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SENATE AMENDMENT

BY Senate Health Education & Social Services

To: \_\_\_\_\_ SENATE BILL No. 723 \_\_\_\_\_

To: \_\_\_\_\_ HOUSE BILL No. \_\_\_\_\_

PAGE:                      LINE:

Page 1, line 12:

~~Delete (shall)~~ and Insert may in its place.

Page 2 line 13:

Add Costs of mediation shall be paid by one party or both as ordered by the court.

Page 3, line 4:

~~Delete (shall)~~ and Insert may in its place.

Introduced: 2/5/82  
Referred: Health, Education &  
Social Services and Judiciary

1 IN THE SENATE

BY FARR

2 SENATE BILL NO. 723

3 IN THE LEGISLATURE OF THE STATE OF ALASKA

4 TWELFTH LEGISLATURE - SECOND SESSION

5 A BILL

6 For an Act entitled: "An Act relating to child custody."

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

8 Section 1. AS 09.55.205 is amended to read:

9 Sec. 09.55.205. JUDGMENTS FOR CUSTODY. (a) In an action for  
10 divorce or for legal separation the court may, if it has jurisdiction  
11 under AS 25.30.020 [,] and is an appropriate forum under AS 25.30.050  
12 and 25.30.060, during the pendency of the action, [OR] at the final  
13 hearing, and [OR] at any time thereafter during the minority of a [ANY]  
14 child of the marriage, make an order for the custody of or visitation  
15 with the minor child that [WHICH] may seem necessary or proper and may  
16 at any time modify or vacate the order.

17 (b) If [ANY APPOINTMENT OF] a guardian ad litem for a child is  
18 appointed in an action under this section, the appointment shall be made  
19 under [THE TERMS OF] AS 09.65.130.

20 (c) The court shall determine custody in accordance with the best  
21 interests of the child under AS 25.20.060. [NEITHER PARENT IS ENTITLED  
22 TO PREFERENCE AS A MATTER OF RIGHT IN AWARDING CUSTODY OF THE CHILD.]  
23 In determining the best interests of the child the court shall consider  
24 [ALL RELEVANT FACTORS INCLUDING:]

25 (1) the physical, emotional, mental, religious, and social  
26 needs of the child;

27 (2) the capability and desire of each parent to meet these  
28 needs;

29 (3) the child's preference;

1 (4) the love and affection existing between the child and  
2 each parent;

3 (5) the length of time the child has lived in a stable, sat-  
4 isfactory environment and the desirability of maintaining continuity;

5 (6) the desire and ability of each parent to allow an open  
6 and loving frequent relationship between the child and his other parent.

7 \* Sec. 2. AS 25.20.060 is amended to read:

8 Sec. 25.20.060. CUSTODY OF THE CHILD. (a) If there is a dispute  
9 over child custody, either parent may petition the superior court for  
10 resolution of the matter under this section [UNLESS AN ACTION BETWEEN  
11 THE PARENTS IS PENDING UNDER AS 09.55]. A court considering a petition  
12 for custody of a child <sup>may</sup> order the parties to participate in pre-  
13 trial mediation of the custody matter under AS 25.20.070. *add*

14 (b) After mediation of the custody matter, the [THE] court shall  
15 award custody on the basis of the best interests of the child. In  
16 determining the best interests of the child, the court shall consider  
17 all relevant factors including those factors enumerated in AS 09.55.205-  
18 (c) [AS 09.55.205].

19 (c) Neither parent, regardless of the question of the child's  
20 legitimacy, is entitled to preference in the awarding of custody.

21 (d) Unless the court finds that it is not in the best interests of  
22 the child,

23 (1) the court shall award custody in accordance with a custody  
24 agreement between the parents; or

25 (2) if the parents do not agree on custody, the court shall  
26 award

27 (A) joint custody; or

28 (B) custody to one parent with frequent visitation rights  
29 to the other parent.

*Costs of mediation shall be paid by one party or both as ordered by the court*

1 \* Sec. 3. AS 25.20 is amended by adding a new section to read:

2 Sec. 25.20.070. MEDIATION OF CUSTODY MATTER. (a) At any time  
3 within 30 days after a petition for child custody is filed under  
4 AS 25.20.060 the court <sup>may</sup> ~~shall~~ order the parties to submit to mediation.  
5 Each party shall have the right to challenge peremptorily one mediator  
6 appointed.

7 (b) Mediation shall be conducted informally as a conference or  
8 series of conferences. The parties to the action and a court-appointed  
9 representative of the minor children shall attend.

10 (c) After the first conference either party may withdraw, or the  
11 mediator may terminate mediation if he determines that mediation efforts  
12 are unsuccessful. Upon withdrawal by either party or termination by the  
13 mediator, the mediator shall notify the court that mediation efforts  
14 have failed, and the custody proceeding shall proceed in the usual  
15 manner.

16 (d) Upon submission of the parties to mediation under this section,  
17 a pending child custody proceeding shall be stayed for a period of 30  
18 days or until the court is notified that mediation efforts have failed.  
19 All court orders made during the pending custody proceeding remain in  
20 effect during the period of mediation.  
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2/25/82

FACT SHEET IN SUPPORT OF SENATE BILL 737

Each year since 1970 the March of Dimes has provided a grant to the University of Alaska to help develop genetics clinics, general pediatric clinics, Ob-Gyn clinics and in-service professional education programs at least every two months in the larger communities throughout Alaska. These are conducted by visiting medical professors from the School of Medicine, University of Washington.

