied by an FM system (a small one-way radio device that allows one to hear conversation and other sounds within a certain range), as well as audiology services.

"Her hearing aids are super important to her," Suzanne said. "It's healthy for brain development to hear sounds." Early intervention helps the child keep pace with language and speech development and not fall behind in school.

When Heinze decided not to run for re-election for the state House of Representatives, she had to liquidate her campaign account and made a \$1,750 donation to HIKE. Chugach Electric Association also made an unsolicited donation. All donations are channeled to the international fund, and contributions are tax-deductible.

Job's Daughters has more than 20,000 members throughout Canada, Australia, the Philippines, Brazil and the United States. Individual organizations of the group are called bethels. In Alaska there is only one -- Bethel No. 1, Anchorage. Established in 1957, it has 18 active members. Past activities of the Anchorage branch include an Aces hockey night, swim parties, lunches, game board nights, and fund-raising projects for HIKE and the group's travel fund.

East High School freshman Kaylynn St. John, 15, joined last year.

"It's more of a team experience," she said. "It's like we're a big family."

After the terrorist attacks of Sept. 11, 2001, the group traveled to Canada on a friendship visit. And this past summer 11 members went to Casper, Wyo., for an international meeting.

The group's community service has included helping a charter school with its fund-raising auction, and conducting food drives, clothing drives and the annual HIKE Penny Drive from April 15 to May 15.

Last year, the Fred Meyer Foundation gave Job's Daughters a \$913 grant to purchase materials and supplies to make no-sew polar fleece blankets for Anchorage organizations. The group is creating 50 blankets for donation to residents of the Anchorage Pioneers' Home and the Salvation Army's McKinnell House. They are looking for a skilled volunteer to make a blanket out of the remaining scraps for a silent auction to raise money for HIKE.

Anderson underscores the value of including the girls in community service at a young age. She enjoys serving as a mentor to them.

"This is an organization where young girls can learn to fail and still succeed, to withstand peer pressure, and above all, to develop logic and reasoning skills that enable them to think for themselves," she said.

Daily News reporter Asta Corley can be reached at acorley@adn.com.

MEETINGS OF THE ANCHORAGE BRANCH OF JOB'S DAUGHTERS are at 10:30 a.m. on the second and fourth Saturdays of each month at the Masonic Temple, 1431 Eagle St. For more information about Job's Daughters or the HIKE program, call Susan Anderson at 344-6475.

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Josh Applebee

From: Phyllis Kiehl [pkiehl@pol.net]
Sent: Friday, February 04, 2005 8:45 AM
To: Rep. Torn Anderson
Subject: HB 109. Hearing screening

Dear Rep. Anderson,

I am writing to ask you to support and vote for House Bill 109 ("related to screening Newborns for Hearing Ability. I am a pediatrician who has been in private practice in Anchorage for 30 years. The American Academy of Pediatrics supports the development of programs for universal screening of all infants for hearing deficits at or soon after birth. This enables early identification of hearing impaired children in order to be able to intervene to maximize their potential. This program is important because:

1. Hearing loss is 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 hearing loss or even when only one side is affected may have long lasting negative effects to the child. It affects interactions in the family, too.

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.

Due to new advancements in screening technology, non-audiologists can administer the screen (and bill appropriately for this service). By 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.

Universal hearing screen for all newborns is essential for Alaskan children.
Please support HB 109.

Thank you.
Sincerely,
Phyllis Kiehl, M.D.

Phyllis' numbers:
Home: 907/345-3394
Office: 907/562-2120
Beeper: 907/275-2030

Testimony in Support of HB 109, "An Act relating to establishing a screening, tracking, and intervention program related to the hearing ability of newborns and infants"

The mission of March of Dimes is to improve the health of babies by preventing birth defects and infant mortality. March of Dimes has been in existence over 65 years and has a long history of advocating for healthy babies. March of Dimes supports mandatory newborn hearing screening and HB 109.

Hearing loss is the most common birth defect, occurring in about 3 of every 1000 births. Children not detected at birth or soon after will not be detected, on average, until 2-3 years of age. 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 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 screening many times over.

