

Approved

Date

3/28/88

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE

The meeting was called to order by Marvin L. Littlejohn at
Chairperson

1:30 a.m./p.m. on March 21, 1988 in room 423-S of the Capitol.

All members were present except:

Committee staff present:

Emalene Correll, Research
Bill Wolff, Research
Norman Furse, Revisor
Sue Hill, Committee Secretary

Conferees appearing before the committee:

Adrienne Horner, Volunteer for Epilepsy Foundation and Epilepsy, Ks.
Irene Mason, Epilepsy Foundation Volunteer
Cassie Lauver, Department of Health & Environment/Bureau of Maternal and Child Health
Jean Strickler, Ks. Advocacy & Protective Services, Inc.
Michael Byington, Epilepsy Kansas, Inc.
Representative Jessie Branson
Marlin Rein, University of Kansas Medical Center, Ks. City
Dr. Charles King, University of Kansas Medical Center, Ks. City
Dr. Pat Schloesser, Director/Division of Health/Department of Health and Environment
Dr. Gary Hulett, Under Secretary/Department of Health & Environment
Lila Pasley, Association of Retarded Citizens

Chairman called meeting to order, noting Agenda will be revised for Thursday to include SB 686.

Chair had invited Ms. Mary Ann Gabel, Behavioral Sciences Board to explain to committee the rationale for HB 3032 in respect to their Board.

Ms. Gabel spoke from a balloon copy that had been prepared to include amendments that carry necessary changes for HB 3032. She noted on line 27, the word "education" be inserted after the word "training". She explained the Board is not intending to prevent persons from using tests. (Psychological Tests). Our concerns are, i.e., what they entitle the tests, and how the tests are utilized. To change the wording in Section (f), is intended to convey that. To include, (so long as user does not refer to the tools, tests, instruments, techniques, by incorporating psychological, psychologist or psychology.) By doing this, it wouldn't prevent teachers, personnel administrators from using the tests. It would only prevent those unqualified to practice psychology.

Briefing began on SB 461.

Mr. Furse explained the bill section by section, who would serve on Task Force, length of term served and benefit of information learned by such Task Force.

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE,
room 423-S, Statehouse, at 1:30 // a.m./p.m. on March 21, 1988

Hearings began on SB 461:--

Adrienne Horner, Volunteer of Greater Kansas City Epilepsy League, (Attachment No. 1), spoke in support of SB 461. She related personal experiences as a parent of a daughter who suffers from epilepsy, and problems of her daughters, the need for a support group for help with medical and social problems. She spoke of job discrimination, prejudices, stigma attached to the disease of epilepsy. She urged for support of SB 461.

Irene Mason, Volunteer of Kansas Epilepsy, offered hand-out, (see Attachment No. 2). She cited problems her daughter Melissa had experienced as a result of seizures suffered with having epilepsy. Currently there is insurance coverage, but soon, because of her age, she will be denied that coverage. The only place they have been able to obtain help is through the Kansas City Epilepsy League and a doctor who was willing to take the time to help. She urged for support of SB 461, noting the urgent need. Perhaps others can be helped, where they have been denied help.

Cassie Lauver, Director Crippled/Chronically Ill Children's program, Department of Health and Environment, (Attachment No. 3), spoke in support of SB 461. She noted in Fiscal Year 1987, there were 355 children served at an average cost of \$125.00 per child, with a total cost of \$44,596. SB 461 would mandate the study of the needs of epileptic individuals and those suffering from other seizure-related disorders. Studies to help concerns of insurance needs, job discrimination, educational needs, holding a drivers license, will eventually help those persons affected by these concerns in relation to epilepsy. She answered questions, i.e., yes, there are issues outside the medical realm in connection with those with epilepsy. The Secretary of Health and Environment could appoint key people to this Task Force, and yes, she would encourage in-put from members of this committee as well as from the business community, people who would be aware of persons who might qualify for the Task Force.

Joan Strickler, Kansas Advocacy & Protective Services, Inc., (Attachment No. 4), spoke in support of SB 461. She noted a year ago, their Governing Board took the position that Kansas should study in depth, the issues related to needs of mentally ill, mentally retarded, developmentally disabled and all Kansans with severely disabling conditions. SB 461 would create a 12 member Task Force on epilepsy that could provide information and recommend solutions to needs of this specific population. Some concerns overlap with others who are disabled, but some concerns are uniquely those of persons suffering from epilepsy, i.e., affecting insurance coverage, job discrimination, drivers licenses, teacher understanding effects of medications on learning abilities. She urged for support.

Michael Byington, Epilepsy, Kansas, gave hand-out, (see Attachment No. 5). Epilepsy is a severe problem, he said. There are wonderful scientific breakthroughs, however, these persons have personal concerns, i.e., ability to maintain a stable employment history, increased hospitalizations. There are times when a well meaning person, though not well informed, would call 911 if they witness an epilepsy patient suffering a seizure. Then an un-wanted and un-necessary hospital emergency room visit takes place. This is very costly. He suggested persons who would be asked to serve on the Task Force should be persons who have epilepsy or other seizure related disorders. They would be the best qualified to speak to the concerns felt by this group of people. SB 461 could be the beginning of much needed help for this group of people.

