COMMITTEE REPORT

HOUSE

FURTHER: FINANCE

(5)

3/26/82

Date: [illegible]

Mr. Speaker:

The Committee on HEALTH, EDUCATION & SOCIAL SERVICES has had SB 737

"An Act making a special appropriation to the Department of Health and Social Services to be used to combat the causes and effects of birth defects; and providing for an effective date."

under consideration and ~~(a majority of the committee)~~ ~~(the committee)~~ reports it back with the following recommendations:

☐ do pass ☐ do not pass

☐ do pass with attached amendments(s)

☐ replace with CS for ______ ☐ same title ☐ new title

and recommends ______

☐ AND attaches a "Letter of Intent" ☑ Zero New Fiscal Note

☑ reports it back without recommendation

☐ referred to the ______ Committee

MEMBERS SIGNING DO PASS

MEMBERS HAVING OTHER RECOMMENDATIONS:

CHAIRMAN

H 60 (Rev. 12/78)

POSITION PAPER/Department of Health & Social Services

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 83 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.

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
PHONE 465-3090

Original: Legislative Finance
cc: Budget and Management
Prime Sponsor (First Legislator Named)

33-001 (Rev. 12/81)

STATE OF ALASKA

DEPT. OF HEALTH AND SOCIAL SERVICES

DIVISION OF PUBLIC HEALTH

JAY S. HAMMOND, Governor

POUCH H-06
JUNEAU, ALASKA 99811-9976
PHONE: 465-3030

April 13, 1982

DOCUMENT NO. 143-82

The Honorable Michael Beirne
Representative
Alaska State Legislature
Pouch V
Juneau, Alaska 99811

Dear Representative Beirne:

In response to your staff's inquiries on SB 737 we have investigated the possibility of charging responsible third parties for genetic counseling services.

Indeed it is possible to get some reimbursement. For instance, genetics clinics in Washington State charge $30 for an intake interview by a genetic associate and charge $40-70 for a physician's extensive or comprehensive evaluation. At the University of Washington charges of $120 for an initial visit and $60 for follow-up visits. Blue Cross will pay these charges if, and only if, there is a patient who has the disease or condition. In about half of the cases managed in these clinics is this the case.

In the other halfof the work load third party recovery would be unlikely. Examples of these cases are families with repeated miscarriages, families where there has been a death with congenital malformations or where a relative has a heritable disease. Much of genetic counseling is in this category.

Regarding travel expenses, we would have to negotiate this with the insurance carriers. In sum, billing of third parties for services under this appropriation is an additional source of revenue which we are willing to pursue. It will not, however, negate the need for the appropriation. The experience of genetic counseling services in other states indicates that only a portion of the necessary funding support will be recovered from third party billing.

Sincerely yours,

Ed Rabeau

E.S. Rabeau, M.D.
Director

ESR/DAS/sd

08-F78LH

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 resouces 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 Myers

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

/bd
Attachment

Distribution:

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

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

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.

FEB 1 1982

C-242

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

University of Alaska	Fairbanks	AK
Grantee Institution	City	State
Wayne W. Myers, M.D.	Northern Alaska Chapter	
Program Director	Grantor Chapter	

Calendar year covered by this Report: 1/1/81-12/31/81

1. Describe briefly the extent to which the activities you planned to initiate or continu 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 itinerant genetics and birth defects program conducted seven clinic tours providing 59 physician-days of clinic sessions and seeing 308 patients from 183 families. The number of patients seen this year increased 15% over the 267 patients seen in 1980. The latter figure similarly represented a 27% increase over the 210 patients seen in 1979.

Professional education conferences for physicians, nurses and special education teachers were conducted in conjunction with each clinic tour.

In addition, the March of Dimes grant supported the following explicitly educational activities. Dr. Louis Gluck traveled from the University of California, San Diego, to present a workshop on neonatal intensive care at the Alaska Perinatal Care Conference in Anchorage, and to present a training session for pediatricians in Fairbanks. Kathe Dobbs, R.N. and Zane Brown, M.D. of the University of Washington presented workshops in Juneau and Fairbanks. Nancy Warren of Childrens Orthopedic Hospital, Seattle, spoke on genetic counselling at the Alaska Year of Persons with Disabilities Conference in Anchorage.

2. Explain briefly any <u>changes</u> 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 hav 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 scattere 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.

[illegible] Myers
Signature of Program Director

28 Jan 82
Date

(original submitted to Dr Salisbury

ALASKA STATISTIC Jan. - Nov. 1981

(by Families)

	No. of Clinics	No. of Clinic Days	No. of Clinic Visits	
			NEW	RETURN
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
			146	37

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	2	3	1	1
	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 leptis	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	[illegible]
?/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
Cyllosomus	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
Cance	1
Urticaria pigmentosa (AD)	1
	35