More recently this program has complemented, and has been complemented by, the WAMI program whereby first year medical students receive their training at the University of Alaska. Communities throughout Alaska have also benefited through the March of Dimes clinics conducted by these same visiting professors. The savings in time and money to both programs has been great.

Needless to say March of Dimes volunteers throughout Alaska have also received excellent cooperation from the Department of Health and Social Services.

The continuation of the genetics portion of the March of Dimes' sponsored clinics is in serious jeopardy because March of Dimes annual grants, this year totaling \$74,952 to the University of Alaska and to the Alaska Department of Health and Social Services, were committed to three different clinic and educational purposes before it was learned that funds from the National Genetics Diseases Act would be cut off.

The March of Dimes grant to the University of Alaska is, this year, committed mainly to the prevention of fetal alcohol syndrome, a condition whereby pregnant women who drink alcohol in excess run the risk of giving birth to seriously defective and mentally retarded children.

Another March of Dimes grant to the Department of Health and Social Services will finance an infant screening program designed to detect congenital adrenal hyperplasia, a serious and usually fatal disease if not detected and treated at birth or very shortly thereafter. This newborn screening program involves the entire State of Alaska and will be used as a model to determine whether similar screening of newborns should be undertaken nationwide. It is reported that the highest incidence of this disease in the world (1 in 500 births) occurs among the Yupik speaking Eskimos.

Funds previously committed for the March of Dimes' sponsored genetics clinics are currently committed (contracts signed) for the above and this was done before it was known that other funds, previously counted on, would not be available for the continuation of the genetics clinics which, for the past 12 years have become a very important part of the medical care services and educational services available to all Alaskans.

The passage of Senate Bill No. 737 will be a life saver in more ways than one, will prevent much suffering among Alaskans needing genetic services and will save literally hundreds of thousands of dollars in tax funds through the prevention of serious birth defects one case of which, over the lifetime of a single patient, can cost more than the entire amount of the requested appropriation.

A BILL

For an Act entitled: "An Act relating to the diagnosis, management and prevention of birth defects in children."

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

The purpose of the bill is to provide clinics staffed by consultants with expertise in pediatrics, birth defects and hereditary disorders for the diagnosis, management, prevention and counseling of common and unusual problems that cause severe disabilities in children. Such clinic activities would be held in the cities of Juneau, Ketchikan, Sitka, Anchorage, Fairbanks, Bethel or other designated sites on a scheduled basis.

The Department of Health and Social Services shall arrange for the services of appropriately trained physicians to deliver such consultations, in collaboration with local physicians, that would benefit the children and their families. Such consultants may also provide information and training to those educational and social service programs that assist in the care of children with handicapping conditions.

The Department of Health and Social Services is further authorized to contract for the service of a coordinator in Alaska to organize and assist with the state-wide itinerant clinic program.

The above contractual arrangements are to include provision for personal services, travel, secretarial support, telephone charges and office expenses.

BUDGET

July 1, 1982 - June 30, 1983

Personal services for physician(s) with expertise in diagnosis and management of birth defects 1 FTE	\$ 50,000
Coordinator for clinics 1 FTE	30,000
One-half secretary	10,000
Travel costs for itinerant clinics	18,300
Office rental (Anchorage) Approximately 300 square feet @ \$1.5/ft <sup>2</sup> /month	3,600
Office supplies, photocopy costs, educational material	1,400
Telephone charges for coordination (in and out of Alaska)	<u>3,000</u>
	\$116,300
Indirect costs for contractual services @ 25%	<u>29,075</u>
TOTAL	<u><u>\$145,375</u></u>

FTE = Full-time equivalent

Salary figures include costs of fringe benefits

## BUDGET JUSTIFICATION

Personal Services for Physician(s): \$50,000

Part-time physician at \$30-40,000 per year with specialty training in birth defects and hereditary disorders is contracted with the University of Washington. This physician serves as the primary person to arrange for the visits to each city in Alaska, to offer diagnosis, management and counseling services in each clinic, to select an appropriate subspecialist in birth defects to accompany him/her to each clinic and to assure prompt consultative reports to the private physicians of each family. This physician will also assist with the coordination of care for children sent to Seattle for necessary diagnostic studies.

The remaining funds in this category are to allow for the services of subspecialists in birth defects with special skills in neuromuscular disease, hereditary eye disorders, hereditary bone disease, hereditary skin disease, congenital nervous system disorders and congenital disorders of the urinary tract. Any extra funding in this category could be used to assist with travel costs for the specialists.

Coordinator of Clinics: \$30,000

This position is for a person with special training in counseling of families with birth defects. The position requires a M.S. degree in counseling, especially regarding hereditary disorders. The position will function in Anchorage and act as the coordination center for arranging patient visits, offering follow-up information, responding to family inquiries and counseling of common hereditary disorders or drug exposures during pregnancy.

The coordinator will assure that reports prepared by the consultants will be shared with the families and their private physicians.

Secretary: \$10,000

Secretarial services are required to prepare the consultation reports, letters to families and submitting administrative reports. One-half time secretary should be adequate for this purpose.

Travel Costs:

Consultants in birth defects

Air fare (estimate)

Seattle/Juneau/Ketchikan/Anchorage = \$600/trip

Seattle/Anchorage/Fairbanks

12 trips @ \$600/trip

\$ 7,200

Per diem @ \$75/day (6.7 days/trip--12 trips)

6,000

Supspecialists in eye, skin, neurological, etc.