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE,
room 423-S Statehouse, at 1:30 // a.m./p.m. on March 21, 1988

Hearings closed on SB 461:---
Hearings began on SB 570:

Rep. Branson offered hand-out, (Attachment No. 6). She noted she and Senator Ed. Reilly had been asked by Dr. Cho, Wichita, and Dr. Schemke, KUMC to introduce SB 461. Genetic Counseling and diagnostic services are important in the prevention of birth defects and handicapping conditions in the newborn. Such a program provides education to the public and families, provides counseling in regard to these risks of having children. Funding for this program has been Federal funding. She noted Outreach Clinic sites, called attention to fact sheet in her hand-out. SB 570 provides State Legislative direction for a Genetic Services Program, and she urged members to give it favorable consideration. She yielded to other conferees.

Marlin Rein, UKMC, noted for several years now the University of Kansas Medical Center has provided a limited program in Genetic Counseling Services. Federal funding that allowed this program is no longer available, so there now is a need to raise funding through State means. He introduced Dr. Charles King.

Dr. Charles King, Professor in School of Medicine, KUMC, Department of obstetrics and gynecology. He stated 15% of all patients have genetic diseases. There is a need for genetic counseling, educational programs in schools, educators being given information that will benefit the students. There are many exciting changes taking place, and new discoveries being made. Since Federal Funding is no longer available, there is a big void. He feels additional funding is very necessary in order that counseling services can continue. He noted also the importance of the Outreach Clinic programs. He answered numerous questions.

Patricia Schloesser, M.D./ Director of Division of Health, Health & Environment, (Attachment No. 7), noted if Out-reach Clinics can be funded and still made available, both patients and physicians in rural parts of Kansas will not have such long distances to travel for Genetic Counseling Services. SB 570 could provide this funding. She noted the Department of Health and Environment is limited to contracting with the University of Kansas Medical center for these services however. For this reason, their Department would recommend wording changes in lines 69,70,77,78, i.e., "Secretary of H&E shall enter into contracts to provide genetic counseling/diagnostic services, including the operation of outreach clinics and information concerning birth defects and genetic diseases to families in Kansas. Further, she noted language in Section 2, might read, i.e., "Information obtained through the provision of genetic counseling/diagnostic services under section 1, by the Secy. of H&E or contractees, is confidential and shall not be disclosed except as provided in this section". She noted their Department supports the concept of SB 570, but as it is not a part of the Governor's budget recommendations, they cannot support passage of the bill this year. She answered questions.

Dr. Gary Hulett, Under Secretary of Department of Health and Environment also answered questions.

Lila Pasley, Association of Retarded Citizens spoke in support of SB 570. She noted the importance of the Genetic Services to families, especially those living outside the Kansas City and Wichita areas. We want our children to get the best start possible. Our families have a difficult time being reimbursed for Counseling Services, so costs are a great concern. This is important legislation, and she urged for favorable consideration.

Hearings closed on SB 570.

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE,
room 423-S, Statehouse, at 1:30 ~~A.M.~~/p.m. on March 21, 1988

Briefing by Staff on SB 593:-----

Ms. Correll explained SB 593 very comprehensively.

There were no conferees present to speak to SB 593 in person. Senator Ehrlich, sponsor of the bill was unable to present testimony this date.

There was a short discussion in regard to SB 593.

Hearings closed on SB 593.

Vice-Chairman (who had taken over the last 10 minutes or so of meeting), asked wishes of members in regard to SB 593.

Rep. Weimer made a motion to pass SB 593 out favorably, seconded by Rep. Hassler, motion carried.

It was noted, Fiscal Note on HB 2464 had been made available to each committee member, and is indicated as (Attachment No. 8) this date.

Meeting adjourned 3:14 p.m.

My name is Adrienne Horner. I am a resident of Shawnee, Kansas and I am here today as a volunteer representing the Greater Kansas City Epilepsy League, which serves Johnson and Wyandotte Counties in Kansas, and Epilepsy Kansas, located in Wichita. Both of these organizations are affiliates of the Epilepsy Foundation of America, located in Landover, Maryland.

I have a 30 year old daughter who had here first epileptic seizure when she was 13 years old. I would like to take a few minutes of your time to relate some of the experiences of the days when her epilepsy was first diagnosed, and some of the problems she still encounters today.

We were awakened early one morning with a persistent tapping noise coming from our daughter's upstairs bathroom. My husband went to the foot of the stairs and called up to her, but when there was no answer and the tapping noise continued, we went up to see what was happening. She was in the throes of what we now know was a gran mal seizure, although at the time we weren't sure what was happening. Her face was contorted, her eyes were opened and fixed, she had saliva coming from her mouth, and the tapping noises that we had heard were her limbs hitting the floor as a result of the muscle jerks. It was a terrifying thing to see happening to a beautiful young girl, who just the night before had gone to bed a healthy, happy, well adjusted person, with no hint of anything being wrong.

In what seemed like a blur we rushed her to the nearest hospital, Shawnee Mission Medical Center in Overland Park, KS. By the time we arrived she was beginning to come around a little. After a two day stay and numerous tests, we took her to Providence Hospital in Kansas City, Kansas for one more test. From there we brought her home and she returned to school the next day.

Several days later the phone rang and a lady who identified herself as our doctor's nurse said. "Dr. ----- asked me to call and tell you that the tests indicated epilepsy and what drug store do you want the prescription phoned in to?" I gave her the name of

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the drugstore and while I was still trying to absorb this news she said , "We'll call this in now", and CLICK she was gone. I had so many questions, but I was left with the feeling that this was something so terrible and shameful that even my doctor didn't want to discuss it. My daughter was due home from school soon and I knew that she was going to have so many questions that I simply couldn't answer. I remember pacing the floor thinking - how can I help her when I know nothing myself. I wanted very badly to talk to someone who knew something about epilepsy, someone who could advise me as to what I could do to help my daughter through this initial shock. I wanted someone who could sit down and talk to my daughter and explain what was happening - someone who could help ease some of her fears and reinforce her with some positives. I knew next to nothing about epilepsy - there was no family history of it, and no one we had ever known had had it. There was, unfortunately, one thing that I did know. And that was that my very gentle and tender-hearted daughter was going to be hurt by the cruelty and misunderstanding that is directed at those who are thought of as "different" because they have epilepsy.

