

Approved 2-23-88
Date

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE

The meeting was called to order by SENATOR ROY M. EHRLICH at
Chairperson

10:00 a.m./p.m. on February 16, 1988, 19 in room 526-S of the Capitol.

All members were present except:

Committee staff present:

Emalene Correll, Legislative Research
Norman Furse, Revisors Office
Clarene Wilms, Committee Secretary

Conferees appearing before the committee:

Patricia T. Schloesser, M.D., Director, Division of Health
Department of Health and Environment
R. Neil Schimke, M.D., Kansas University Medical Center
Sechin Cho, M.D., Director, Medical Genetics, University of Kansas
School of Medicine, Wichita

Dr. Patricia Schloesser appeared before the committee in support of SB-570 which would establish a statewide genetic services program in Kansas to be administered by the Kansas Department of Health and Environment. Dr. Schloesser further stated that a major component of this bill is the development of a general public health policy related to genetic services. Secondly, the bill would develop public health policy with respect to the conduct of scientific investigation including publication of results which are important aspects of genetic services. The bill would also provide for support for clinical genetic counseling services. When questioned by the committee concerning the statement, "the fiscal impact on the state general fund is considerable," Dr. Schloesser stated that this item was not in the budget nor had the Governor been approached concerning funding. Attachment 1

Dr. R. Neil Schimke spoke to the committee concerning genetic disease, stating that more than 25% of admissions to children's hospital wards are for complications related to inherited conditions. Dr. Schimke stated that genetic services are labor intensive. At the present time Dr. Schimke and Dr. Cho are the only two persons working on genetics other than genetic counselors. Legislative help is needed to stop the erosion of funds and permit out reach programs to continue. Attachment 2

Sechin Cho, M.D., appeared to request committee support of SB-570. Dr. Cho stated that at the present time the out reach programs have been very successful in helping patients who need genetic services but are unable to reach Wichita or Kansas City. Dr. Cho also stated that early detection and treatment enable many to live more normal lives and many times prevents institutionalization costs. Attachment 3

Senator Francisco introduced his pages from Mulvane, also the student group from Haysville's Campus High School which is in Senator Morris' and Senator Francisco's District.

The meeting adjourned at 10:54 a.m. The next committee meeting will be held Wednesday, February 17, 1988 at 10:00 a.m. in Room 526-S.

SENATE
PUBLIC HEALTH AND WELFARE COMMITTEE

DATE February 16, 1988

(PLEASE PRINT)
NAME AND ADDRESS

ORGANIZATION

Chip Wheeler

Ks Medical Society

Tom Ball

Ks. Hosp. Assn

John Green

Ks Homes for Aging

Bob Bethell

—

Dennis V. ALVAREZ

NONE

St. Francis

St Francis - Wichita

Mary Ellen Conlee

St. Francis - Wichita

Carolyn & Vatti Domingo

KDHE

Virginia & Tucker, M.D.

KDHE

Lela Paslay

ARC/Kansas

Sechin Cho, M.D

Univ. of KC School of Med-Wichita

Phal Schumbeles

Univ Ks Med School - KC

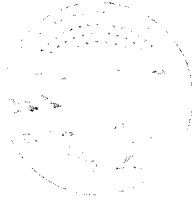
Gary K. Huletts

KDHE

KEITH LANDIS

CHRISTIAN SCIENCE COMMITTEE
ON PUBLICATION FOR KANSAS

STATE OF KANSAS



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Mike Hayden, *Governor*

Stanley C. Grant, Ph.D., *Secretary*

Gary K. Hulett, Ph.D., *Under Secretary*

Testimony Presented to

Senate Public Health and Welfare Committee

by

The Kansas Department of Health and Environment

Senate Bill 570

Senate Bill 570 establishes a statewide genetic services program in Kansas administered by the Kansas Department of Health and Environment. Statewide genetic counseling and diagnostic services are needed to decrease the number of individuals born with serious genetic anomalies. Genetic related disorders that modify the normal functioning or structure of the body are present in 12-15% of the population. Scientists have discovered 3000 inherited disorders that stem from genetic defects. Some of these disorders are rare while others occur more frequently. Some of the more commonly known inherited disorders that result from a genetic defect include Huntington's disease, cystic fibrosis, muscular dystrophy, sickle cell anemia, hemophilia, diabetes, cleft lip and palate, spina bifida, Down's syndrome, and congenital heart disease. Individuals can develop genetic related disorders at any period during their lifetime.

Genetic services include the identification of the disorder; treatment; and counseling to assist the individual and family to incorporate this knowledge into their lives.