4 trips/year @ \$600/trip	2,400
(5.3 days/trip) (\$75/day per diem) (4 trips)	1,600

Travel for coordinator to SE Alaska and Fairbanks  
once each year

Estimated air fare @ \$600	600
6.6 days per diem @ \$75	<u>500</u>

\$18,300

Indirect Costs:

The University of Washington is currently charging 23% indirect costs for contracts of this nature.

# Birth defects can be reduced, youth meeting told

By GALE METCALF

Herald Staff Writer

Although birth defect causes are mostly unknown, would-be mothers can reduce chances of bearing an infant with a major defect, Tri-City high school students were told Monday. Those attending the Second Annual Youth Conference on Birth Defects at

Pasco High School were told by Dr. Sterling Clarren and Charlene Butler of the University of Washington that causes for most birth defects can't be pinpointed.

But, steps taken by parents, particularly pregnant women, can reduce potential effects from known and perhaps unknown causes, the two said.

Clarren is assistant professor of pediatrics and director of Craniofacial and Community Clinics at UW. Ms. Butler is with the university's Division of Congenital Defects.

The youth conference here was cosponsored by grants from the Hanford Environmental Health Foundation and the Mid-Co-

lumbia Chapter of the March of Dimes Birth Defects Foundation.

Dr. Clarren said 500,000 drugs or chemicals exist which little is known about in terms of effects on unborn children.

"About the only advice I can give you about drugs when you're pregnant is you shouldn't be exposing yourself to the unknown," Clarren said. "If you wouldn't give it to a baby, you probably shouldn't be taking it yourself unless you absolutely have to."

Clarren said only about six of the 500,000 drugs and organic chemicals sold by prescription and across the counter, or encountered, are absolutely known to

cause birth defects. Medical specialists are suspicious of another 25 to 25, but the remainder are complete unknowns.

"About 25 percent of the birth defects are caused by genetic defects," Ms. Butler said. "The largest number of birth defects are unknown."

Alcohol now is known to cause about 10 percent of the mental retardation in birth defects, Clarren said, but until the early 1970s alcohol was still not known to be a problem.

"Is marijuana dangerous? We don't know," Clarren said. "We know very little about marijuana. We know very little about medication."

Everyone has from three to a dozen minor birth defects that are virtually not noticeable, Dr. Clarren said. A few major birth defects may occur, eventually go away and some can be cured, he said.

Ms. Butler told the students to learn as much as possible about their own genes. Quizzing older generation family members may uncover knowledge of birth defects that might help a genetic counselor. RH negative blood, for example, could cause birth defects, she said, and tests can determine if blood is negative.

The ideal age for giving birth is between 18 and 30, she told would-be mothers.



DR. STERLING CLARREN



CHARLENE BUTLER

Ms. Butler cautioned against taking medicines unless necessary, smoking, drinking alcohol, radiation

directly to the stomach and exposure to infectious disease, particularly venereal disease.

JAN 29 1982.

THE NATIONAL FOUNDATION-MARCH OF DIMES  
REPORT OF PROGRESS UNDER MEDICAL SERVICE GRANT

University of Washington School of Medicine	Seattle	WA
Grantee Institution.	City	State
Ronald C. Scott, M.D.	King	
Program Director	Grantor Chapter	
	1/1/81-12/31/81	

Calendar year covered by this Report: \_\_\_\_\_

1. Describe briefly the extent to which the activities you planned to initiate or continue under this grant actually were carried out during the year covered by this report. If the volume of services rendered can be expressed quantitatively, please do so, e.g. number of patients by diagnostic category, initial visits, return visits, etc. or numbers served with genetic services, prenatal care or other service.

The March of Dimes has been a driving force in initiating genetic services within the Pacific Northwest. They have initiated funding in support of diagnostic facilities to evaluate children with congenital defects, the counseling of families with genetic diseases, the diagnostic and treatment programs for children with metabolic disorders, and an educational program to the professional and lay community of the region.

The current grant has supported this program by funding part of a physicians salary and by supporting a genetic associate. The funding of these positions has allowed the above mentioned goals to be achieved in a highly organized manner and within the frameworks of an academic discipline at a major University.

The grant allowed for services to be extended to the Children's Orthopedic Hospital in Seattle and for the development of regional clinics within the Pacific Northwest. These regional clinics were established at Spokane and Tacoma, Washington and more recently at Walla Walla and Yakima. As a regional extension of genetic services, the program provides consultative services to the State of Alaska. Such services have been provided to the cities of Anchorage, Fairbanks, Juneau, Ketchikan, and Sitka on a routine and scheduled basis. Two physicians trained in Medical Genetics spend one week

-2-

every other month in the State of Alaska at the above mentioned cities. On those visits they offer diagnostic expertise to the physicians of the region who request their genetic expertise. Laboratory support in cytogenetics and metabolism remain centralized in Seattle with specimens being sent from Alaska to the appropriate laboratory. As part of the program in Alaska, an educational component is a strong contributing arm. Advanced announcements of the consultants visit are made by newspaper articles or short announcements on television programs. The visiting geneticists offer a wide ranging educational interview with one of the public newspapers or television stations in support of the birth defects and genetics program.

The strength of the program is the concept that specialize genetic and perinatal services can be centralized within a tertiary care center, but with coordination, dedication, commitment, and clinical support to a large region. It is our belief that this can be achieved at minimum expense and in an effective manner through professional commitment to the concept of regional responsibility. To this end, we believe we have been successful and have developed a model program in offering genetic services to the Pacific Northwest.

