

**SB313**

# SENATE FINANCE COMMITTEE REPORT

DATE: 2/5/92

FURTHER:

DATE TURNED INTO OFFICE: 2-20-92

The Finance Committee considered

SENATE BILL NO. 313

"An Act relating to insurance coverage for the treatment of PKU (phenylketonuria)."

and recommends:

replace with \_\_\_\_\_ CS \_\_\_\_\_ (FINANCE)

or  adopt previous \_\_\_\_\_ CS \_\_\_\_\_ (\_\_\_\_\_)

attaches amendment(s)

same title  
 new title  
 technical title change (HB only)

adopts \_\_\_\_\_ Letter of Intent

further referral to the \_\_\_\_\_

do pass

do not pass

no recommendation

individual recommendations

**NEW FISCAL NOTES:** Dept/Date

zero fiscal notes \_\_\_\_\_

fiscal notes \_\_\_\_\_

**appropriation--no fiscal note**

**PREVIOUS FISCAL NOTES:** Dept/Date

zero fiscal notes DHSS 1-24-92

DNA 1-30-92

DCED 2-3-92

fiscal notes \_\_\_\_\_

**DO PASS:**

**OTHER RECOMMENDATIONS:**

1. [Signature]  
Co-Chair: Signature/Recommendation

2. [Signature]  
Co-Chair: Signature/Recommendation

# FISCAL NOTE

No. 1

Bill Version: SB 313

(S) Publish Date: 2-5-92

STATE OF ALASKA  
1992 LEGISLATIVE SESSION

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: Sturqulewski  
 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        |
| <b>TOTAL OPERATING</b> | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> |

|         |  |  |  |  |  |  |
|---------|--|--|--|--|--|--|
| CAPITAL |  |  |  |  |  |  |
|---------|--|--|--|--|--|--|

|         |  |  |  |  |  |  |
|---------|--|--|--|--|--|--|
| REVENUE |  |  |  |  |  |  |
|---------|--|--|--|--|--|--|

**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        |
| <b>TOTAL</b>  | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> |

**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

No. 2

Bill Version: SB-313

(S) Publish Date: 2-5-92

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 |
|---------|---|---|---|---|---|---|

|                         |   |   |   |   |   |   |
|-------------------------|---|---|---|---|---|---|
| REVENUE<br>FUND SOURCE: | 0 | 0 | 0 | 0 | 0 | 0 |
|-------------------------|---|---|---|---|---|---|

FUNDING: (Thousands of dollars)

|                      |   |   |   |   |   |   |
|----------------------|---|---|---|---|---|---|
| GENERAL FUND         | 0 | 0 | 0 | 0 | 0 | 0 |
| FEDERAL FUNDS        | 0 | 0 | 0 | 0 | 0 | 0 |
| OTHER<br>FUND SOURCE | 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 Usher *NBU*  
Agency: Department of Administration

Date: 1/30/92

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

FISCAL NOTE

No. 3

Version: 58 313

(S) Publish Date: 2-5-92

STATE OF ALASKA  
1992 LEGISLATIVE SESSION

Revision Date: 2/4/92 Department A:

Title: An Act relating to insurance cover- BRU: Insurance

age for treatment of phenylketonuria Component: Operations

Sponsor: Senator Sturqulewski

Requestor: \_\_\_\_\_

COMPONENT SERIAL NO.

|   |   |   |   |
|---|---|---|---|
| 0 | 3 | 5 | 4 |
|---|---|---|---|

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<br>FUND SOURCE: | 0 | 0 | 0 | 0 | 0 | 0 |
|-------------------------|---|---|---|---|---|---|

FUNDING: (Thousands of Dollars)

|                       |   |   |   |   |   |   |
|-----------------------|---|---|---|---|---|---|
| GENERAL FUND          |   |   |   |   |   |   |
| FEDERAL FUNDS         |   |   |   |   |   |   |
| OTHER<br>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