I can't begin to tell you what a difference it would have made if I had known that an organization such as the Epilepsy League existed. The value of a support group at a time such as this would have been immeasurable. What a difference it would have made if we had been more educated as to epilepsy at that time. What a difference it would have made to my daughter's psychological adjustment if there had been an educational program at my daughter's school.

Fortunately, medication has kept my daughter seizure free. She was a cheerleader in Junior High School, she graduated from Kansas State University, married her college sweetheart, has held down many jobs, and now has a little 3-1/2 year old boy and is expecting her second baby in July. She has led a full and productive life.

Last summer, however, an incident occurred that brought home once more the prejudices and injustices that people with epilepsy face. My daughter had held down a part-time

job for almost a year at a ladies clothing store. She had just changed her medication to a new drug that had fewer side effects and the dosage prescribed was too strong. She began to feel ill at work one evening, explained to her boss that she was on a new prescription, was not feeling well, and asked if she could go home. When her manager asked her what kind of a prescription it was, she explained that she had epilepsy. Her manager acted mortified and screamed, "Why didn't you tell me you had epilepsy? You could have had a seizure right here on the floor in front of the customers!". She let my daughter go home, but from that day forward, her hours were slowly cut back, until she was working only 3 hours a week, and she quit. No - she wasn't fired - they were too smart for that - but there is no doubt that she was forced out.

I urge the formation of the task force to study epilepsy in Kansas. Certainly great strides have been made in the treatment of epilepsy, and at least we can now talk about it openly, but in many ways we are still back in great-great grandma's day in our thinking. There is still so much that needs to be done and the stigma still attached to epilepsy causes many people to withdraw and retreat. We need to reach out, find these people, and let them know help is available. They too can lead full and productive lives.

Thank you.

From: Irene Mason

I am the mother of a 18 year old girl with epilepsy. my daughter, Melissa, went into non-stop seizures, was hospitalized for two weeks and missed three months of school. Melissa has experienced a number of problems related to her seizures. It was difficult to find a doctor to diagnose her seizures correctly. Her former doctor said it wasn't epilepsy. She had more seizures when her current doctor withdrew one of the medications which had been incorrectly prescribed.

She was fired from her part-time job during the time she had the non-stop seizures.

Her personality has changed because of the medications and just dealing with the seizures, and Melissa has lost friends.

Currently my daughter is covered on the father's insurance, but she will be 19 soon and will no longer be eligible to remain on his policy. Medications, lab tests plus hospital expenses are very high, but necessary. We are still paying the 20% not covered for her recent hospital stay.

This year Melissa failed some of her classes due to missing school while in the hospital. She suffered a seizure on a band trip in front of her classmates. This caused personal problems. She doesn't want kids to know about her seizures. Melissa cannot drive until she's seizure free for a year.

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At one point, her doctor thought that she might have a brain tumor. When it was discovered that it was a cyst and not a tumor, the school staff were relieved that it was "just epilepsy."

The only place we've found help and information is through the Kansas City Epilepsy League and through a doctor who was willing to answer our questions.
We need more services in Kansas to meet various needs that I've mentioned.

Please recommend the formation of a Task Force to study these needs and come up with solutions. Thank you.

STATE OF KANSAS



DEPARTMENT OF HEALTH AND ENVIRONMENT

Forbes Field

Topeka, Kansas 66620-0001

Phone (913) 296-1500

Mike Hayden, Governor

Stanley C. Grant, Ph.D., Secretary

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

Testimony Presented to
House Public Health and Welfare Committee

by

The Kansas Department of Health and Environment

SB 461

Services provided to the residents of Kansas under twenty-one years of age through Crippled and Chronically Ill Children's Program (CCICP) focus on prior authorized medical specialty services for those with handicaps. Diagnostic services are available for any individual under the age of twenty-one suspected to have a severe handicap, disability or chronic disease. Treatment services are limited to those individuals with a medically eligible condition and whose families meet the financial guidelines of the program. The medically eligible conditions, method used to determine financial eligibility and other information pertaining to the program activities are found in KAR 28-4-400 through 28-4-408. At this time, the diagnosis of seizures, is medically eligible through CCICP.

Seizures were added to the list of medically eligible conditions in the CCICP program in 1978, but were deleted in 1980 because the budget was insufficient to absorb the cost associated with this coverage. The 1984 legislature appropriated \$30,000 to reinstate seizure services and determine the future need. Legislative intent was that a pediatric seizure clinic be established in Wichita to augment the existing services in Kansas City. In FY 85, additional services were made available. These services included laboratory tests, x rays and medications.

A multidisciplinary team consisting of a pediatric neurologist, psychologist and nurse/coordinator began seeing patients at the University of Kansas School of Medicine-Wichita in December, 1984. Several meetings were held with members of the health care delivery team in Wichita to establish a permanent place for a multidisciplinary clinic. These meetings culminated in the rejection of a contract by St Francis Regional Medical Center in December, 1985. Beginning in the summer of 1986, the

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HB 461

multidisciplinary clinic site was transferred to Dr William Svoboda's private office in Wichita. This clinic is currently held one-half day per month. Payment is made to the team members using a fee per clinic day and to Dr Svoboda for management of the clinic. Other services are available as needed to meet the needs of the individual. Professionals, other than the team members, are paid on a fee for service basis.