The actual number of families receiving assistance from this grant during 1981 are as follows:

I. Seattle Area

- A. Children's Orthopedic Hospital Genetics Clinic: 301 families
- B. University Hospital Genetics Clinic: 151 families
- C. Biochemical Genetics Clinic: 118 families
- D. Prenatal Diagnostic Clinic
  - 1. University Hospital: 704
  - 2. Swedish Hospital: 364
  - TOTAL 1068

II. Regional Clinics Within the State of Washington

- 1. Spokane Genetics Services: 169 families  
    Prenatal Diagnostic Services: 83 families  
       TOTAL 252
- 2. Tacoma Genetics Program: 66 families  
    Prenatal Diagnostic Services: 50 families  
       TOTAL 116
- 3. Walla Walla Genetics Program: 103 families  
    Prenatal Diagnostic Services: 24 families  
       TOTAL 127

III. Clinic Sites Within the State of Alaska

- 1. Anchorage  
    12 clinic days: 158 families
- 2. Fairbanks  
    3 clinic days: 22 families
- 3. Juneau  
    3 clinic days: 32 families
- 4. Ketchikan  
    2 clinic days: 10 families
- 5. Sitka  
    1 clinic day: 7 families

- 2. Explain briefly any changes made during the year in
  - (a) the kinds of services rendered under this grant;
  - (b) the geographic area or population served;
  - (c) the location or time schedule for these services;
  - (d) the sources of referral used;
  - (e) the schedule of charges, if any, for these services;
  - (f) the composition of the professional staff engaged in rendering these services;

Several significant changes were made during this years grant period:

- (a) Dr. Judith Hall has moved to University of British Columbia in Canada. Her loss represents a significant loss of clinical skills

that are available to our program. She represented a very dynamic and high quality force for the region.

- (b) Dr. Virginia Sybert has assumed the responsibility for coordinating genetic services to the State of Alaska. One-half of her salary is funded by the State of Alaska to assist with this program. She participates in each visit to Alaska and selects an appropriate genetic specialist to assist her with these visits. We anticipate continued support from the State of Alaska for this aspect of the program.

Those individuals who served as consultants to Alaska during 1981 consist of the following:

Dr. Thomas Bird  
Associate Professor  
Division of Neurology

Dr. Peter Byers  
Assistant Professor  
Department of Medicine/Biochemistry

Dr. Judith Hall  
Professor  
Department of Medicine/Pediatrics

Dr. Arno Motulsky  
Professor  
Department of Pediatrics

Dr. Roberta Pagon  
Assistant Professor  
Department of Pediatrics

Dr. C. Ronald Scott  
Professor  
Department of Pediatrics

No visiting faculty was used during 1981.

Postdoctoral fellows in Medical Genetics participate in the clinical services and offered consultative assistance under faculty guidance as participants in the regional clinics. Participating fellows for 1981:

Dr. Susan Cassidy  
Dr. Philip Chance  
Dr. Robert Mueller  
Dr. Jack Jung  
Dr. Margot Van Allen  
Dr. Jeff Murray

3. What, in your view, are the major strengths or accomplishments of your program?

The strength of the program has been the interdisciplinary nature and quality of the clinical faculty. We have been fortunate in having a well organized and centrally integrated program in which the members work well together and have been supportive of the service needs of the region. We have a sophisticated and supportive medical community that has been receptive to receiving genetic information for improving the quality of care for their patients. A significant administrative concept has been that of "in place" clinics under the direct medical supervision of local physicians who take the responsibility of supervising the regional clinics. The University personnel serve as "consultants" to the clinics. In this manner, local control for patient referral remains at the direction of the community with the University personnel only offering advice and assistance as requested.

4. What weaknesses or deficiencies do you see in your program, and what measures do you suggest for improvement?

The major problem in offering genetic services are the financial constraints that exist in offering time dependent, nonprocedure oriented medical services. With the decreasing availability of federal funds and the shifting of money into the "block-grant" concept, we once again will need strong support at the local level to assure continued support for genetic services.

*C. Howard Leatt*

Signature of Program Director

*1/25/82*

Date



2. Explain briefly any changes made during the year in

(a) The kinds of services rendered under this grant:

No substantive changes.

(b) The geographic area or population served:

Continue to serve entire state of Alaska.

(c) The location or time schedule for these services:

No change.

(d) The sources of referral used: .

Both public and physician outreach has been improved since the state of Alaska hired a half-time genetics associate in Anchorage October 1, 1981. Referrals have increased 25-30% for the last 2 clinics of the year.

(e) The schedule of charges, if any, for these services:

No charges, no changes.

(f) The composition of the professional staff engaged in rendering these services:

Dr. Virginia Sybert of Childrens Orthopedic Hospital in Seattle has been retained on half-time salary through contract with the state of Alaska to provide continuity of care. She participated in 5 of the 7 clinic tours.

3. What, in your view, are the major strengths or accomplishments of your program?

The itinerant specialist clinic program appears to be the only cost-effective approach to providing highly qualified consultants to Alaska's small and widely scattered population. The state of Alaska is now assuming financial responsibility for the program.

4. What weaknesses or deficiencies do you see in your program and what measures do you suggest for improvement?

The itinerant program is now well organized and smoothly running as we turn its support over to the state of Alaska. We may be calling for support from the National Foundation officers in addition to local chapters in this effort.

5. Any additional comments?

Without the support of the National Foundation, the development and maturation of the birth defects program in Alaska would not have been possible.

