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FISCAL NOTE

BILL NO. SB 313

STATE OF ALASKA
1992 LEGISLATIVE SESSION

Revision Date: _____
Title: An Act relating to insurance coverage for the treatment of phenylketonuria.

Department Affected: All State
BRU: All State

Sponsor: Sturgulewski
Requestor: Senate HESS Committee

Component: _____
COMPONENT SERIAL NO. _____

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY 93	FY 94	FY 95	FY 96	FY 97	FY 98
PERSONAL SERVICES	0	0	0	0	0	0
TRAVEL	0	0	0	0	0	0
CONTRACTUAL	0	0	0	0	0	0
SUPPLIES	0	0	0	0	0	0
EQUIPMENT	0	0	0	0	0	0
LAND & STRUCTURES	0	0	0	0	0	0
GRANTS, CLAIMS	0	0	0	0	0	0
MISCELLANEOUS	0	0	0	0	0	0
TOTAL OPERATING	0	0	0	0	0	0

CAPITAL	0	0	0	0	0	0
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REVENUE FUND SOURCE:	0	0	0	0	0	0
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FUNDING: (Thousands of dollars)

GENERAL FUND	0	0	0	0	0	0
FEDERAL FUNDS	0	0	0	0	0	0
OTHER FUNDSOURCE	0	0	0	0	0	0
TOTAL	0	0	0	0	0	0

POSITIONS

FULL-TIME:	0	0	0	0	0	0
PART-TIME:	0	0	0	0	0	0
TEMPORARY:	0	0	0	0	0	0

Estimate of current year impact: None

ANALYSIS: (attach a separate page if necessary.)

Despite the expansion of coverage under this bill, the occurrence of phenylketonuria (PKU) in newborns is so small, the application of an insurance rate increase would be impossible to quantify.

Prepared By: Gary Bader *Gary M. Bader*
Division: Retirement and Benefits

Phone: 465-4470
Date: January 30, 1992

Approved by Commissioner: Nancy Bear Usura *NBE*
Agency: Department of Administration

Date: 1/30/92

Distribution (by preparer): Legislative Finance, Legislative Sponsor, Requestor, OMB & Impacted Agency(ies).

FISCAL NOTE

**STATE OF ALASKA
1992 LEGISLATIVE SESSION**

BILL NO. SB 313

Revision Date:
Title: "An Act relating to insurance coverage for the treatment of
phenylketonuria.
Sponsor: Senator Sturgulewski
Requestor:

Dept: University
BRU: All
Component: All

Component Serial No. 730

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY93	FY94	FY95	FY96	FY97	FY98
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL	0.0	0.0	0.0	0.0	0.0	0.0
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
TOTAL OPERATING	0.0	0.0	0.0	0.0	0.0	0.0

CAPITAL						
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REVENUE						
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FUNDING: (Thousands of Dollars)						
GENERAL FUND	0.0	0.0	0.0	0.0	0.0	0.0
FEDERAL FUNDS						
OTHER						
TOTAL	0.0	0.0	0.0	0.0	0.0	0.0

POSITIONS:						
FULL-TIME						
PART-TIME						
TEMPORARY						

Estimate of current year impact: None

ANALYSIS: (Attach a separate page if necessary.)
Incidence rate is so low as to preclude estimation of budget impact. Prescription drug treatment is estimated to be \$575/month/person
per Jean Freeman of Human Resources 2/28/92

Prepared by: Marsha Hubbard, Director
Division: Statewide Budget Office

Phone: 474-7593
Date: 3/5/92

Approved by: Brian Rogers, Vice President for Finance
Agency: University of Alaska

Date: 3/5/92

Distribution (by preparer): Legislative Finance, Legislative Sponsor, Requestor, OMB, & Impacted Agency(ies).