## SENATE BILL NO. 313

IN THE LEGISLATURE OF THE STATE OF ALASKA

SEVENTEENTH LEGISLATURE - FIRST SESSION

BY SENATOR STURGULEWSKI

Introduced: 5/21/91

Referred: HES, Finance

## A BILL

## FOR AN ACT ENTITLED

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

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

3 \* Section 1. AS 21.42 is amended by adding a new section to read:

4 Sec. 21.42.375. COVERAGE FOR TREATMENT OF PHENYLKETONURIA. (a) An  
5 insurer authorized under AS 21.09 to offer, issue for delivery, deliver, or renew an individual or  
6 a group disability insurance policy for major medical coverage on an expense-incurred basis in  
7 the state, or a hospital or medical service corporation authorized under AS 21.87 to offer or  
8 renew a group contract for major medical coverage in the state, must provide coverage for the  
9 formulas necessary for the treatment of phenylketonuria. This subsection does not apply to

10 (1) a Medicare supplement insurance policy;

11 (2) long-term care insurance;

12 (3) an insurance policy regulated under 5 U.S.C. 89 or 42 U.S.C. 1395mm;

13 (4) an insurance policy that provides services or reimbursement exclusively for  
14 optometric or vision care, dental or orthodontic care, podiatric, ambulance, mental health, or

1 chiropractic care;

2 (5) an insurance policy that the director has, in writing, determined should be  
3 excluded from this subsection.

4 (b) The insurer or service corporation providing coverage under this section may impose  
5 reasonable contract limitations but may not refuse coverage based on a preexisting condition of  
6 phenylketonuria or require that the insured or subscriber pay a higher deductible or copayment  
7 for the cost of treating phenylketonuria than for the cost of treating another condition or illness.

8 (c) In this section

9 (1) "copayment" means the portion of the cost to be paid by the insured or  
10 subscriber in excess of the deductible;

11 (2) "cost" means the lowest of the following:

12 (A) the actual charge for the treatment received for phenylketonuria;

13 (B) the usual, customary, and reasonable charge for the treatment as  
14 determined by the contract of coverage; or

15 (C) the charge agreed to by contract between the provider and the insurer,  
16 hospital service corporation, or medical service corporation;

17 (3) "deductible" means the portion of covered costs that must be incurred before  
18 benefits become payable;

19 (4) "long-term care insurance" has the meaning given in AS 21.53.200;

20 (5) "major medical coverage" means a disability insurance contract, or a  
21 subscriber contract, that provides benefits for hospital and medical care with potential lifetime  
22 maximum benefits for the insured or subscriber of at least \$10,000.

23 \* Sec. 2. AS 21.87.340 is amended to read:

24 Sec. 21.87.340. OTHER PROVISIONS APPLICABLE. In addition to the provisions  
25 contained or referred to previously in this chapter, the following chapters and provisions of this  
26 title also apply with respect to service corporations to the extent applicable and not in conflict  
27 with the express provisions of this chapter and the reasonable implications of the express  
28 provisions, and for the purposes of the application the corporations shall be considered to be  
29 mutual "insurers":

30 (1) AS 21.03

31 (2) AS 21.06

- 1 (3) AS 21.09, except AS 21.09.090
- 2 (4) AS 21.18.010
- 3 (5) AS 21.18.030
- 4 (6) AS 21.18.040
- 5 (7) AS 21.18.120
- 6 (8) AS 21.21.321
- 7 (9) AS 21.36
- 8 (10) AS 21.69.400
- 9 (11) AS 21.69.520
- 10 (12) AS 21.69.600, 21.69.620, and 21.69.630
- 11 (13) AS 21.78
- 12 (14) AS 21.90
- 13 (15) AS 21.42.345 - 21.42.365, and 21.42.375
- 14 (16) AS 21.89.040
- 15 (17) AS 21.89.060.