The Foundation should, I believe, count this as one of its many successes in improving the health of American families.

Stanley D. Myers  
Signature of Program Director

28 Jan 82  
Date

Original submitted to Dr. Salisbury

1/30/76

ALASKA STATISTIC Jan. - Nov. 1981

(by Families)

	No. of Clinics	No. of Clinic Days	No. of Clinic Visits	
			<u>NEW</u>	<u>RETURN</u>
Anchorage	5	10	97	24
Fairbanks	2	2	10	3
Juneau	3	3	25	7
Ketchikan	2	2	8	2
Sitka	1	1	6	1
			<u>146</u>	<u>37</u>

REFERRAL SOURCE

	Physicians	Self	Agency	Return
Anchorage	85	9	3	24
Fairbanks	10	1	0	3
Juneau	22	3	0	7
Ketchikan	8	0	0	2
Sitka	<u>2</u>	<u>3</u>	<u>1</u>	<u>1</u>
	127	16	4	37

## DIAGNOSTIC CLASSIFICATION

GENERALLY 1 Diagnosis = 1 Family (except in cases where are multiple diagnoses per family). Does not reflect total number of patients seen.

### Single Gene Disorder

Aarskog syndrome	1
Adrenal hyperplasia	1
Aniridia	1
Cleft lip/palate and periorbital edema	1
Coloboma	1
Cystinosis	1
Carrier (Duchenne muscular dystrophy)	1
Ectopia lentis	1
Ehlers-Danlos (III)	2
Friedreich's Ataxia	1
Hemophilia	1
Juvenile onset diabetes mellitus	1
Lymphedema & distichiasis	1
Marfan syndrome	3
MR, hypotonia, dysmorphic, CHD, hernia, hyperextensibility	1
Metaphyseal epiphyseal dysplasia	1
Muscular dystrophy (? type)	1
Myotonic dystrophy	1
Neurofibromatosis	5
Osteogenesis Imperfecta II	1
PKU	2
Renoglycosuria	2
Retinal disease	1
Retinitis pigmentosa	1
Sickle trait	2
Stargaardt's disease	1
Tay-Sach's screen	2
Tuberous sclerosis	1
Waardenburg	1

40

### Polygenic/Multifactorial

Asthma	1
Cleft lip/palate	1
Congenital hip dislocation	1
Constitutional short stature	9
Diabetes mellitus	1
Hypospadias	1
Mental retardation	2
Psoriasis	2
Neural tube defect	2
Seizures	3

23

### Chromosomal

Trisomy 21	3
14/21 Translocation	1
? Translocation Down syndrome	1
Turner syndrome	3
Trisomy 18	1
Triploidy	1
Ring 22	1
46XX/47XX+mar	2
47XXY	1
46XYp+	1
48XXXX	1

16

### Environmental

Mysoline during preg.	1
Radiation exposure	3
Cerebral palsy	2
In utero constraint	1
Herpes encephalitis	1
Fetal alcohol syndrome	1
Hydrocephaly	1
Metopic craniosynostosis	1
Birth anoxia	2
Ricketts	1

14

Genetic Etiology Unclear, Not Genetic

Abnormal arm musculature	1
Amniotic band syndrome	1
Anterior placed anus	1
Aplasia cutis congenita (AD)*	1
Beckwith syndrome (AR)	1
Behavior problems	1
Bladder extrophy	1
Congenital hypothyroidism	1
Cornelia de Lange	1
Cylosomus	1
Esotropia	1
Giant hairy nevus	1
Hemangioma	5
Holoprosencephaly	1
Klippel-Trenaunay-Weber	3
Marcus Gunn phenomenon	1
Microcephaly	2
Moebius syndrome (AD)	1
Nevus of Ota	1
Pectus excavatum	1
Poland's anomaly (AD)	1
Radial ulner synostosis	1
Tight frenulum	1
Unilateral limb reduction defect	1
Unilateral pulmonary hypoplasia	1
Urethral malformation complex	1
Cancer	1
Urticaria pigmentosa (AD)	1

? Diagnosis 35

Achondroplasia VS	
Hypochondroplasia	1
Hypothyroidism	1
Leigh's encephalopathy	1
MR, R/O metabolic disease	1
Noonan VS Leopard syndrome	1
Mucopolysaccharidosis	1
Psychiatric problems	1
Tuberous sclerosis	1
Turner syndrome VS	
Neurofibromatosis	1
Urticaria pigmentosa	1
Urea cycle abnormality	1
X-linked mental retardation	1

12

Normal, Condition R/O

Down syndrome	1
Klinefelter's syndrome	2
Hypothyroidism	1
Premature thelarche	1
Head growth	1
Developmental delay	1
Prader-Willi syndrome	1
Failure to thrive	1
Peutz-Jehger	1

10

Other

Multiple miscarriages	3
Advanced maternal age	2
Infertility	1

6

Unknowns

See page 4

\* - (AD) (AR) Cases have been reported with these modes of inheritance in the literature. ? etiology in our cases above.