FISCAL NOTE

STATE OF ALASKA
1992 LEGISLATIVE SESSION

BILL NO. Senate Bill No. 313

Revision Date: _____ Dept. Affected Health & Social Services
 Title: Insurance coverage for the treatment BRU: State Health Services
of phenylketonuria Component: Maternal, Child & Family Health
 Sponsor: Sturgulewski
 Requestor: HES COMPONENT SERIAL NO. 0-60-40602-290

Expenditures/Revenues (Thousands of Dollars)

OPERATING	FY93	FY94	FY95	FY96	FY97	FY98
PERSONAL SERVICES	0.0	0.0	0.0	0.0	0.0	0.0
TRAVEL	0.0	0.0	0.0	0.0	0.0	0.0
CONTRACTUAL	0.0	0.0	0.0	0.0	0.0	0.0
SUPPLIES	0.0	0.0	0.0	0.0	0.0	0.0
EQUIPMENT	0.0	0.0	0.0	0.0	0.0	0.0
LAND & STRUCTURES	0.0	0.0	0.0	0.0	0.0	0.0
GRANTS, CLAIMS	0.0	0.0	0.0	0.0	0.0	0.0
MISCELLANEOUS	0.0	0.0	0.0	0.0	0.0	0.0
TOTAL OPERATING	0.0	0.0	0.0	0.0	0.0	0.0

CAPITAL						
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REVENUE						
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FUNDING: (Thousands of Dollars)

GENERAL FUND	0.0	0.0	0.0	0.0	0.0	0.0
FEDERAL FUNDS	0.0	0.0	0.0	0.0	0.0	0.0
OTHER	0.0	0.0	0.0	0.0	0.0	0.0
TOTAL	0.0	0.0	0.0	0.0	0.0	0.0

POSITIONS:

FULL-TIME	0.0	0.0	0.0	0.0	0.0	0.0
PART-TIME	0.0	0.0	0.0	0.0	0.0	0.0
TEMPORARY	0.0	0.0	0.0	0.0	0.0	0.0

Estimate of current year impact: none

ANALYSIS: (Attach a separate page if necessary)

No fiscal impact

Prepared by: Peter M. Nakamura, MD, MPH
 Division: Public Health

Phone: (907) 465-3090

Date: 1/23/92

Approved by Commissioner: Theodore Mala, MD, MPH
 Agency: Department of Health and Social Services

Date: 1/24/92

Distribution (by preparer):

Legislative Finance OMB
 Legislative Sponsor Impacted Agency(ies)
 Requestor

FISCAL NOTE

STATE OF ALASKA
1992 LEGISLATIVE SESSION

BILL NO. SB 313

Revision Date: 2/4/92 Department Affected: Commerce & Econ. Dev.
 Title: An Act relating to insurance cover- BRU: Insurance
age for treatment of phenylketonuria Component: Operations
 Sponsor: Senator Sturqulewski
 Requestor: _____ COMPONENT SERIAL NO.

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EXPENDITURES/REVENUES: (Thousands of Dollars)

OPERATING	FY 93	FY 94	FY 95	FY 96	FY 97	FY 98
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
TOTAL OPERATING	0	0	0	0	0	0
CAPITAL	0	0	0	0	0	0
REVENUE						
FUND SOURCE:	0	0	0	0	0	0

FUNDING: (Thousands of Dollars)

GENERAL FUND						
FEDERAL FUNDS						
OTHER FUND SOURCE:						
TOTAL	0	0	0	0	0	0

POSITIONS:

FULL-TIME	0	0	0	0	0	0
PART-TIME						
TEMPORARY						

Estimate of current year impact: _____

ANALYSIS: (Attach a separate page if necessary.)

Prepared By: Don Koch, Chief of Market Surveillance Phone: 465-2577
 Division: Insurance Date: 2/4/92
 Approved by Commissioner: Glenn A. Olds
 Agency: Department of Commerce & Economic Development Date: 2.3.92

(1) Because PKU affects so few individuals, Aetna + Blue Cross do not oppose SB 313

Why Introduced

(2) Arliss knew a family in Darlington that had 3 children w/ PKU that suffered mental retardation

(3) Constituent in Anchorage with PKU baby unable to get insurance coverage

(4) There has been no testimony in opposition to the bill

Alaska State Legislature



SENATOR
ARLISS STURGULEWSKI

311 C STREET, SUITE 550
ANCHORAGE, ALASKA 99503
(907) 561-7615


While in Juneau
STATE CAPITOL
JUNEAU, ALASKA 99801-1182
(907) 465-3818

Senate

MEMORANDUM

April 21, 1992

TO: Representative Johnny Ellis, Chairman
House Rules Committee

FROM: Senator Arliss Sturgulewski 
Senate District F

RE: Calendaring request for SB 313 "An Act relating to
insurance coverage for the treatment of phenylketonuria."