In Kansas City, a contract was developed to provide a multidisciplinary clinic which meets two half days per month. The professionals in the clinic include a pediatric neurologist, counselor/educator, social worker and clinic coordinator. Other services are available as needed to meet the needs of the individual. Professionals, other than the team members, are paid on a fee for service basis.

The following table shows the increase in expenditures for the seizure program from FY 85 to FY 87. Factors contributing to the increase in the average amount paid per child included the increased use of magnetic resonance imaging, increase in medical care costs, coverage of medications in FY 86 and FY 87 and the increase in the number of children without any other third-party payment source.

| | FY 85 | FY 86 | FY 87 |
|---------------------------------|---------|----------|----------|
| Unduplicated number of children | 207 | 269 | 355 |
| Total amount of dollars spent | \$9,550 | \$31,008 | \$44,596 |
| Average amount per child | \$46 | \$115 | \$125 |

The Kansas Department of Health and Environment supports this bill which mandates the study of the needs of epileptic individuals and individuals suffering from other seizure-related disorders, resources available to meet these needs and the coordination of available resources. The result of this study would go beyond the medical needs aspect by comprehensively defining the multifaceted needs of this target population. Additionally, it would plan for future coordination and collaboration between the organizations and state agencies delivering a variety of services to and otherwise affecting the lives of individuals with epilepsy and seizure-related disorders.

Testimony presented by Cassie Lauver, ACSW, Director
Crippled and Chronically Ill Children's Program
Kansas Department of Health and Environment

March 21, 1988

Kansas Advocacy & Protective Services, Inc.



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513 Leavenworth
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Chairperson
R. C. (Pete) Loux
Wichita

TO: The House Committee on Public Health and
Welfare
Representative Marvin Littlejohn

Vice Chairperson
Robert Anderson
Ottawa

FROM: Kansas Advocacy and Protective Services, Inc.,
R.C. Loux, Chairperson

Secretary
Neil Benson
El Dorado

RE: SB 461

DATE: March 21, 1988

Treasurer
Robert Epps
Topeka

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Neodesha

Sen. Norma Daniels
Valley Center

Sen. Ross O. Doyen
Concordia

Harold James
Hugoton

James Maag
Topeka

W. Patrick Russell
Topeka

Rep. Jack Shriver
Arkansas City

Raymond L. Spring
Topeka

W. H. Weber
Topeka

Liaison to the Governor
Jose A. de la Torre

Executive Director
Joan Strickler

KAPS assists children and adults with disabilities in gaining access to the rights and services to which they are entitled. We administer two federal programs protection and advocacy as provided for by the Developmental Disabilities Act (PL 94-103 as amended) and the Protection and Advocacy for Mentally Ill Individuals Act (PL 99-319) We also administer the Kansas Guardianship Program, a program funded by and unique to Kansas. KAPS is a private nonprofit corporation with authority to pursue legal, administrative and other appropriate remedies on behalf of the persons it serves. There are 56 similar agencies serving our states and territories.

At its meeting one year ago, our Governing Board took a position that Kansas should study, in depth, the issues related to the needs of mentally ill, mentally retarded, developmentally disabled and all Kansans with severely disabling conditions. The Board noted that it was time for Kansas to develop policies and to make long range plans to guide us now and decades to come.

In its position paper KAPS suggests that existing programs in Kansas and other states be examined and that attention also be given to looking at innovative approaches to meeting needs. Such approaches might include:

- Investigating possible use of existing technology or developing new technology to assist disabled persons to lead more independent lives i.e. rehabilitation engineering.

*attm. #4
3-21-88
PHW*

- Considering volunteerism as it has successfully been implemented through Vista and the Kansas Guardianship Program.
- Pursuing cooperative relationships and shared responsibilities involving the states, local governments, private business, churches and charitable organizations.

SB 461, which would create a 12 member task force on epilepsy and other seizure related disorders, could provide information and recommendations targeted toward the unique needs of that specific population of Kansans with disabilities.

While some issues and concerns affecting persons with epilepsy cross over into other disability areas, some are unique to persons with seizure disorders - affecting insurance, job discrimination, drivers licences and, in education, teacher understanding of effects of medications on learning abilities. As the State addresses the needs of persons with epilepsy and other seizure conditions, and the needs of all persons with severely disabling conditions, it makes sense to study and plan for those needs in ways that will strive for maximal human benefit per dollar expended.

Respectfully submitted,



Joan Strickler

January 21, 1988

TO: Huse Committee on Public Health and Welfare

FROM: Michael J. Byington, Registered Lobby
Epilepsy, Kansas

SUBJECT: Senate Bill 461

I was pleased to have an opportunity to address some of the needs of persons having epilepsy and other seizure related disorders in some depth during the interim consideration of Proposal #30. I now come forward in support of S461.

While I do some voluntary lobbying for Epilepsy - Kansas Inc., I speak here more as a service provider attempting to case manage, and sometimes provide directly, human services to persons having epilepsy or other seizure related disorders. I do these things through my employment as the Advocacy Coordinator for the Topeka Resource Center for the Handicapped.