Current genetic services coordinated by the Kansas Department of Health and Environment are limited and have been incompletely developed over the years by utilizing a variety of funding sources. Senate Bill 570 would enhance current limited program activities. K.S.A. 65-180 through 65-183 specifically identifies the diseases to be screened in the newborn period and K.S.A. 65-1,105 through 65-1,106 provides for screening for sickle cell anemia. Senate Bill 570 allows for the establishment of additional screening programs including procedural specifications, and the designation and monitoring of laboratories to perform additional screening tests. This makes the screening more responsive to the needs and the availability of appropriate laboratories.

A major component of this bill is the development of a general public health policy related to genetic services. This policy will be used to provide direction to all programs administered by the Kansas Department of Health and Environment and guidance to local public health agencies and other agencies providing direct services to individuals.

This proposal also calls for developing public health policy with respect to the conduct of scientific investigation including publication of results which are important aspects of genetic services. This activity has not received the attention from the Kansas Department of Health and Environment staff that is needed due to erosion of personnel and dollars. With this bill, these activities could assume major importance.

Another major component of the bill is support for clinical genetic counseling services. This will allow continued support of outreach genetic services clinics in Topeka, Salina, Hays, Great Bend, Parsons, Fort Riley/Junction City and Salina which provide counseling and education activities. In the years 1984 through 1986, 4,745 individual Kansans from 103 counties were provided genetic counseling services through the outreach genetic services clinics and the community based clinics - a cooperative endeavor between KUMC at Kansas City and Wichita, and the Kansas Department of Health and Environment. Additionally, 10,239 Kansans were present at the genetic counseling sessions.

There have been unprecedented advances in the last several years in genetic research and related fields. This bill allows for timely response to the knowledge and information that will benefit Kansans and decrease the number of individuals born with serious genetic anomalies.

Although we support the concept of this bill, the fiscal impact on the state general fund is considerable and is not a part of our FY 1989 budget request or the Governor's recommendation.

Presented by:

Patricia T. Schloesser, M.D.
Director, Division of Health
Department of Health and Environment
February 16, 1988

The Impact of Genetic Disease

R. Neil Schimke, M.D.

Genetic diseases are collectively common diseases. More than 25% of admissions to children's hospital wards are for complications related to inherited conditions. Progress in molecular biology has established that many adult disorders also have a genetic component; e.g., diabetes, hypertension and even cancer. Relatively few people, and unfortunately, often not many more physicians and nurses, recognize certain diseases as being genetic. Simply because a given condition is the only one in a family does not mean it cannot be heritable. The condition may be a new dominant mutation or a rare recessive, or even due to interaction of genes and environment, as is true with virtually all birth defects.

Genetic disease is chronic disease. Even if it can be effectively treated, as is the case with phenylketonuria (PKU), the problem remains. Fully treated and otherwise normal women may give birth to mentally retarded children without diet restriction during pregnancy. Hence, newborn screening programs mandate long term responsibility since treatment regimens may be expected to improve.

As genetic disease is chronic, it is frequently expensive. Too often it occurs in families with limited means. Such families are not as likely to seek genetic services because of additional expense, long distances, and basically, lack of knowledge that the condition could be genetic. They may subsequently have other affected children because of no contact with a genetics service program. Conversely, they may stringently limit family size because the perceived recurrence risk is felt to be much higher than the actual risk.

Genetic services are labor intensive. While some medical insurers recognize the value of genetic services, it is clearly not totally compensatable. Many hours are required to obtain the family history, to check the accuracy of previous diagnoses, and to confirm (or make) the diagnosis in question. While genetic diseases are collectively common, a given disorder may be quite rare, requiring much special effort. Parents of affected individuals and the individuals themselves expect, and should receive, full knowledge not only of the genetic impact of the disorder, but its prognosis, the psychosocial aspects of the disorder, and the availability of or prospects for treatment. A recent study from Johns Hopkins concluded that only about 25% of the cost involved in providing genetic services is recoverable.