I respectfully request an early calendaring of SB 313 which is in the House Rules Committee.

I have enclosed a sponsor statement and packet of information on SB 313. If you have any question regarding this legislation, please contact me or Betty Hargrave on my staff.

Thank you for your consideration of this request.

Enclosures

Alaska State Legislature



SENATOR
ARLISS STURGULEWSKI
3/11/92

311 C STREET, SUITE 550
ANCHORAGE, ALASKA 99503
(907) 561-7615

Whale in Juneau
P.O. BOX V
JUNEAU, ALASKA 99811
(907) 465-3818

Senate

Sponsor Statement on:

SB 313 "An Act relating to insurance coverage for the treatment of phenylketonuria."

Senate Bill 313 would amend state law by adding a new section to AS 21.42 requiring insurers and hospital or medical service corporations that offer individual or group disability insurance to provide coverage for treatment of phenylketonuria(PKU).

PKU is a rare inherited metabolic disorder. Babies born with PKU are unable to process proteins, such as milk, and so in order to remain healthy, they must maintain a strict diet and are placed on a mineral and vitamin enriched formula. If this is not done, then the build up of proteins causes severe brain damage and mental retardation. This bill would require insurance companies to cover the cost of PKU formula.

Enclosed is a position paper from Commissioner Mala in support of this bill. Commissioner Mala points out that the cost of the formula is far less than the cost of treatment for the permanent and long term damage caused by the lack of treatment. The Department of Health and Social Services, Division of Public Health has submitted a zero Fiscal Note.

Michael Ford, Legislative Counsel, Division of Legal Service prepared a sectional analysis of SB 313 which I have enclosed.

Also enclosed are zero Fiscal Notes from the Department of Administration, Division of Retirement and Benefits; the Department of Commerce and Economic Development, Division of Insurance; and the University of Alaska, Statewide Budget Office.

DIVISION OF LEGAL SERVICES

LEGISLATIVE AFFAIRS AGENCY STATE OF ALASKA

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

240 Main Street, Suite 500
Juneau, Alaska 99801-2101

MEMORANDUM

December 10, 1991

SUBJECT: Sectional analysis (SB 313)

TO: Senator Arliss Sturgulewski

FROM: Michael F. Ford *M. F.*
Legislative Counsel

The following is a section by section analysis of SB 313:

Section 1 - Requires insurers and hospital or medical service corporations that offer individual or group disability insurance, to provide coverage for treatment of phenylketonuria. Provides that certain insurance policies are excluded from this required coverage. Allows the insurer or service corporation to impose reasonable contract limitations on the required coverage, not including a preexisting condition exclusion or higher deductible or copayment than for other conditions.

Section 2 - Technical amendment that imposes the required coverage in section 1 upon hospital or medical service corporations.

Section 3 - Applicability section that requires that coverage mandated under section 1 only applies to insurance policies and contracts entered into or renewed on or after the effective date of the Act.

MFF:LMB
91-304.lmb

SENATE BILL NO. 313

For an Act entitled: "An Act relating to insurance coverage for the treatment of phenylketonuria."

Summary

This bill amends AS 21.42, The Insurance Contract, by adding a new section, AS 21.42.375, Coverage for Treatment of Phenylketonuria.

AS 21.42.375 requires an insurer, authorized under AS 21.09 or AS 21.87, to provide coverage for the formulas necessary for the treatment of phenylketonuria (PKU). This section does not apply to

1. a Medicare supplemental insurance policy;
2. long-term care insurance;
3. an insurance policy regulated under 5 USC 89 or 42 USC 135mm;
4. an insurance policy that provides services or reimbursement exclusively for optometric or vision care, dental or orthodontic care, podiatric, ambulance, mental health or chiropractic care; and
5. an insurance policy that the director has, in writing, determined should be excluded from this section.