The key to success of universal newborn hearing is the monitoring and tracking components, conducted by the Early Hearing Detection and Intervention Program. Testing alone is not enough. As well meaning as most parents are, it's not unusual for follow-up of a child's hearing problem to fall between the cracks, with potentially devastating and far-reaching consequences. This is why the small fiscal note is necessary. Monitoring and tracking protects vulnerable infants and reduces special education costs that would otherwise be incurred. And while it's true that facilities often do voluntary testing, many babies are left out. Passing HB 109 will help assure all babies in our state have access to these services.

Experts have emphasized the need to detect hearing loss early in life for 50 years. Thirty-nine states have enacted newborn hearing legislation. Concerned Alaskans have been trying to have good newborn hearing screening legislation enacted for several years. HB 109 is an excellent bill and the fiscal note is extremely modest. Please give HB 109 a chance to become law this session. PLEASE pass HB 109 NOW! Thank you.

Respectfully submitted,

Debbie Golden, MS, RN, BC
Director of Program Services
March of Dimes, Alaska Chapter
255 East Fireweed Lane, Suite 102
Anchorage, Alaska 99503
(907) 276-2290

HB

109

SFIN

FILE

SENATE FINANCE COMMITTEE REPORT

REPORTED OUT
 MAY 08 2006
 SENATE FINANCE COMMITTEE

DATE: 3/7/06

FURTHER:

DATE TURNED IN TO OFFICE: 8 May 2006

Finance Committee considered CS FOR HOUSE BILL NO. 109(FIN)

HB 109 SCREENING NEWBORN FOR HEARING/AUDIOLOGIST

"An Act relating to establishing a screening, tracking, and intervention program related to the hearing ability of newborns and infants; providing an exemption to licensure as an audiologist for certain persons performing hearing screening; relating to insurance coverage for newborn and infant hearing screening; and providing for an effective date."

and recommends:

- be replaced with 5 CS CS HB 109 ~~100~~ (FIN)
- adopt previous _____ CS CS forthcoming (_____)
- attached amendment(s)
- adopt Letter of Intent by _____ Committee
- further referral to _____ Committee

CS Senate Bill:
 Same Title
 New Title

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

NEW FISCAL NOTE(S):

Department	Date	Fiscal	Ind.	Zero	FN#

PREVIOUS FISCAL NOTE(S):

Department	Date	Fiscal	Ind.	Zero	FN#
DCCAED	3/11/05			✓	#2
DE+ED	4/12/05			✓	#3
DH+SS	3/7/06	39.4			#5

APPROPRIATION - no fiscal note

SIGNATURES AND RECOMMENDATIONS:	DO PASS	DO NOT PASS	NO REC	AMEND
<i>A. Bunde</i>	✓			
<i>[Signature]</i>	✓			
<i>[Signature]</i>	✓		✓	
<i>[Signature]</i>	✓			
<i>[Signature]</i>			✓	
COCHAIR: <i>Amy Wells</i>			✓	
COCHAIR: <i>Lynne Green</i>			1	✓

REPORTED OUT
MAY 08 2006
SENATE FINANCE COMMITTEE

FISCAL NOTE

STATE OF ALASKA
2005 LEGISLATIVE SESSION

Fiscal Note Number: 2
Bill Version: CSHB 103(FIN)
(H) Publish Date: 4/14/05

Revision Date/Time (Note if correction):
Title Screening Newborns for Hearing Ability
Sponsor Ramras, et al
Requester House Finance

Dept. Affected: Commerce
RDU Occupational Licensing (117)
Component Occupational Licensing
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 CMB)

COMMITTEE COPY

FISCAL NOTE

REPORTED OUT
MAY 08 2006
SENATE FINANCE COMMITTEE

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, track- RDU: TLS
ing, and intervention program, related to the hearing of newborns" Component: Special & Supplemental Services
 Sponsor: Representative Rammas
 Requester: Labor and Commerce Component No.: 106

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: Karon Rehfeld, Deputy Commissioner Date: 04/12/2005
 Agency: Education & Early Development