Unknowns

Vertebral anomalies, facial assymetry, microphthalmia	1
MR, precocious puberty	1
Craniosynostosis, polydactyly, syndactyly, situs inversus	1
Triphalangeal thumbs, short forearms, pyloric stenosis, hypospadias	1
Anal atresia	1
Cystic kidneys, rudimentary bladder, bicornate uterus, dupl. vagina	1
Short stature and delayed puberty	1
Hernia, cryptorchidism, bilateral dislocated hips, hypospadias	1
Short stature, club foot, MR	1
Hernia, omphalocele, dysmorphic facies, scoliosis, craniosynostosis	1
Nystagmus, microcephaly, micrognathia, microphallus	1
Microcephaly, IUGR, short stature, MR, dysmorphic facies	1
Developmental delay and hypodontia	1
Absent right thumb	1
Genuvarum	1
Sensorineural hearing loss & seizures	1
Mental retardation	3
Dysmorphic facies, pulmonary stenosis	1
Short stature	2
Congenital heart block and genitourinary abnormalities	1
Sensorineural hearing loss	1
Choanal atresia and mental retardation	1
Hydranencephaly, large ears, abnormal scrotum	1
Developmental delay, hydrocephaly, dysmorphic facies	1
Dev. delay, dysmorphic, overlap of toes 2 & 3, tapering fingers	1
Dysmorphic, fixed joints, synostosis, motor delay	1
Devl delay, minor dysmorphic facies, ear abnormalities	1

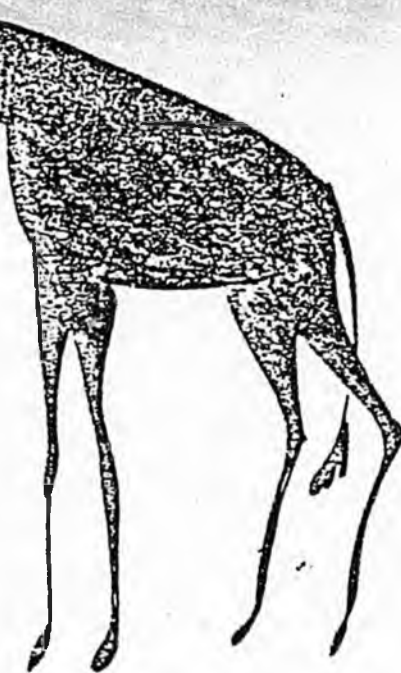


# what's up?

## FETAL MONITORING

### EDUCATIONAL PROGRAM

SPONSORED BY: MARCH OF DIMES



PRESENTED BY: Kathe Dobbs, R.N. and Zane Brown, M.D.  
Regional Perinatal Care Program, University of Washington

DATE: Friday, October 9, 1981 10:30 a.m. - 4:45 p.m.  
Saturday, October 10, 1981 9:00 a.m. - 12:30 p.m.  
Self-assessment quiz 12:30 p.m. - 1:30 p.m. (may be taken here)

PLACE: Chandler Room, Fairbanks Memorial Hospital

FEE: None TO REGISTER: Call 452-8181, ext. 503

#### SCHEDULE OF TOPICS:

- October 9 - Introduction to Monitoring (for those new to fetal monitoring)  
Premature Labor  
Antepartum Fetal Assessment  
Workshop A - Strip Interpretation - Antepartum Tracings  
Workshop B - Strip Interpretation - Baseline and Variability Examples  
Mechanics of Monitoring and Fetal Arrhythmias
- October 10 - Labor and Implications for the Fetus  
Workshop C - Strip Interpretation - Periodic Changes  
Workshop D - Strip Interpretation - Decreasing Fetal Reserve with  
Periodic Changes  
Strip Interpretation - Your Cases - Stump the Expert!

NOTE: Workshop portions will have two presentations: one for the beginning level, one for advanced. Please indicate which level you are planning to participate in when registering.

Physicians and nurses are invited to attend.

FMH nurses are urged to schedule time off with their Head Nurse or Supervisor.

C E A R P credit has been applied for.



# March of Dimes

BIRTH DEFECTS FOUNDATION

Public Information Department / 1275 Mamaroneck Avenue, White Plains, New York, 10605 / 914-428-7100

## News Release

contact: Martha Kongschaug  
914-428-7100

FOR IMMEDIATE RELEASE  
(mailed Feb. 25, 1982)

Expanded medical insurance coverage to include services related to genetic illnesses is being studied by the Blue Cross and Blue Shield Associations.

The one-year study is being supported by grants from the March of Dimes Birth Defects Foundation and by the Bureau of Community Health Services, Department of Health and Human Services.

Support for counseling services for inherited disorders such as Down Syndrome, sickle cell anemia, or Tay Sachs disease now comes chiefly from March of Dimes and programs administered by HHS. Those agencies are funding the study to investigate the possibility of private reimbursement that will remove financial barriers to obtaining genetic services.

The \$181,968 study will focus on payments for screening and diagnostic work for a host of genetically transmitted disorders.

Coverage to include counseling services for prospective parents at risk of transmitting a genetic disease will also be investigated.

"Many insurance plans do not cover genetic services at all, and there is little consistency among those that do," said Dr. Arthur J. Salisbury, March of Dimes vice president for medical services.

Although most genetic illnesses are rare, collectively they have a major impact. It is estimated that 30 percent of admissions to children's hospitals are the result of genetically related disorders and that such disorders account for 40 percent of pediatric mortality. Approximately 4.8 million Americans are retarded as a result of genetically related diseases.

Insurers have been reluctant to pay for screening services or for the services of non-physician genetic counselors, according to Dr. Vincent Hutchins, Director of the Office of Maternal and Child Health, Health Services Administration.

"Without these components, the victims of these illnesses will not have adequate information or explanations of options to make educated decisions about having a family," Hutchins said.