Discussion

PKU is a rare inherited genetic disorder occurring in approximately 1 in 11,000 live births. Testing for PKU is required during the first week of life (between 48 hours and 7 days of age) and is done with a simple heel prick. Children with PKU are unable to metabolize an essential amino acid (phenylalanine), which is found in the proteins of most foods. To remain healthy, children with PKU must maintain a strict diet and ingest a mineral and vitamin enriched formula. If the protein intake is not severely restricted, the build up of proteins causes severe brain damage and mental retardation. The use of special formulas and a controlled diet can prevent the excess of protein in the individual's body and the brain

POSITION PAPER

STATE OF ALASKA * DEPARTMENT OF HEALTH AND SOCIAL SERVICES

damage can be prevented, allowing the individual an opportunity to develop normally. There is an average of one new PKU infant diagnosed yearly in the State of Alaska.

The Department's Section of Maternal, Child, and Family Health sponsors PKU genetic counseling and follow-up services (clinics) in Anchorage (one in the spring and one in the fall). Each clinic is staffed by a physician, nutritionist, social worker, and a genetics counselor. Currently, there are 12 individuals with PKU utilizing the services provided by the State's PKU clinics. Beyond the clinics, the PKU individuals are given a monthly blood test. The results of the blood tests are forwarded to the Anchorage Genetics counselor, then distributed to the PKU individual's pediatrician.

In addition to the blood tests, the diets of PKU individuals are monitored on a monthly basis. Special formula, for PKU individuals, serves the same health and life sustaining purpose that medications do for many other diseases. The cost for formula and special foods vary depending on the child's age. One case of formula costs about \$180. Depending on the child's age, they may use two to three cases of formula per month.

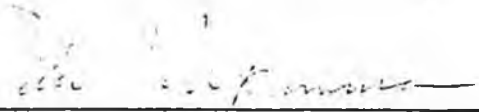
Without the special diet, the cost to the PKU individual is a lifetime as a severely mentally retarded citizen. The financial cost to the State for institutionalization could exceed a million dollars per person over a lifetime. The cost of the formula is far less than the cost of treatment for the permanent, long-term damage caused due to the lack of the special diet.

Many states require, by statute, that insurance companies cover PKU formula, one of which is the State of Washington. Many insurance companies that serve Alaska residents will not cover PKU formula without the statutory requirement. Due to the cost of the special diet to the family of a PKU individual, especially low-income families, there is the risk that the necessary precautions are not taken, thereby subjecting the PKU individual to the risk of permanent, long-term damage.

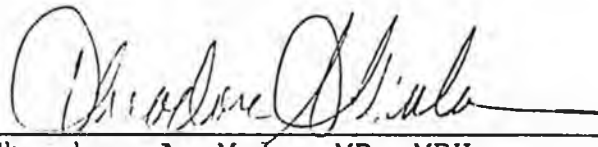
SB 313
Page 3

Recommendation

The Department supports SB 313, which will require insurance coverage of formula necessary for the treatment of phenylketonuria.


Peter M. Nakamura, MD, MPH, Director
Division of Public Health

Date: 1/27/92


Theodore A. Maia, MD, MPH
Commissioner
Department of Health and Social Services

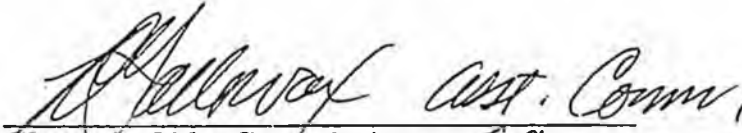
Date: 24 Jan 1992

SB 313: "An Act relating to insurance coverage for treatment of phenylketonuria."

SB 313 mandates insurance coverage for phenylketonuria. The department is neutral on this bill.

Phenylketonuria (PKU) is an affliction impacting newborn children which requires treatment with a special and expensive formula for survival. Alaska has about one case per year.