This bill marks a beginning. Interim studies often result in the conclusion that yet more study is necessary, and this is apparently what happened in the case of this study and subsequent introduction of this bill. The question now to be addressed is that of why it is so important to study this issue, and why it is necessary to develop a special task force just to do so. The answer is found in looking at the State human services structure. There are for almost all other disability groups, specialized human service sections assigned duties with reference to serving and researching services relating to the specific disability in question. Within Rehabilitation Services of S.R.S., there is a special Division of Services for the Blind and a Commission for the Deaf and Hearing Impaired. S.R.S. also has an entire Division committed to serving persons having mental health and/or mental retardation problems. Yet another S.R.S. Division is committed specifically to serving persons having drug and/or alcohol problems. Despite these specializations, there is no special unit, no niche, to address the problems of persons having epilepsy or other seizure related disorders. This results in a situation where information, case management, and service coordination are extremely difficult to bring together.

Epilepsy is a severe problem. Although certainly some wonderful medical breakthroughs have taken place, many persons having epilepsy can not fully control seizures via medication and treatment. These individuals generally have very unstable employment histories and increased hospitalizations.

The proposed task force will not answer any of the concerns listed above. It may, however, be a beginning. It warrants your support and favorable action.

My only concern about the bill is that I certainly feel that a significant number of individuals on the task force should be persons having epilepsy or other seizure related disorders. I am surprised that the bill is not specific to this requirement, but careful appointments should assure a good task force with an adequate number of persons having epilepsy or other seizure related disorders.

*Attm # 5
3-21-88
PH/KW*

JESSIE M. BRANSON
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TOPEKA

HOUSE OF
REPRESENTATIVES

COMMITTEE ASSIGNMENTS
RANKING MINORITY MEMBER: PUBLIC HEALTH AND WELFARE
VICE CHAIRMAN: COMMISSION ON ACCESS TO SERVICES FOR THE MEDICALLY INDIGENT AND THE HOMELESS
MEMBER: EDUCATION
TAXATION
STATE ADVISORY COMMISSION ON SPECIAL EDUCATION

March 21, 1988

TO: Representative Marvin Littlejohn, Chairman
and Members
House Committee on Public Health and Welfare
FROM: Representative Jessie Branson
RE: S.B. 570 -- Genetic Counseling Services

Jessie

A genetics counseling and diagnostic services program is extremely important in the prevention of birth defects and handicapping conditions. Such a program provides education to the public and to families, provides communication with families, and counsels families regarding risk of having children.

The following is a statement regarding the genetic services program in Kansas to date, and attached is a Genetic Fact Sheet.

GENETIC SERVICES PROGRAM OF KANSAS

Purpose: Expand, strengthen and link genetic services through development of outreach clinics, education and common data reporting.

Funding to date: MCH block grant set aside for Special Projects of Regional and National Significance (SPRANS). Final year of a four year funding period, with extension until March 31, 1987.

Type of service provided: Genetic counseling and education activities.

Outreach clinic sites

- Garden City
- Parsons
- Hays
- Salina
- Topeka
- Great Bend

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Education offerings from 6/1/85 through 3/15/86
Kansas City Center - 27
Wichita Center - 16

Attachment: Genetics Fact Sheet

Genetics Fact Sheet

- * All persons are products of genetic inheritance.
- * Interest in recent years has pervaded all aspects of society.
- * Knowledge about human genetics is not new:
Chaldeans, 6000 years ago were aware of heredity
Talmud recognizes that hemophilia affects boys
- * Genetic Services include diagnosis and counseling.
- * Genetic counseling is basically a communication process:
about the disease in question,
the way it is inherited in families,
reproductive and family planning options available,
assisting family to identify personal goals and values, and
assisting family to incorporate the information into their
lifestyle.
- * Genetic services were available at centers in Kansas City and
Wichita and at outreach clinics in Topeka, Salina, Hays, Colby,
Garden City, Parsons, and Pittsburg during the grant period.

1984-1986
Statistics--Comments
Genetics Services Program

- * 4745 Kansans were provided genetic services through grant activities.
- * 10,239 Kansans were present at the genetic counseling sessions.
The 7267 additional Kansans accompanied the 4745
individuals to the genetic counseling sessions.
- * These Kansans were from 103 of the 105 counties in the state.
- * Of the individuals where sex of the individual was noted, more
females (2074) than males (1080) requested the genetic services.

* The following, based on the individuals identified with a race/ethnic background, is the statistics for race/ethnic background.

| | | |
|----------|-------|-----|
| White | 3,062 | 65% |
| Black | 125 | 3% |
| Hispanic | 67 | 1% |
| Others | 62 | 1% |

Data on race/ethnic background is not kept in a consistent format across agencies, thus making it difficult to compare data. The United States Bureau of the Census, 1980 Report, indicates that Blacks made up 5.3% of the Kansas population and whites 91.8%

* The 1986 data shows that 35% of the 688 households identifying their annual income earned less than \$10,000. This is consistent with previous years. Data from the 1980 Census Report indicates that 25% of the Kansas households earned less than \$10,000 annually.

* Education, measured by years of completion, is another factor for which data is accumulated. Thirty-three percent of the identified population in the 1986 data completed high school and 10% had less education for a total of 43% with high school or lower education. In 1984 and 1985 combined data, 35% of the individuals were educated at this level. Data from the 1980 Census Report indicates that 69% of Kansans, over 15 years of age, are high school graduates.