Each year, the birth of genetically handicapped children in the U.S. creates a future commitment to custodial care of more than \$2 billion. Dr. Hutchins noted that "insurance coverage for screening, diagnostic and counseling services will make more money available to support scientific research into the prevention and treatment of genetic illnesses."

Screening of prospective parents who might be carriers of certain genetic disorders enables them to know the risks of having a handicapped child before they conceive. After conception, diagnostic tests often can determine whether a child has been affected by a genetic disorder. In some instances treatment for the disorder can begin before the child is born.

Among items to be investigated are what services could be included under a genetic services benefit, how much it would cost, and its market potential. The study will also review related administrative issues.

Though the study's immediate impact may be to affect the coverage of the Blue Cross and Blue Shield Plans, in the long run it could shape coverage provided by other insurers and federal health care programs.

# # #

The entire State of Alaska is serviced by the MARCH OF DIMES BIRTH DEFECTS FOUNDATION through the four Chapters listed below together with the name and address of the Chapter Chairman.

Local community representatives of these four March of Dimes Chapters are appointed yearly for fund raising and other programs of the March of Dimes Birth Defects Foundation.

NORTHERN ALASKA CHAPTER

Mrs. Ardelia Telfer  
CHAPTER CHAIRMAN  
2740 Kuskokwim  
Fairbanks, Alaska 99701  
TEL: (907) 452-2461

*People file*

SOUTHCENTRAL ALASKA CHAPTER

Ms. Iyillamae Olsonoski  
CHAPTER CHAIRMAN  
1317 Crescent Avenue  
Anchorage, Alaska 99504  
TEL: (B) (907) 264-7412  
(R) (907) 278-9177

Ms. Lora Alexander  
EXECUTIVE DIRECTOR  
P. O. Box 164  
Anchorage, Alaska 99510  
TEL: (907) 279-2622

STATE VOLUNTEER ADVISOR

Mrs. Grayce Oakley  
2458 Sprucewood  
Anchorage, Alaska 99504  
TEL: (907) 277-7407

SOUTHEASTERN ALASKA CHAPTER

Mrs. Pat Vadman  
CHAPTER CHAIRMAN  
P. O. Box 410  
Juneau, Alaska 99802  
TEL: (907) 789-9112

STATE VOLUNTEER ADVISOR

Mrs. Venetta Hildebrand  
Box 184  
Douglas, Alaska 99824  
TEL: (907) 364-3222

TONGASS CHAPTER, ALASKA

Mrs. Phyllis Yetka  
CHAPTER CHAIRMAN  
Box 928  
Ward Cove, Alaska 99928  
TEL: (907) 225-5146

STATE VOLUNTEER ADVISOR

Mrs. Phyllis Yetka

REGIONAL DIRECTOR

Mr. Felix A. Montes  
414 Securities Building  
Seattle, Washington 98101  
TEL: (206) 624-5470

The areas covered by the Chapters named above correspond to the four judicial areas of Alaska with the First Judicial Area having been divided into two Chapter areas with the Wrangell Narrows as the dividing line. The two Chapters resulting are the Southeastern Alaska Chapter and the Tongass Chapter, Alaska. The Northern Alaska Chapter encompasses the Second and Fourth Judicial Division.

To: Charlie  
From: Nancy  
RE: Proposal for Birth Defects Specialist from WAMI

All reports show that this has been an excellent program in the past, and in view of the high rate of congenital abnormalities in Alaska, it would seem that it should be continued.

zthe Department of Health and Social Services does not have the flexibility of budget to request money for this, though Dr. Dave Spence has drawn up a proposal for considerably less money than the one submitted by Dr. Meyers of the U of A.

Dr. Spence's budget is for \$53,000 and will rely heavily on volunteers from the March of Dimes to make this program work. The money is for 1/2 time genetic associate (\$13,000) and the remainder to go to the University of Washington for the salary, travel and per diem of the Birth Defects specialist.

Traditionally, the Department has paid for diagnostic services for every child, and then has a sliding scale for treatment costs through the Handicapped Children's Program. This is subject to sporadic use, and the fund can be easily used up by one very ill child. Unfortunately, at the end of the last fiscal year, there was an overrun of \$290,000 and consequently the BRU was cut by the legislature. The fund is empty this year, and no more children can be served, and they have been told that there will be no supplemental appropriation.

This is a good program, and there is no specialist in the state. Families will have to go outside for diagnosis and treatment with no public funds available this fiscal year. It seems like a minor appropriation and a good use of WAMI.

Would you like to submit a bill?



UNIVERSITY OF ALASKA, FAIRBANKS  
Fairbanks, Alaska 99701  
WAMI Medical Education Program  
January 25, 1982

The Honorable Charles Parr  
The Alaska Senate  
Pouch V  
Juneau, AK 99811

Dear Charley:

Would you please give serious consideration to supporting legislation, based on the attached draft material, to maintain and strengthen a birth defects prevention and treatment program for Alaska?

Birth defects exert lifelong impairments for affected children. Medical understanding of these conditions has enormously expanded in the past two decades. Today over 600 syndromes are recognized. Most are individually rare but in the aggregate affect at least 4 percent of all newborns--500 infants in Alaska each year.

Because of the rarity and complexity of many of these problems, their management requires the services of physicians specializing in this area. Such physicians are only found in major medical centers. No such specialists are currently practicing in Alaska.

An itinerant birth defects clinic program in Alaska was initiated by the March of Dimes in the early 70s and has been supported by MOD thru a series of annual grants to the WAMI Program. The March of Dimes is no longer able to continue this support.