The treatment of PKU is expensive and beyond the ability of most persons to bear. Fortunately, its occurrence is sufficiently infrequent as to pose a negligible overall public cost.


Glenn A. Olds, Commissioner *GA*

Date: 2-3-92

Hal Ingalls
Vicki R. Diemer
2811 Pribilof Street
Anchorage, AK 99517

February 3, 1992

Senator Arliss Sturgulewski
P.O. Box V
Anchorage, AK 99517

Dear Senator Sturgulewski:

We want to offer you our sincere "thank you" for your efforts in introducing bill #313, "An Act Relating to Insurance Coverage for Phenylketonuria". Hopefully, with your hard work and our prayers this bill will be passed.

We are fortunate that at the present time that we can shoulder the additional costs of Derek's medical foods, but no one knows what the future holds in store for them and with the passage of this bill a lot of families in this state will sleep easier. So few children are born each year with this birth defect that the health care insurance companies will barely feel the affects of bill #313's passage. However, the families that have borderline incomes that are affected by the birth of a PKU child may find the added expense overwhelming without health care coverage. If that should happen the burden would fall upon the state (all of us as taxpayers). No one wants that to happen.

Please contact us any time if you need any information or if we can assist in the passage of this bill.

Sincerely,



Hal Ingalls



Vicki R. Diemer

BROOK & CANDY KRISTOVICH
P.O. Box 103383
430 W. 89th Avenue
Anchorage, Alaska 99510
(907) 344-6364

Senator Arliss Sturgelewski
Juneau, Alaska

Dear Senator:

We would like to take this opportunity to express our support for SB 313.

Candy and I have a daughter, Melissa, who was born April 13, 1989, with Phenylketonuria (PKU). We feel that we are one of the lucky parents to have an insurance company such as Blue Cross of Washington and Alaska, which is covering eighty percent (80%) of Melissa's medical and formula.

The Lofenalac that Melissa is required to take in order to survive costs us approximately \$250.00 a month or \$3,000.00 a year, not to mention the other foods she is able to eat in very limited quantities. Her food budget alone is just about as much as it is for the other three in our family (my wife, four year old son, and myself). Without the insurance coverage, we don't know how we would afford to eat.

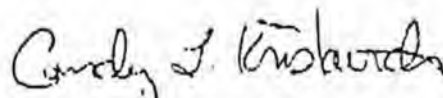
Requiring insurance companies who do business in Alaska to cover people with PKU is a must! We support any Bill that requires this type of coverage!

If we can provide any other support for SB 313, please don't hesitate to call either Candy or myself. Thank you for all your work!

Sincerely,



Brook B. Kristovich



Candy L. Kristovich

February 3, 1992

Sheree Elliott
HCO3-8100-B
Palmer, Alaska 99645

RE: Senate Bill #313 - An Act Relating to Phenylketonuria (PKU)

Senator Sturgulewski,

I am writing you in support of the bill you are introducing to the State legislature regarding insurance coverage for Phenylketonuria (PKU).

My husband, Tom and I have a five year old daughter with PKU. When Morgan was born in Anchorage in 1986 I was employed at National Bank of Alaska. My medical insurance is with Blue Cross. When it came time to purchase formula for Morgan I had to fight with Blue Cross to cover the cost of 80%. I finally won. However, if the time comes when I choose to quit work, I will not have medical insurance. If I can not be sure that I can get an insurance company to cover the special formula Morgan must have to insure she is a normal and healthy child I will be forced to keep employment with NBA just so my husband and I have insurance coverage on our daughter.

The number of children affected by PKU in Alaska is so small that we wouldn't be talking more than pocket change for the insurance companies. Also, it should be noted that most other states have already mandated insurance companies to cover phenylketonuria if they want to do business in their state.

Your support to this bill is imperative. Please give it so that all health care policies, group and individual, will provide insurance coverage for phenylketonuria in the state of Alaska.