* Individuals with the following conditions have been provided genetic counseling:

- Down syndrome,
- Autosomal Chromosome Abnormality,
- Sex Chromosome Abnormality,
- Developmental/Growth Delay,
- Neural Tube Defect,
- Metabolic Disorder,
- Cleft lip and palate,
- Hemoglobinopathy,
- Muscular Dystrophy,
- Neurofibromatosis,
- Skeletal Abnormality,
- Coagulation Disorder,
- Mental retardation,
- Multiple Congenital Anomalies and
Teratogen Exposure

STATE OF KANSAS



DEPARTMENT OF HEALTH AND ENVIRONMENT

Forbes Field
Topeka, Kansas 66620-0001
Phone (913) 296-1500

Mike Hayden, Governor

Stanley C. Grant, Ph.D., Secretary
Gary K. Hulett, Ph.D., Under Secretary

Testimony Presented to
Committee on Public Health and Welfare
of the House of Representatives

by

The Kansas Department of Health and Environment

SENATE BILL 570

Senate Bill 570 provides for the establishment of genetic counseling and diagnostic services, including the operation of outreach clinics. However, the Department of Health and Environment is limited to contracting with the University of Kansas Medical Center for these services.

The University of Kansas Medical Center would need to contract with the employers of Dr Neil Schimke and Dr Sechin Cho, the only clinical geneticists practicing in this state, to provide services. This situation could dilute the amount of funds spent on genetic services as there is a potential of charging for administrative costs. There would be an additional time lag from the initiation of the contract with the University of Kansas Medical Center to the delivery of services by the clinical geneticists as a subcontract would be required.

For these reasons, we recommend that the name of the agency with which to contract for services be deleted. This would require changes in the wording in lines 0069, 0070, 0077, and 0078. The wording from line 0069 through 0079 would be:

Section 1. The secretary of health and environment shall enter into contracts to provide genetic counseling and diagnostic services, including the operation of outreach clinics and information concerning birth defects and genetic diseases, to families in Kansas.

Section 2. Information obtained through the provision of genetic counseling and diagnostic services under section 1 by the secretary of health and environment or the contractees, or both, is confidential and shall not be disclosed except as provided in this section.

We support the concept of this bill, but SB 570 was not a part of the Governor's budget recommendation. Therefore, we can not support passage of this bill this year.

Presented by: Patricia Schloesser, M.D.
Director, Division of Health

3/21/88

Office Location: Landon State Office Building—900 S.W. Jackson

Attn: #1
3-21-88
P/W

Crippled and Chronically Ill Children's Program

ADMINISTRATIVE OFFICE

Kansas Crippled and Chronically Ill Children's Program
Kansas Department of Health and Environment
Forbes Field, Building 740
Topeka, Kansas 66620-7110
(913) 862-9360, Ext. 455

FIELD OFFICES

Kansas Crippled and Chronically Ill Children's Program
University of Kansas Medical School at Wichita
1010 N. Kansas
Wichita, Kansas 67214-3199
(316) 261-2671

Kansas Crippled and Chronically Ill Children's Program
Kansas University Medical Center
39th and Rainbow, Room 129-CRU
Kansas City, Kansas 66103-2918
(913) 588-6343

The Kansas Crippled and Chronically Ill Children's Program is funded by State and Federal Title V funds.



Kansas Department of Health
and Environment

Forbes Field
Topeka, Kansas 66620-7110
913-862-9360

Jack D. Walker, M.D., Secretary
Mike Hayden, Governor

PURPOSE: To promote the functional skills of young persons in Kansas who have a handicap, disability, or chronic disease.

METHOD: By providing or supporting needed specialty health care.

SERVICES

DIAGNOSTIC services are available, without regard to family income, to all Kansas youth under the age of 21 who are suspected to have a severe handicap, disability, or chronic disease. Prior authorization is required and may be obtained by phone or by letter from program staff.

TREATMENT services include medical specialists, outpatient care, hospitalization, surgery, durable medical equipment, and reimbursement for transportation to medical specialty care. A limited amount of speech therapy is provided for preschool children with severe hearing loss or with cleft palate/cleft lip. A limited amount of rehabilitative physical therapy or occupational therapy is available for youth with severe burns or with eligible orthopedic conditions.

All treatment services must be prior authorized. Conditions that are eligible for treatment include:

- * Spina Bifida
- * Cleft palate/Cleft lip
- * Acquired or congenital heart disease
- * Gastro-intestinal or genito-urinary conditions requiring surgery
- * Burns
- * Major orthopedic problems
- * Genetic and metabolic conditions (PKU, sickle cell, cystic fibrosis, hypothyroidism, galactosemia, hemophilia)
- * Hearing loss
- * Vision disorders
- * Craniofacial anomalies (selected)
- * Seizures

OUTREACH clinics bring specialty diagnosis, consultation, and follow-along care as close to the child's home as possible. Clinics

are conducted for hearing loss, orthopedic conditions, neurological impairments, cardiac diseases, and genetic diseases.

SPECIAL services include counseling and planning for health care needs, developing an individual plan of health care, and follow-along for each person accepted for services. Where CCICP cannot provide the needed health services, an effort is made to identify other resources in the State.

WHO ARE ELIGIBLE FOR TREATMENT SERVICES?

- * Youth who live in Kansas
- * Youth under the age of 21 years
- * Youth with a medical condition covered by the program
- * Persons and families who meet the financial guidelines
- * Kansas residents of any age who have hypothyroidism, sickle cell disease, PKU, cystic fibrosis, galactosemia, or hemophilia

WHAT PART OF THE COST DOES CCICP PAY?