16 \* Sec. 3. AS 21.42.375, enacted by sec. 1 of this Act, applies to individual and group disability  
17 insurance policies and hospital or medical service subscriber contracts entered into or renewed on or after  
18 the effective date of this Act.

# Alaska State Legislature



SENATOR  
ARLISS STURGULEWSKI

3111 C STREET, SUITE 550  
ANCHORAGE, ALASKA 99503  
(907) 561-7615

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

Senate

MEMORANDUM

February 5, 1992

TO: Senator Pat Pourchot, Co-Chairman  
Senate Finance Committee

FROM: Senate Arliss Sturgulewski (AS)  
Senate District F

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

Senate Bill 313 is now in the Senate Finance Committee. As it has no fiscal impact, would it be possible for the Senate Finance Committee to waive the bill. If it is not possible to waive SB 313, I respectfully request a hearing for the bill.

Senate Bill 313 was heard and passed out the Senate HESS Committee on February 4, 1992. It has three zero Fiscal Notes from the Departments of Health and Social Services, Administration, and Commerce and Economic Development.

I have enclosed a sponsor statement and packet of information for Senate Finance Committee members. If you have any questions on SB 313, please do not hesitate to contact me or Betty Hargrave on my staff.

Thank you for your consideration of this request.

Enclosures

# Alaska State Legislature



SENATOR  
ARLISS STURGULEWSKI

2/4/92

Senate

3111 C STREET, SUITE 550  
ANCHORAGE, ALASKA 99503  
(907) 561-7615

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

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 and the Department of Commerce and Economic Development, Division of Insurance.

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

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.

RECEIVED  
DEPARTMENT OF HEALTH AND SOCIAL SERVICES  
JAN 24 1992


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: \_\_\_\_\_



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

Date: 24 Jan 1992

# 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

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.

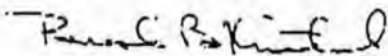
Candy and I have a daughter, Melissa, who was born April 13, 1989, with Phenylketonuria (PKU). We feel that we are one of the lucky parents to have an insurance company such as Blue Cross of Washington and Alaska, which is covering eighty percent (80%) of Melissa's medical and formula.

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.

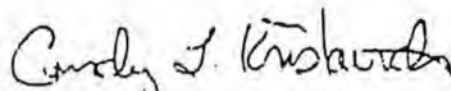
Requiring insurance companies who do business in Alaska to cover people with PKU is a must! We support any Bill that requires this type of coverage!

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:

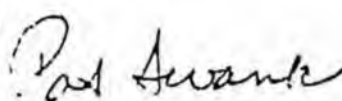
Please accept this letter as our show of support for bill #313, An Act Relating to Insurance Coverage for treatment of Phenylketonuria. We believe Alaska should join the bulk of the rest of the country in mandating insurance companies to provide health insurance coverage for people affected by this birth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

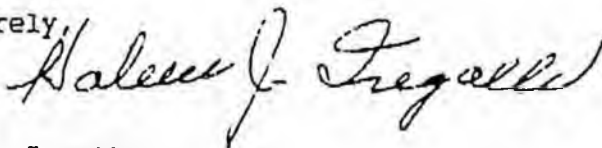
Senator Arliss Sturgulewski  
P.O. Box V  
Juneau, AK 99811

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

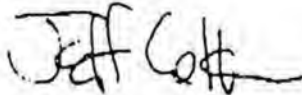
Dear Senator Sturgulreski:

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.

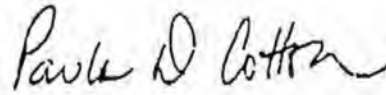
Having been neighbors of the Ingalls family since their son, Derek, was born and knowing what problems they have encountered trying to obtain health insurance for Derek, we feel it's time that our state passed this bill so that no other family has to endure what the Ingalls have had to to get insurance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

A handwritten signature in cursive script, appearing to read "Lorell Bonnet".

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**

**19216 B MONASTERY DR.**

**EMBLE RIVER AK 99577**

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 diastrous 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