Sincerely,

Sheree Elliott

Sheree Elliott,
Thomas Elliott

257-3457

Mark and Pat Swank
1000 Whitney Road
Anchorage, AK 99501

February 2, 1992

Senator Arliss Sturgulewski
P.O. Box V
Juneau, AK 99811

Dear Senator Sturgulewski:

Please accept this letter as our show of support for bill #313, An Act Relating to Insurance Coverage for treatment of Phenylketonuria. We believe Alaska should join the bulk of the rest of the country in mandating insurance companies to provide health insurance coverage for people affected by this birth defect.

The Ingalls family have been friends of ours for more than ten years and we have watched them go through the horror of being told they have a handicapped child and seen the joy this child has brought to them in his "normalcy". We've also seen the fight they've had to obtain health insurance coverage for Derek and feel that no one should have to go through that battle again.

We hope your concern and efforts in presenting this bill will be rewarded.

Sincerely,



Mark Swank



Pat Swank

Haleen Ingalls
118 W. 10th Avenue
Anchorage, AK 99501

February 2, 1992


Senator Arliss Sturgulewski
P.O. Box V
Juneau, AK 99811

Dear Senator Sturgulewski:

Please accept this letter as my support for bill #313, "An Act Relating to Insurance Coverage for Phenylketonuria". Alaska's laws need to reflect most of the other states and make insurance companies offer health care coverage for the children that are affected by this birth defect.

My grandson, Derek Ingalls, has PKU and we count our blessings every day that it was caught in time and that his family is able to get the medical foods he needs to keep him sound. I have seen his family struggle with the health insurance issue and shoulder the financial burden of his extra needs and know that it's a hardship that no one should have to bear alone. It's time we made the health insurance companies assist these few families in their special needs.

Sincerely,

A handwritten signature in cursive script that reads "Haleen Ingalls". The signature is written in dark ink and is positioned to the right of the word "Sincerely,".

Haleen Ingalls

Jeff and Paula Cotton
2800 Pribilof Street
Anchorage, AK 99517

February 1, 1992

Senator Arliss Sturgulewski
P.O. Box V
Juneau, AK 99811

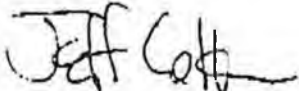
Dear Senator Sturguleski:

We are sending this letter to you to offer our support for bill #131, An Act Relating to Insurance Coverage for treatment of Phenylketonuria. It's time the insurance companies that are doing business in this state are made to do the responsible thing and give health insurance coverage to any and all persons who have this birth defect.

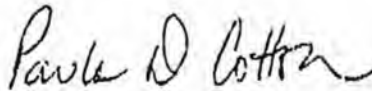
Having been neighbors of the Ingalls family since their son, Derek, was born and knowing what problems they have encountered trying to obtain health insurance for Derek, we feel it's time that our state passed this bill so that no other family has to endure what the Ingalls have had to to get insurance for their healthy "normal" son.

Your efforts in presenting this bill are greatly appreciated.

Sincerely,



Jeff Cotton



Paula Cotton

January 31, 1992

Lorell Bonnet
2801 Pribilof Street
Anchorage, AK 99517

Senator Arliss Sturgulewski
P.O. Box V
Juneau, AK 99811

Dear Senator Sturgulewski:

Please accept this letter as showing my support for bill #313
"An Act Relating to Insurance Coverage for the treatment of
Phenylketonuria".

I have been a neighbor of Derek Ingalls since before his birth
and have had the pleasure of watching him grow into a happy,
healthy, "normal" three year old. What a tragedy it would
have been or be for him to become mentally handicapped because
insurance coverage was not available to his family to help
differ the costs of his medical foods. What a tragedy that
any family should have to face this kind of problem.

Let's make the insurance companies take the burdon off the
state and parents of PKU children. It's time they were made
to take the responsible position of providing insurance cover-
age for the few children affected by this rare birth defect.

Sincerely,



Lorell Bonnet

February 2, 1992

Senator Arliss Sturgulewski
P.O. Box V
Juneau, AK 99811

Dear Senator Sturgulewski:

I would like to add my name to your list of supporters for Bill #313, "An Act Relating to Insurance Coverage for Phenylketonuria". It's time the insurance companies in this state were made to take the responsible stand on this matter and not leave the full burden of keeping the children affected by this birth defect healthy on the parents or the State of Alaska.