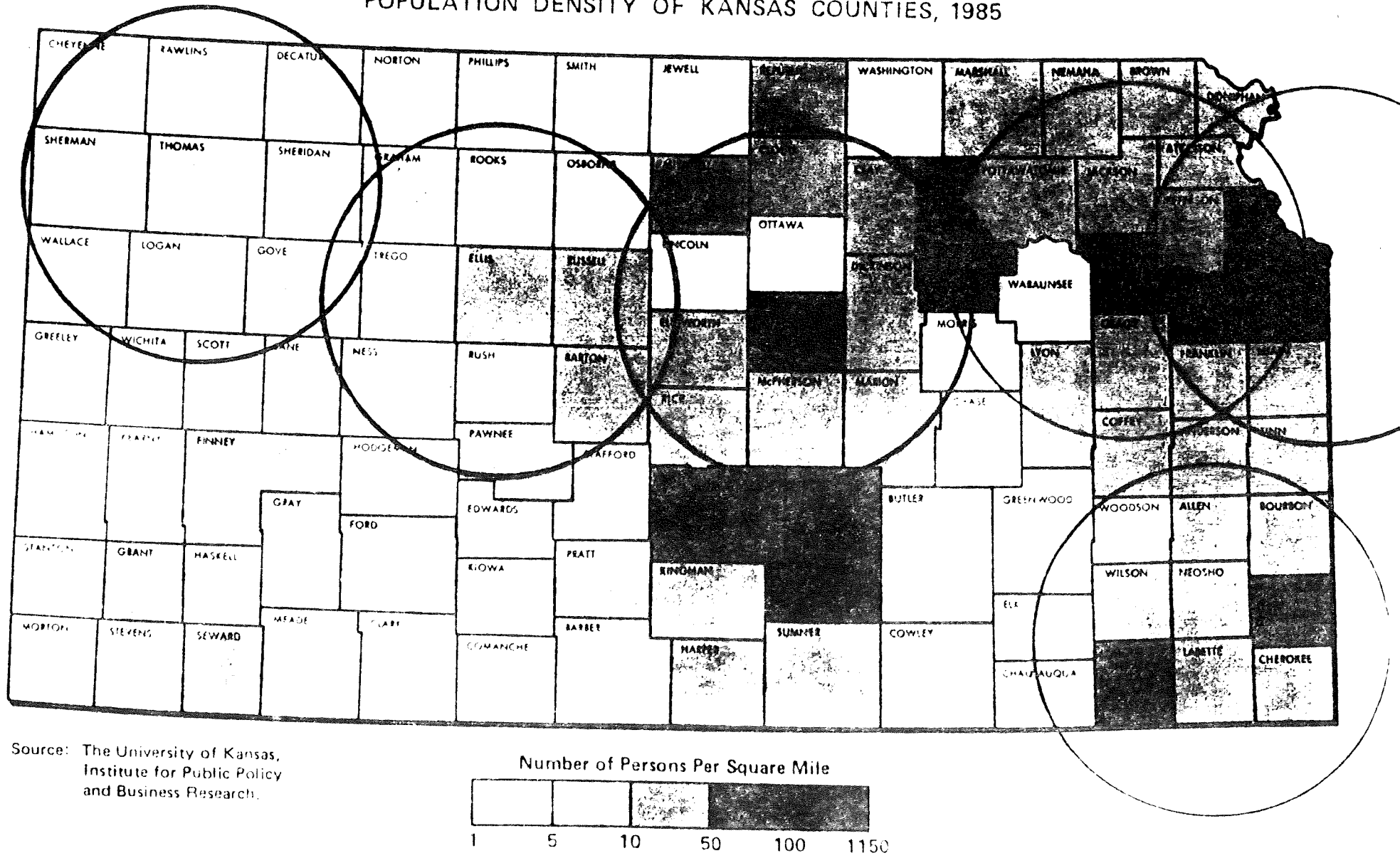
Genetic services imply education. Knowledge of contemporary genetics must be imparted not only to medical practitioners but to nurses, social workers and to others who care for the chronically ill. Moreover, it is essential that young parents be apprised of genetics and to this end it is important to address this issue in contemporary biology classes, not only at the state universities, but in the primary and secondary schools as well. Prospective parents have a right to know their risks.

Despite the obvious long term value of a genetics service program, fiscal support has been continuously eroding. Newborn screening programs for hypothyroidism PKU and galactosemia are well established. These three entities represent merely the tip of the genetic iceberg. Staffing problems constrict the ability of existing genetic service programs to detect, diagnose and counsel all those who are in need. The recent explosion in molecular genetics has allowed for precise chromosome mapping of many human genetic diseases. This leads to the possibility not only of earlier diagnosis, but also actual gene isolation and precise determination of the basic defect.

More rational therapy can then be developed, often to the extent that severe crippling disorders can be turned into easily treatable conditions; i.e., virtual non-diseases.

The need is actual, continuous, and growing. Legislative help is needed now if genetic services are to be continuously available to all the people in Kansas, irrespective of geographic location or family means. I strongly urge you to support SB 570.