? Diagnosis

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

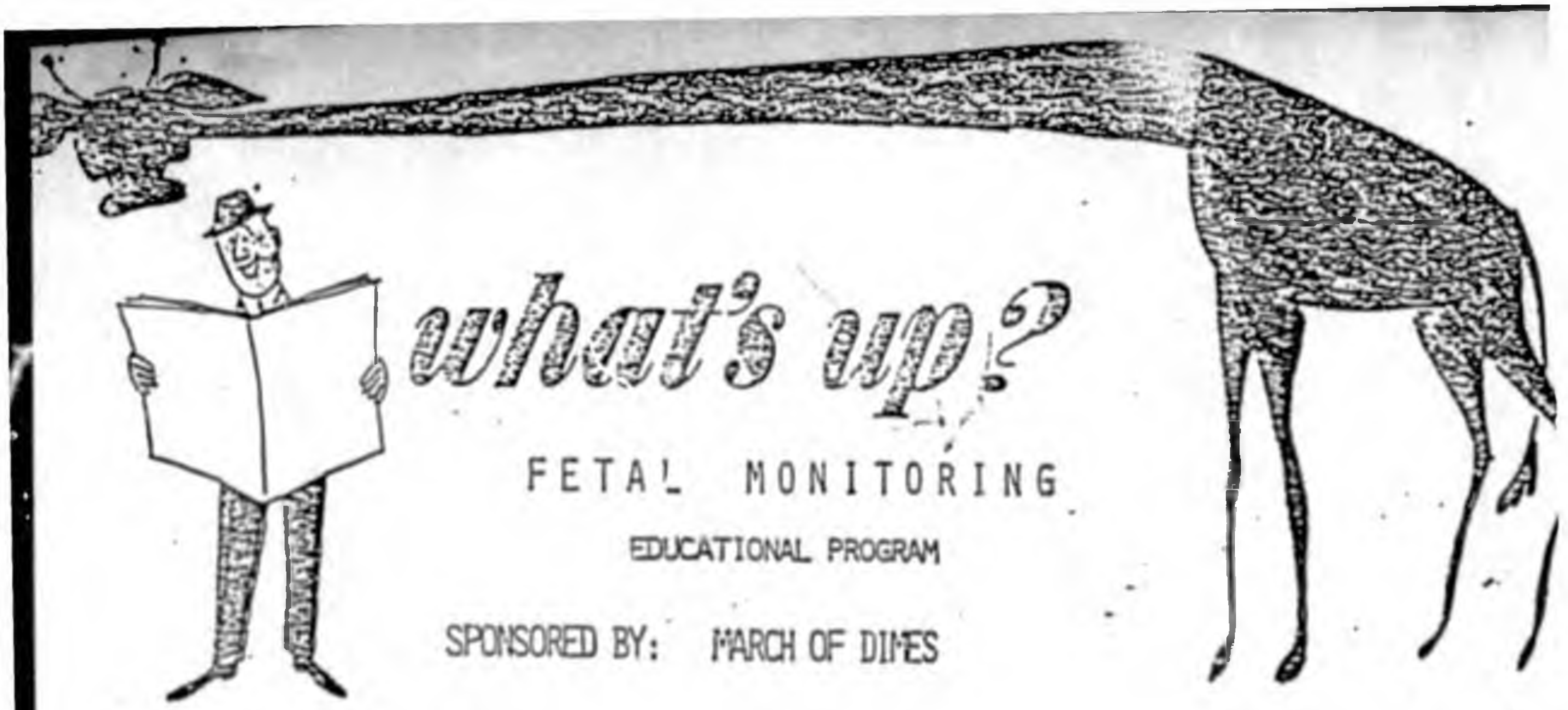
Unknowns

See page 4

* = (AD) (AR) Cases have been reported with these modes of inheriitence in the literaturre. ? etiology in our cases above.

Unknowns

Vertebral anomalies, facial assymmetry, microophthalmia	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
	30



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

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.

JAN 29 1982

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

University of Washington School of Medicine — Grantee Institution
Seattle — City
WA — State

Ronald C. Scott, M.D. — Program Director
King — Grantor Chapter

Calendar year covered by this Report: 1/1/81-12/31/81

---

1. Describe briefly the extent to which the activities you planned to initiate or continu 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 Childrern'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 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. <u>Seattle Area</u>

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 Ronald Scott
Signature of Program Director

1/25/82
Date

March of Dimes
BIRTH DEFECTS FOUNDATION
Public Information Department / 1275 Mamaroneck Avenue, White Plains, New York 10605 / 914-428-7100

News Release

contact: Martha Kongshaug
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.

-MORE-

"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."

-MORE-

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.

# # #

For 12 years, a carefully planned program for the prevention ~~of~~ and ca of children with birth defects has been developed within the State of Alaska. This program is now in jeopardy because of a sudden and unexpected termination of federal funds to the Pacific Northwest. The loss of this program will result in significant costs to the State of Alaska for the care of children with birth defects.

The program supports the visits of pediatricians with special training in human genetics to assist with the diagnosis, management and counseling of children or families with congenital defects. These visits often result in the prevention of progressive retardation in infants by specific therapy or in the prevention of further children being born with serious and untreatable illness through family counseling. During 1981, 250 families sought assistance through this program in the cities of Anchorage, Fairbanks, Juneau, Ketchikan and Sitka. If only one child is prevented from becoming a burden on the State, the savings is estimated at $800,000 over the lifetime of that child in 1980 dollars.

The loss of this program would immediately increase the medical and transportation costs to Alaska citizens who would seek this service outside of Alaska. Worse still, would be the birth and suffering of small children with serious defects who would need the resources of the State to assist with their medical and custodial care.

The infusion of $100,000 to carry-over the program is a small price to prevent this financial burden.