FISCAL NOTE

STATE OF ALASKA
2006 LEGISLATIVE SESSION

Fiscal Note Number: 5
Bill Version: CSHB 109(FIN)
(S) Publish Date: 3/7/06

Revision Date/Time (Note if correction): Updated 3/3/06

Dept. Affected: Health & Social Services

Title: RELATING TO NEWBORN HEARING SCREENING

RDU: Public Health
Component: Women, Children and Family Health

Sponsor: RAMRAS

Requester: SENATE (HES)

Component No.: 2788

Expenditures/Revenues (Thousands of Dollars)

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

OPERATING EXPENDITURES	FY 2007	FY 2008	FY 2009	FY 2010	FY 2011	FY 2012
Personal Services						
Travel						
Contractual						
Supplies						
Equipment						
Land & Structures						
Grants & Claims	39.4	47.4	55.8	64.6	64.6	64.6
Miscellaneous						
TOTAL OPERATING	39.4	47.4	55.8	64.6	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)	(126.2)
1003 GF Match						
1004 GF	39.4	77.1	67.4	180.5	184.4	190.8
1037 GF/Mental Health						
Other(Specify Type-do not abbreviate)						
Other(Specify Type-do not abbreviate)						
TOTAL	39.4	47.4	55.8	64.6	64.6	64.6

Estimate of any current year (FY2006) cost: _____
 Mark this box (X) if funding for this bill is included in the Governor's FY 2007 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) 95% of newborns would be screened by FY 07; and 98% by FY 08 and beyond. (Continued on P.2)

Prepared by: Richard Mandasager, M.D.
 Division: Public Health
 Approved by: Karleen Jackson, Commissioner
 Agency: Department of Health and Social Services

Phone: 465-3090
 Date/Time: 03/03/2006
 Date: 03/07/2006

STATE OF ALASKA
2006 LEGISLATIVE SESSION

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 Public Health is receiving two federal grants to support the maintenance of this program. One grant, scheduled to expire in March 2008, covers the expenses associated with maintaining 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 2008 and covers costs associated with the statewide early detection/intervention surveillance and tracking system. This provides funds for infrastructure costs through FY08. 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 fund switch from Federal to GF.

The increased line item expenditures shown on page 1 will be utilized for:
GRANTS AND CLAIMS (\$39.4 in FY 07): 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 (12 new infants in FY 07; 14 in FY 08; 16 in FY 09; and 18 in FY 10, FY 11 and FY12).

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
2006 LEGISLATIVE SESSION

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.

Adopted

WORK DRAFT

WORK DRAFT

WORK DRAFT

24-LS04501
Mischel
5/6/06

SENATE CS FOR CS FOR HOUSE BILL NO. 109()
IN THE LEGISLATURE OF THE STATE OF ALASKA
TWENTY-FOURTH LEGISLATURE - SECOND SESSION

BY

Offered:
Referred:

Sponsor(s): REPRESENTATIVES RAMRAS, Gara, Elkins, Wilson, Gruenberg, McGuire, Anderson, LeDoux, Guttenberg, Lynn, Joule, Kerttula, Dahlstrom, Stoltze, Kelly, Foster, Holm, Gardner, Chenault, Thomas, Cissn.

SENATORS Davis, Guess, Elton, Kookesh, Ellis

A BILL

FOR AN ACT ENTITLED

1 "An Act relating to establishing a screening, tracking, and intervention program related
2 to the hearing ability of newborns and infants; providing an exemption to licensure as
3 an audiologist for certain persons performing hearing screening; relating to insurance
4 coverage for newborn and infant hearing screening; and providing for an effective
5 date."