POPULATION DENSITY OF KANSAS COUNTIES, 1985



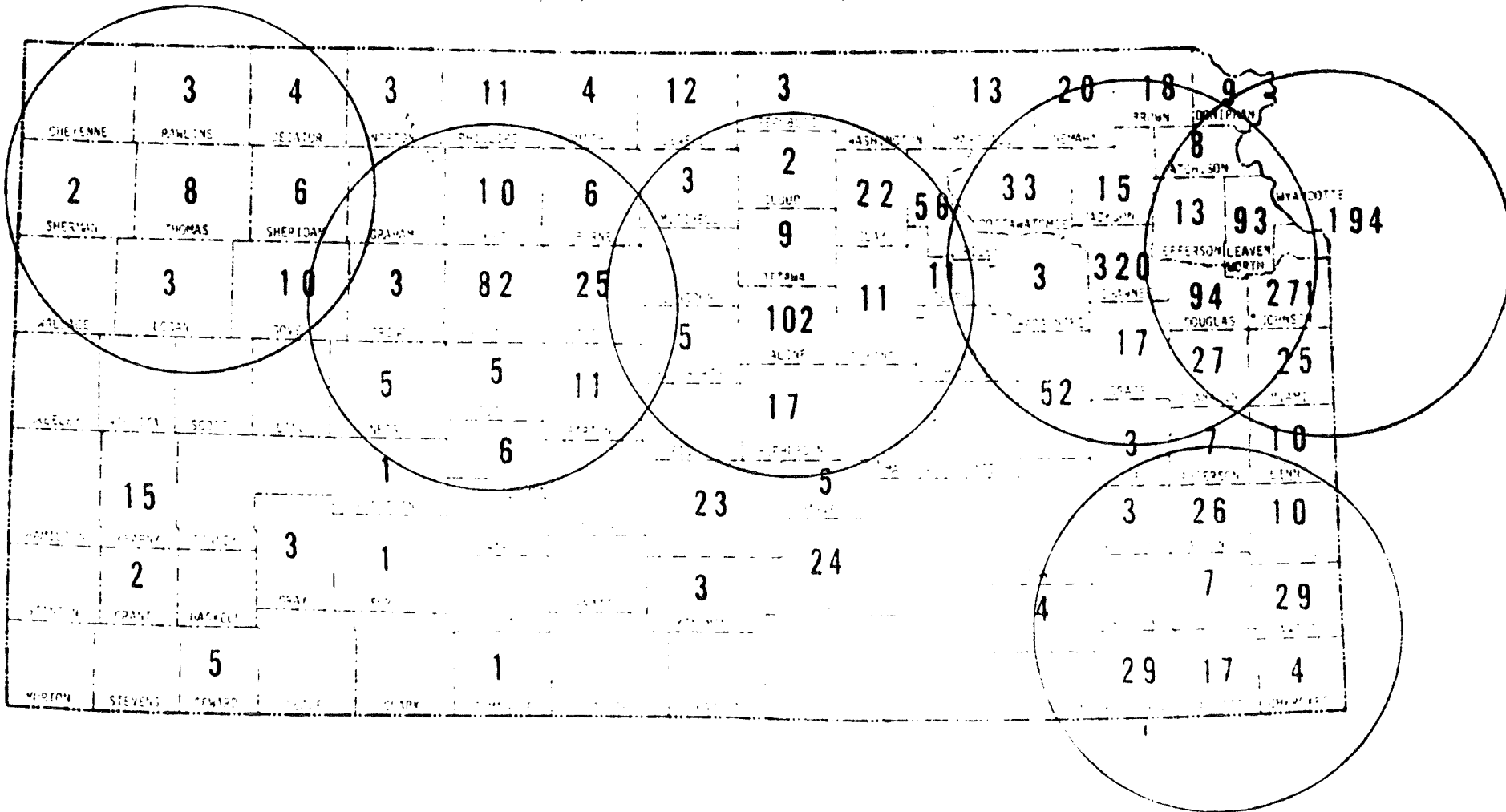
Source: The University of Kansas, Institute for Public Policy and Business Research.

More than 70% of Kansas population and access to private goods is concentrated in this area.