CCICP may pay for all or part of the cost of medical services. Each case is considered individually, and the amount paid is based on family income and the anticipated cost of the health services.

HOW DO YOU APPLY?

Contact one of the listed CCICP offices, any community public health department, or social service departments of major hospitals for information, assistance, or application forms.

Referral may be initiated by any concerned person.

INFORMATION IS NEEDED ABOUT:

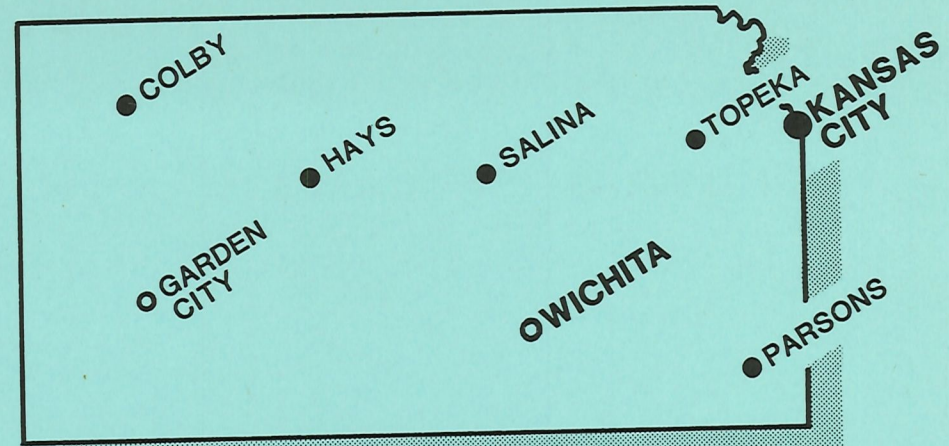
1. Family members.
2. Health insurance.
3. Financial status.
4. The youth's diagnosis or health problem.
5. Names and addresses of doctors and hospitals providing care to the youth who is referred for service.

HOW IS ELIGIBILITY DETERMINED?

Each application is individually reviewed and a decision is made according to guidelines established for financial and medical eligibility. The special needs of the person with the handicap and those of the family are considered as a part of each decision.

APPEAL

The family may appeal a decision to deny or to terminate services. The appeal should be addressed to the Director of the Crippled and Chronically Ill Children's Program, who will review the application information and provide a response. Further appeal may be directed to the Secretary of the Department of Health and Environment.



SATELLITE OUTREACH CLINICS

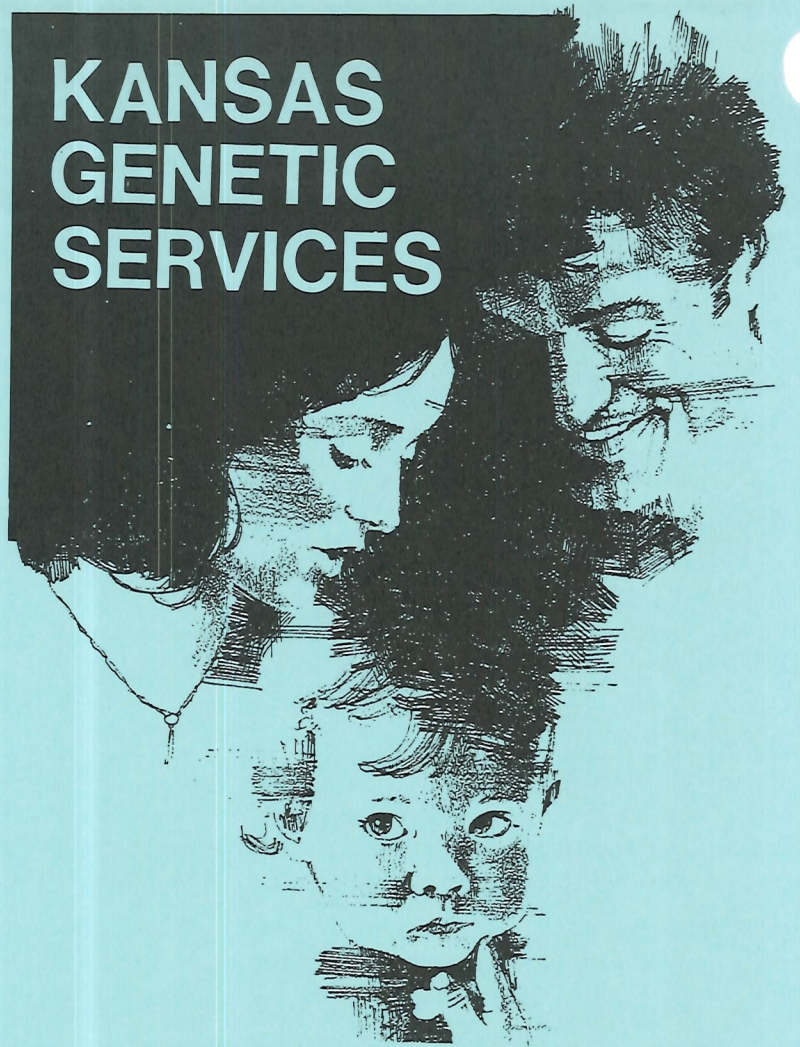
- Topeka (913) 232 - 0957
- Parsons 1-800-362-0390
(316) 421-6550 x227
- Salina (913) 827-9376
- Hays (913) 628-6128 x29
- Colby..... (913) 462-7511 x254
- Garden City (316) 265-3530