6 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

7 * Section 1. The uncodified law of the State of Alaska is amended by adding a new section
8 to read:

9 LEGISLATIVE FINDINGS. The legislature finds that

10 (1) hearing loss occurs in newborns and infants more frequently than any other
11 health condition for which newborn or infant screening is required;

12 (2) 80 percent of the language ability of a child is established by the time the
13 child is 18 months of age, and appropriate language training is vitally important to the healthy

1 development of cognitive, social, emotional, and academic skills;

2 (3) early detection of hearing loss in a child and early intervention and
3 treatment have been demonstrated to be highly effective in facilitating a child's healthy
4 development in a manner consistent with the child's age and cognitive ability;

5 (4) children with hearing loss who do not receive early intervention and
6 treatment frequently require special education services, and these services are publicly funded
7 for the vast majority of children with hearing needs in the state; and

8 (5) appropriate screening and identification of newborns and infants with
9 hearing loss will facilitate early intervention and treatment and may serve the public purpose
10 of promoting the healthy development of children while reducing public expenditures.

11 * Sec. 2. The uncodified law of the State of Alaska is amended by adding a new section to
12 read:

13 LEGISLATIVE INTENT. Subject to the availability of appropriations to implement
14 AS 47.20.300 - 47.20.390, enacted by sec. 6 of this Act, the Department of Health and Social
15 Services shall implement the program required by this Act so that 100 percent of all newborns
16 and infants in the state are being screened for hearing loss by January 1, 2008.

17 * Sec. 3. AS 08.11.120(b) is amended to read:

18 (b) Notwithstanding the provisions of this chapter,

19 (1) a nurse licensed under AS 08.68 may perform hearing sensitivity
20 evaluations;

21 (2) an individual licensed as a hearing aid dealer under AS 08.55 may
22 deal in hearing aids;

23 (3) an individual holding a class A certificate issued by the Conference
24 of Executives of American Schools of the Deaf may teach the hearing impaired;

25 (4) an individual may engage in the testing of hearing as part of a
26 hearing conservation program that complies with the regulations of the Occupational
27 Safety and Health Administration of the federal government if the individual is
28 certified to do the testing by a state or federal agency acceptable to the Occupational
29 Safety and Health Administration;

30 (5) an individual may perform hearing screening under
31 AS 47.20.310 if authorized to do so under a protocol adopted under

1 **AS 47.20.310(e) by the Department of Health and Social Services.**

2 * **Sec. 4.** AS 18.:) is amended by adding a new section to read:

3 **Sec. 18.50.162. Notification about hearing screening.** When the bureau
4 receives a certificate of live birth under AS 18.50.160 for a newborn who was
5 delivered outside of a hospital, the bureau shall forward the names and addresses of
6 the parents to the department employees who administer the screening program set out
7 in AS 47.20.310 - 47.20.390. Those department employees shall notify the child's
8 parents of the merits of having the child screened for hearing ability.

9 * **Sec. 5.** AS 21.42 is amended by adding a new section to read:

10 **Sec. 21.42.349. Coverage for newborn and infant hearing screening.** (a)
11 Except for a fraternal benefit society, a health care insurer that offers, issues for
12 delivery, delivers, or renews in this state a health care insurance plan shall provide
13 coverage for newborn and infant hearing screening under the schedule described in (b)
14 of this section if the plan covers services provided to women during pregnancy and
15 childbirth and the dependents of a covered individual.

16 (b) The minimum coverage required under (a) of this section includes

17 (1) a newborn or infant hearing screening to be performed within 30
18 days after the child's birth; and

19 (2) if the initial screening under (1) of this subsection determines that
20 the child may have a hearing impairment, a confirmatory hearing diagnostic
21 evaluation.

22 (c) The coverage required by this section may be subject to standard policy
23 provisions that are applicable to other benefits, such as deductible or copayment
24 provisions.

25 * **Sec. 6.** AS 47.20 is amended by adding new sections to read:

26 **Article 2. Newborn and Infant Hearing Screening, Tracking, and Intervention**
27 **Program.**

28 **Sec. 47.20.300. Department to implement program.** The department shall
29 plan, develop, and implement a hearing screening, tracking, and intervention program
30 to facilitate compliance with the requirements of AS 47.20.310 - 47.20.390.