Patients and Family Members Seen For Diagnosis and Counseling

Through Kansas City Based Genetic Service Program

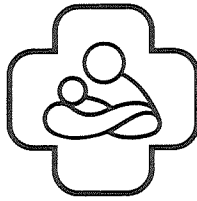
January 1, 1985 - December 31, 1986



Kansas Total = 1,918

CATEGORIES OF GENETIC PATIENTS AND FAMILIES SEEN

<u>DIAGNOSIS NAME</u>	<u>NUM SEEN IN 1986</u>	<u>NUM SEEN IN 1987</u>
ANENCEPHALY, SPINA BIFIDA	10	11
ANESTHESIA PROBLEMS		1
CARDIOVASCULAR AND CONGENITAL HEART DEFECTS	7	4
DOWN SYNDROME	8	8
TRISOMY 18, TRISOMY 13, OTHER TRISOMY	2	5
OTHER AUTOSOMAL ABNORMALITIES	10	7
SEX CHROMOSOMOME ANOMALY/FRAGILE-X SYNDROME	5	4
CLEFT LIP AND/OR PALATE	48	27
CLEFT LIP AND/OR PALATE W/OTHER ANOMALIES	5	12
CONNECTIVE TISSUE/COLLAGEN RELATED DISORDERS	6	11
CRANIOFACIAL, UNUSUAL FACIAL FEATURES/ DYSMORPHIC FACIES	10	12
CYSTIC FIBROSIS	9	9
DEAFNESS/HEARING IMPAIRMENT OR DISORDERS	2	
DEVELOPMENTAL DELAY	2	6
DEVELOPMENTAL DELAY WITH GROWTH DELAY (FTT)/ MENTAL RETARDATION	20	33
DWARFISM/SKELETAL DYSPLASIA	8	7
ENDOCRINE (DIABETES, CONGENITAL ADRENAL HYPOPLASIA, OTHER)	17	14
EYE (BLIND, ANIRIDIA, NYSTAGMUS, CATARACTS, ETC.)	5	5
GASTROENTEROLOGY PROBLEMS	1	
HEMATOLOGY, HEMOPHILIA/COAGULATION DISORDER		1
SICKLE CELL ANEMIA & OTHER HEMOGLOBINOPATHIES	1	3
HUNTINGTON DISEASE	8	9
IMMUNE SYSTEM DISORDERS	3	
KIDNEY ANOMALIES/DISEASE	3	6
LIMB DEFECTS/HAND ANOMALIES	5	11
LYMPH SYSTEM	1	3
MARFAN SYNDROME	6	10
METABOLIC/BIOCHEMICAL/AMINO ACID DISORDERS	3	15
MICROCEPHALY	3	3
MULTIPLE CONGENITAL ANOMALIES (BIRTH DEFECTS, INTERNAL ORGAN PROBLEMS, FACIAL/LIMB ANAMOLIES	29	19
MUSCULAR DYSTROPHY/ATROPHY OR OTHER	29	21
NEUROMUSCULAR DISORDERS		
NEOPLASIA/CANCER SYNDROMES	7	15
NEUROFIBROMATOSIS	14	16
NEUROLOGIC - NOT MR OR MUSCULAR DYSTROPHY	9	12
ORTHOPEDIC - NOT SKELETAL DYSPLASIA	1	1
OSTEOGENESIS IMPERFECTA	2	3
PHENYLKETONURIA (PKU)		1
PREGNANCY LOSS (MISCARRIAGE, STILLBORN)	8	3
PSYCHOLOGICAL & MENTAL ILLNESS	7	
SKIN DISORDERS	12	4
TERATOGENS (DRUG INGESTION, INFECTIONS, MATERNAL DISEASE)	5	5
UROGENITAL ANOMALIES (AMBIGUOUS GENITALIA, ETC)	3	7
GENETIC DIAGNOSIS/CONCERN/RULED OUT	18	14
ONGOING EVALUATION FOR DIAGNOSIS	8	1
OTHER SPECIFIC DIAGNOSIS	2	
TOTAL PATIENTS SEEN IN 1986	362	
TOTAL PATIENTS SEEN IN 1987		359



STATEWIDE GENETIC SERVICE PROGRAM

Wichita Based Programs:

Established in 1978 at The University of Kansas School of Medicine-Wichita

1. Pediatric Genetic Clinic
2. PKU Clinic
3. Inherited Metabolic Disease Clinic
4. Perinatal Genetic Service
5. Cleft Lip & Cleft Palate Clinic (2 sites)
6. Meningomyelocele Clinic
7. KCC Birth Defects Clinic
8. Affiliated Programs & Clinics
 - a. Cerebral Palsy Clinic
 - b. Cystic Fibrosis Clinic
 - c. KCC Orthopedic Clinics
 - d. Muscular Dystrophy Clinic
 - e. Huntington Disease Clinic

Outreach Genetic Clinics:

1. Garden City Genetic Outreach Clinic
at Garden Clinic
2. Parsons Genetic Outreach Clinic
at Labette County Medical Center
3. Great Bend Genetic Outreach Clinic
at Central Kansas Family Practice Group

DIVISION OF PERINATAL MEDICINE

Wesley Medical Center • University of Kansas School of Medicine-Wichita • 550 N. Hillside • (316) 688-2360

State of Kansas Regional Perinatal Care Program

Senate Public Health & Welfare
February 16, 1988
Attachment 3