Sincerely,

James Patras

JAMES PATRAS
PATRAS
19216 B MONASTERY DR.
EAGLE RIVER AK 99577



Representative Mark Hanley
Alaska State Legislature

MEMORANDUM

To: Senator Arliss Sturgulewski, Chair
Senate Committee on Health, Education and
Social Services

From: Representative Mark Hanley *MH*

Re: SB 313 "Insurance for PKU"

Date: January 30, 1992

Please see the attached letter from my constituent regarding Senate Bill 313.

I'd like to respectfully request that this letter and the comments of Lewis Johnston be submitted into the official hearing record on this legislation.

I appreciate your consideration. If you have questions or concerns, please contact either myself or my staff person, Michelle Tohey.

7927 Cranberry St.
Anchorage, Ak. 99502
10-5-91

OCT 03 1991

Mr. Mark Hanley
311 C St.
Anchorage, Ak. 99503

Dear Mr Hanley

This letter is to ask for your support for bill #313 "An Act Relating to Insurance Coverage for the Treatment of Phenylketonuria". This bill was introduced in the spring 1991 session by Senator Sturgulewski and would require insurance companies to provide health insurance to people with Phenylketonuria, PKU, and to cover the medical foods necessary for their treatment.

Phenylketonuria is a rare birth defect that can cause severe mental retardation if the medical foods needed to control the phenylalanine level in the affected persons system are not used. It would be disastrous for a person with PKU to be denied health insurance and coverage for their medical foods. This would not only affect them and their families, but also the rest of the state by costing us millions of dollars in special education and/or institutional care for an untreated person with PKU. This would be money out of all of our pockets. To mandate insurance companies to cover the required formula and health care on their policies would only cost them three to four thousand dollars per year per PKU applicant as the medical food is the only additional expense needed for a PKU person. Certainly, this amount is not enough to even put a dent in the insurance companies coffers since only one in fifteen thousand babies born has PKU. This would be enough, though, for someone with a marginal income to take themselves out of the workforce and have the state pick up the additional expense of medical foods and welfare costs if they found themselves with a PKU child and no health insurance coverage. This, again, would be a severe draw on "our" pockets.

Most other states have already passed similar bills and I hope Alaska will take the same stand. Insurance companies need to be made to take the responsible position of providing health insurance coverage for Phenylketonuria and its required foods on both group and individual policies.

Sincerely,

Lewis N. Johnston

Lewis Johnston
7927 Cranberry St
Anch, 99502

February 3, 1992

Sheree Elliott
HCO3-8100-B
Palmer, Alaska 99645

RE: Senate Bill #313 - An Act Relating to Phenylketonuria (PKU)

Senator Sturgulewski,

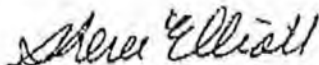
I am writing you in support of the bill you are introducing to the State legislature regarding insurance coverage for Phenylketonuria (PKU).

My husband, Tom and I have a five year old daughter with PKU. When Morgan was born in Anchorage in 1986 I was employed at National Bank of Alaska. My medical insurance is with Blue Cross. When it came time to purchase formula for Morgan I had to fight with Blue Cross to cover the cost of 80%. I finally won. However, if the time comes when I choose to quite work, I will not have medical insurance. If I can not be sure that I can get an insurance company to cover the special formula Morgan must have to insure she is a normal and healthy child I will be forced to keep employment with NBA just so my husband and I have insurance coverage on our daughter.

The number of children affected by PKU in Alaska is so small that we wouldn't be talking more then pocket change for the insurance companies. Also, it should be noted that most other states have already mandated insurance companies to cover phenylketonuria if they want to do business in their state.

Your support to this bill is imperative. Please give it so that all health care policies, group and individual, will provide insurance coverage for phenylketonuria in the state of Alaska.

Sincerely,



Sheree Elliott,
Thomas Elliott

257.3457