31 **Sec. 47.20.310. Screening requirements.** (a) Subject to (b) of this section,

1 the physician in attendance at or immediately after the birth of a child in a hospital in
2 this state, or, if a physician is not in attendance at or immediately after the birth, the
3 person attending the newborn child in a hospital in this state, shall, unless medically
4 contraindicated, cause the child to be screened to determine whether the child has a
5 potential hearing impairment using the methods determined by the department under
6 (e) of this section. Unless medically contraindicated, the screening shall occur before
7 the newborn is released from the hospital or before the infant is 30 days old,
8 whichever is earlier. Each birthing center that provides maternity and newborn care
9 services shall provide that each newborn in the center's care is referred for an
10 appointment to a licensed audiologist or to a hospital or other newborn hearing
11 screening provider before discharge. Unless medically contraindicated, the screening
12 shall occur before the infant is 30 days old.

13 (b) Notwithstanding (a) of this section, the physician or other person at or
14 immediately after the birth of a child in a hospital or birthing center that averages less
15 than 20 births a year is not required to screen the child as described in (a) of this
16 section but shall, before the newborn is released from the hospital or birthing center,
17 refer the child for screening at another facility or with another provider. Unless
18 medically contraindicated, the screening shall occur before the child is 30 days old.

19 (c) If it is determined by screening that a newborn child may have a hearing
20 impairment, the physician or other person who is required under (a) of this section to
21 cause the child to be screened shall

22 (1) refer the child for confirmatory diagnostic evaluation;

23 (2) make reasonable efforts to promptly notify the child's parent that
24 the child may have a hearing impairment and explain to the parent the potential effect
25 of the impairment on the development of the child's speech and language skills and
26 psychosocial and cognitive development; and

27 (3) notify the department of the hearing screening results on a form
28 approved by the department.

29 (d) When the Bureau of Vital Statistics receives a certificate of live birth
30 under AS 18.50.160 for a newborn who was delivered at a place other than a hospital,
31 the bureau shall notify the department employees who administer AS 47.20.310 -

1 47.20.390. The department employees shall notify the child's parents of the merits of
2 having a hearing screening performed, and the department shall provide information to
3 the parents to assist the parents in accomplishing the hearing screening within 30 days
4 after the child's birth.

5 (e) The hearing screening required under this section shall use protocols
6 established by the department. At a minimum, the protocols must include the use of at
7 least one of the following physiologic technologies: automated or diagnostic auditory
8 brainstem response (ABR) or otoacoustic emissions (OAE). The department shall
9 consider updating the protocols as information is provided to the department that new
10 physiologic technologies or improvements to existing physiologic technologies will
11 substantially enhance newborn and infant hearing assessment.

12 (f) Notwithstanding (a) of this section, a physician or other person required to
13 cause a newborn hearing screening under this section is exempt from this requirement
14 if the parent of the newborn child objects to the screening procedure on the grounds
15 that the procedure conflicts with the religious or other tenets and practices of the
16 parent. The parent shall sign a statement that the parent knowingly refuses the
17 services, and the physician or other person shall have a copy of the signed statement
18 retained in the hospital records of the birth and sent to the department for tracking
19 under AS 47.20.320.

20 (g) The physician or other person required to cause a newborn hearing
21 screening under this section shall report the results of newborn hearing screening as
22 required by the department under AS 47.20.320.

23 **Sec. 47.20.320. Reporting and tracking program.** (a) The department shall
24 develop and implement a reporting and tracking system for newborns and infants
25 screened for hearing loss in order to provide the department with information and data
26 to effectively plan, establish, monitor, and evaluate the newborn and infant hearing
27 screening, tracking, and intervention program. Evaluation of the program must
28 include evaluation of the initial hearing screening, follow-up components, and the use
29 and availability of the system of services for newborns and infants who are deaf or
30 hard of hearing and their families.

31 (b) A physician or other person attending the birth in the state, or a hospital on

1 behalf of a physician or other person attending the birth, shall report information
2 related to hearing screening required under (a) of this section as specified by the
3 department. A person who provides audiological confirmatory evaluation and
4 diagnostic services for newborns and infants whose hearing was screened under
5 AS 47.20.310 shall report information as specified by the department in regulation.