The Department of Health and Social Services has provided assistance as its resources have permitted, largely thru the use of certain Federal funds which are now disappearing.

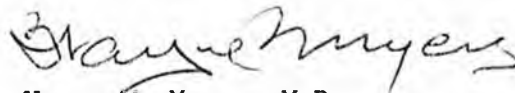
Both the March of Dimes funds and state funds have been used to partially support a birth defects specialist position thru the University of Washington School of Medicine, travel expenses for 7 to 8 itinerant clinics per year serving Ketchikan, Juneau, Sitka, Anchorage, Fairbanks and occasionally Bethel, and a trained coordinator in Anchorage.

The attached draft authorizing bill and budget are intended to permit Department of Health and Social Services support of this program. The alternative is expensive with disruptive and recurring travel to medical centers

outside of Alaska for the children and their families. This is often at state expense. It is more cost effective to bring one or two specialists to substantial numbers of children, than to bring families to the specialists. The added benefit of education, advice and training provided by these itinerant specialists to local school, medical and nursing personnel further contribute to the day-to-day care of the children and assistance to these families.

I have initiated this modest legislative effort simply because I am convinced that it is in the best interest of the citizens of Alaska. The program which I administer anticipates no financial interest in this arrangement.

Sincerely,



Wayne W. Myers, M.D.  
Director, WAMI Program

Attachment.

Distribution:

Senate

Don Bennett  
Richard Eliason  
Vic Fischer  
Jalmar Kerttula  
Charles Parr  
Bill Ray  
Arliiss Sturgulewski  
Robert Ziegler

House

Michael Beirne  
Thelma Buchholdt  
Terry Martin  
Mike Miller  
Joe Montgomery  
Sarah J. Smith

POSITION PAPER  
SENATE BILL NO. 737

"An Act making a special appropriation to the Department of Health and Social Services to combat the causes and effects of birth defects."

This bill appropriates \$100,000 to this Department that may be utilized over the next 5 years, for which will continue to enhance a birth defects counseling service. In the past, this program was initiated and continued for several years by the National Foundation for Prevention of Birth Defects. It is anticipated that we will have to find another source to fund this service as that voluntary organization has indicated that other priorities have emerged for their support.

The Birth Defects program provides services ranging from diagnoses or confirmation of diagnoses, management and counseling. The categories covered include genetic disorders, chromosomal disorders (e.g. Down Syndrome), environmental (e.g. fetal alcohol syndrome) and those syndromes and malformations of unknown origin. They also receive many requests for information regarding amniocentesis, sickle-cell screening, drug exposure during pregnancy, etc.

The needs for services are rapidly increasing. The March of Dimes Birth Defects Foundation estimates that 1 out of 12 babies born has a significant birth defect. In Alaska during 1981, the Department of Vital Statistics recorded approximately 9550 live births, which statistically could represent almost 800 babies with significant birth defects. This is twice the number they can see in one year. A viable contracting mechanism has been established with the University of Washington using available Federal funds in addition to Foundation money. Federal funds are not available for FY 82 or beyond. This mechanism serves four cities in Alaska every two to four months. A continuation level would require close to \$50,000 per year. An expansion of the frequency and geographic availability of this service would require the expenditure of some additional funds.

POSITION

This service is considered by the Department to be a much needed preventive and cost effective program.

*85% children in gen hosp there because of birth defects  
clinics 6 yr in Anchorage  
" 1 " " Fairbanks  
" 3 " " Juneau & Kotzebue*

Recommended by:

*E.S. Rabeau*

E.S. Rabeau, M.D., Director  
Division of Public Health

Date:

*March 3, 1982*

Approved by:

*Helen D. Beirne*

Helen D. Beirne, Commissioner  
Department of Health and  
Social Services

Date:

*3-3-82*

THE LEGISLATURE OF THE STATE OF ALASKA  
TWELFTH LEGISLATURE

FISCAL NOTE

I. REQUEST

Bill/Resolution No. Senate Bill No. 737  
Title "An Act making a special appropriation to the Department of Health and Social Services to combat the causes and effects of birth defects."  
Requested by Senate HESS Date 2/10/82

II. FISCAL DETAIL

Agency Affected Department of Health and Social Services  
Program Category Affected Health/Public Health  
BRU, Program, Or Subprogram(s) Affected Child & Family Health  
(Note: If more than one budget component is affected, separate line-item amounts and funding for each component in the analysis section.)

EXPENDITURES (Thousands of Dollars)

	FY 82	FY 83	FY 84	FY 85	FY 86	FY 87
100 PERSONAL SERVICES	0	0	0	0	0	0
200 TRAVEL	0	0	0	0	0	0
300 CONTRACTUAL	0	0	0	0	0	0
400 COMMODITIES	0	0	0	0	0	0
500 EQUIPMENT	0	0	0	0	0	0
600 LAND & STRUCTURES	0	0	0	0	0	0
700 GRANTS, CLAIMS, ETC.	0	0	0	0	0	0
TOTAL	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 (Specify Source)	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

III. ANALYSIS (See Fiscal Note Preparation Instruction, Section III)

The \$100,000 appropriation in this bill may be expended over a 5 year period.

IV. DATE March 3, 1982 PREPARED BY E.S. Rabeau, M.D.  
AGENCY Dept. of Health & Social Services  
Original: Legislative Finance PHONE 465-3090  
cc: Budget and Management  
Prime Sponsor (First Legislator Named)  
33-001 (Rev. 12/81)