6 (c) The information received under (b) of this section shall be compiled and
7 maintained by the department in the tracking system. The information shall be kept
8 confidential in accordance with the applicable provisions of 20 U.S.C. 1439
9 (Individuals with Disabilities Education Act), as amended by P.L. 105-17. Data
10 collected by the department that was obtained from the medical records of the
11 newborn or infant shall be for the confidential use of the department and are not public
12 records subject to disclosure under AS 40.25.110. Aggregate statistical data without
13 identifying information compiled from the information received is public information.

14 (d) A hospital or other health facility, clinical laboratory, audiologist,
15 physician, registered nurse, certified nurse midwife, direct-entry midwife, officer or
16 employee of a health facility or clinical laboratory, or an employee of an audiologist,
17 physician, or registered nurse is not criminally or civilly liable for furnishing
18 information in good faith to the department or its designee under this section. The
19 furnishing of information in accordance with this section is not a violation of AS 08 or
20 AS 18 or regulations adopted under AS 08 or AS 18 for licensees under those statutes.

21 **Sec. 47.20.330. Intervention program.** (a) The department shall establish
22 guidelines for the provision of follow-up care for newborn and infant children in the
23 state who have been identified as having or being at risk of developing a hearing loss.
24 The services recommended must include appropriate follow-up care for newborns and
25 infants with abnormal or inconclusive screening results, such as diagnostic evaluation,
26 referral, and coordination of early intervention service programs if the newborn or
27 infant is found to have a hearing loss.

28 (b) The parents of all newborns and infants diagnosed with a hearing loss, as
29 reported to the department, shall be provided by the department with written
30 information on the availability of follow-up care through community resources and
31 government agencies, including those provided in accordance with 20 U.S.C. 1400 -

1 1491 (Individuals with Disabilities Education Act), as amended. Information provided
2 by the department must include listings of local and statewide nonprofit deaf and hard
3 of hearing consumer-based organizations, parent support organizations affiliated with
4 deafness, counseling and educational services, and programs offered through the
5 department and the Department of Education and Early Development.

6 **Sec. 47.20.340. Outreach campaign.** The department shall conduct a
7 community outreach and awareness campaign to inform medical providers, pregnant
8 women, and families of newborns and infants of the newborn and infant hearing
9 screening, tracking, and intervention program and the value of early hearing screening,
10 tracking, and intervention.

11 **Sec. 47.20.350. Report.** The department shall prepare an annual report for the
12 governor about the newborn and infant hearing screening, tracking, and intervention
13 program administered under AS 47.20.310 - 47.20.390. The report must include
14 recommendations on improving the early screening, tracking, and intervention
15 program, including strategies to increase the rate of early screening and the use of
16 appropriate early intervention techniques. The department shall notify the legislature
17 that the report is available.

18 **Sec. 47.20.360. Performance evaluation.** (a) The department shall collect
19 and compile performance data on the early hearing screening, tracking, and
20 intervention program established under AS 47.20.300 - 47.20.390 to ensure that the
21 program is in compliance with AS 47.20.300 - 47.20.390 and the regulations adopted
22 under AS 47.20.300 - 47.20.390. The performance evaluation must include

23 (1) a comparison of the number of infants born in the state to the
24 number of infants screened;

25 (2) the referral rate for confirmatory diagnostic evaluation;

26 (3) the follow-up rate for intervention; and

27 (4) the number of false screening results.

28 (b) In conducting a performance evaluation, the department shall
29 establish hearing screening performance standards that must include a false positive
30 rate and a false negative rate for screening results of less than or equal to three percent.

31 **Sec. 47.20.390. Definitions.** In AS 47.20.300 - 47.20.390,

- 1 (1) "commissioner" means the commissioner of health and social
2 services;
- 3 (2) "department" means the Department of Health and Social Services;
- 4 (3) "follow-up care" means all of the following:
- 5 (A) services necessary to diagnose and confirm a hearing loss;
- 6 (B) ongoing audiological services to monitor hearing;
- 7 (C) communication services, including aural rehabilitation,
8 speech, language, social, and psychological services;
- 9 (D) support services for the infant and family; and
- 10 (E) early intervention services described in 20 U.S.C. 1431 -
11 1445 (Individuals with Disabilities Education Act), as amended;
- 12 (4) "health care insurer" means an entity regulated by the director of
13 insurance, Department of Commerce, Community, and Economic Development, and
14 includes a health, hospital, or medical service plan corporation, and a health
15 maintenance organization;
- 16 (5) "hearing loss" means a hearing loss of 40 decibels or greater in the
17 frequency region important for speech recognition and comprehension in one or both
18 ears, approximately 500 through 4000 Hz;
- 19 (6) "hearing screening" means automated auditory brain stem
20 response, otoacoustic emissions, or other appropriate screening procedure approved by
21 the department;
- 22 (7) "infant" means a child 30 days to 24 months old;
- 23 (8) "newborn" means a child less than 30 days old;
- 24 (9) "parent" means a natural parent, stepparent, adoptive parent, legal
25 guardian, or other legal custodian of the child;
- 26 (10) "program" means the newborn and infant hearing, tracking, and
27 intervention screening program established under AS 47.20.310 - 47.20.390.

28 * Sec. 7. The uncodified law of the State of Alaska is amended by adding a new section to
29 read:

30 TRANSITION: REGULATIONS. Notwithstanding sec. 9 of this Act, the
31 Department of Health and Social Services may proceed to develop and adopt regulations

1 required to implement this Act. The regulations take effect under AS 44.62 (Administrative
2 Procedure Act), but not before the effective date of the relevant provision of this Act.

3 * Sec. 8. The uncodified law of the State of Alaska is amended by adding a new section to
4 read:

5 INSTRUCTION TO REVISOR. In AS 47.20.060 - 47.20.290, the revisor shall delete
6 "this chapter" and insert "AS 47.20.060 - 47.20.290."

7 * Sec. 9. AS 47.20.300, enacted by sec. 6 of this Act, and secs. 7 and 8 of this Act take
8 effect immediately under AS 01.10.070(c).

9 * Sec. 10. Except as provided in sec. 9 of this Act, this Act takes effect January 1, 2008.

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House District 10

House of Representatives

Sponsor Statement

CSHB 109(FIN)

Each year in Alaska approximately 10,000 babies are born. 30 to 40 of these children will be born with congenital hearing defects. Hearing loss is more prevalent than any other birth defect. Studies have shown that children with a hearing impairment not detected at birth, will likely not have their impairment detected until two to three years of age. Unfortunately, studies have also shown that the most critical time for speech and cognitive development is from birth to three years of age.

HB 109 will require infants to be screened for hearing loss before leaving the hospital, or within thirty-days of being born, if not born in a hospital. HB 109 will further provide diagnostic intervention. A child who fails an initial hearing screening will be referred for re-screening. Once a child has been diagnosed with a hearing impairment, parents will be provided by the Department of Health and Social Services with written information on the availability of services through community resources, government agencies, parent support organizations affiliated with deafness, counseling and educational services, and programs offered through the Department of Health and Social Services and the Department of Education and Early Development.

Ultimately, this bill will save the State of Alaska money due to the fact that when infants are not identified with a hearing impairment and aided early, the special education costs for a child with a hearing loss may cost the state an additional \$420,000.

When hearing impaired children reach school age they become the fiscal responsibility of their respective school districts. The cost of educating a special needs student can range up to \$12,000 per year versus the Base Student Allocation amount of \$4,919 (proposed FY06) per student. Sooner or later children identified with hearing loss become the financial responsibility of the state's education system.

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Sectional Summary HB 109(FIN) Infant Hearing Bill Work Order 24-LS0450\Y

“An Act relating to establishing a screening, tracking, and intervention program related to the hearing ability of newborns and infants; providing an exemption to licensure as an audiologist for certain persons performing hearing screening; relating to insurance coverage for newborn and infant hearing screening; and providing for an effective date.”

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 this 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 hearing screening.

Section 6. Establishes a newborn and infant hearing screening, tracking, and intervention program with 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 sections 6 through 8 of the act.

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