- or contact Kansas City office
- or contact Wichita office

Crippled and Chronically Ill Children's Program
 Kansas Department of Health and Environment
 Barbara J. Sabol, Secretary
 Dan Carlin, Governor
 Forbes Field
 Topeka, KS 66620



KANSAS GENETIC SERVICES



FOR PATIENTS CONCERNED ABOUT :

- a hereditary condition in their family
- a child with a birth defect or mental retardation
- women age 35 or over at delivery
- the likelihood of genetic conditions or birth defects in their children

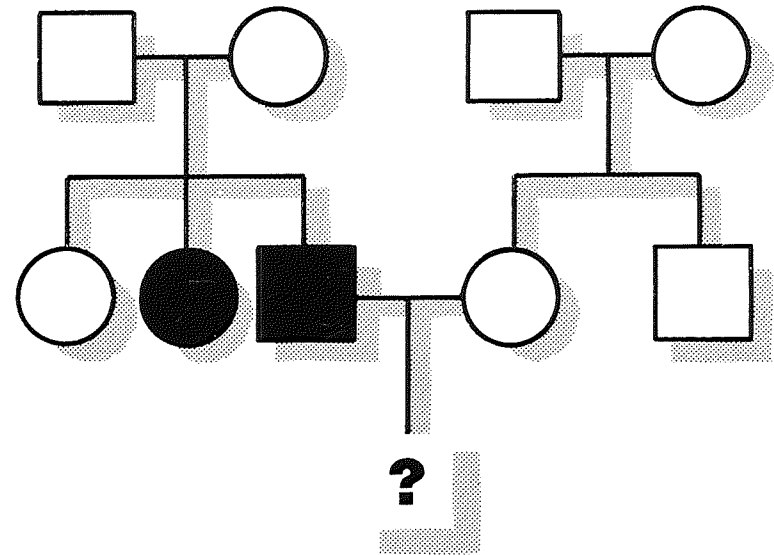
Crippled and Chronically Ill Children's Program
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Forbes Field
Topeka, Kansas 66620

GENETIC COUNSELING CAN HELP THE FAMILY:

- understand the cause of the disorder
- know the chance of future children having the condition
- learn about current research, testing procedures, prenatal diagnosis
- contact community resources and, if possible, other families or patients with the same condition
- adjust to the personal and family issues related to a genetic disorder

WHO MIGHT BENEFIT FROM GENETIC SERVICES?

- Patients or families with congenital anomalies such as cleft lip and/or palate, congenital heart defects, or spina bifida
- Those with diagnoses such as Down syndrome, Huntington disease, cystic fibrosis, muscular dystrophy, and other inherited diseases
- Patients or families with mental retardation, blindness, deafness, short stature (under 4' 10"), or other conditions which might be genetic
- Couples with a history of multiple or repeated spontaneous miscarriages, stillbirths, or early infant deaths with multiple congenital anomalies
- Women age 34 and over who are pregnant or are planning a pregnancy
- Individuals concerned about the effects on a pregnancy of medications, chemicals, infectious agents, or x-rays
- Patients with specific religious, ethnic or geographic backgrounds with a higher incidence of certain disorders



WHAT IS INVOLVED IN GENETIC EVALUATION AND COUNSELING?

- Information collected (family and medical history, family photographs)
- Consultation with other specialists or additional tests, as needed
- Medical evaluation of affected individual
- Explanation of disorder, inheritance pattern, risk of recurrence
- Discussion of options available to deal with the condition
- Follow-up care and treatment planned
- Written summary to primary care physician and family

WHERE ARE SERVICES PROVIDED?

Services are provided through a statewide network which includes the two center sites and six outreach clinic locations.

THE UNIVERSITY OF KANSAS MEDICAL CENTER, KANSAS CITY

Departments of Medicine and Pediatrics

R. Neil Schimke, M.D.

Debra L. Collins, M.S.

Laura L. Thomson, M.S.

(913) 588-6043/6022

or 1-800-332-4199 x6043

Department of Obstetrics and Gynecology

Charles R. King, M.D.

(913) 588-6248 Prenatal diagnosis

THE UNIVERSITY OF KANSAS SCHOOL OF MEDICINE, WICHITA

Department of Pediatrics/Obstetrics and Gynecology

Sechin Cho, M.D.

Bonnie Loewen, R.N.

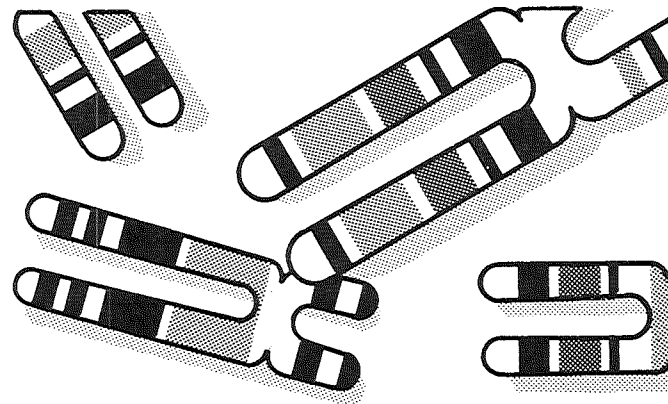
Paula Floyd, M.S.N.

(316) 261-2622 genetic clinic

Wesley Medical Center

(316) 688-2360 prenatal diagnosis and genetics

MIX 1-800-362-0288 x2360



The Genetic Services Program in Kansas is a newly expanded service offered by the University of Kansas Medical Center in cooperation with the Kansas Department of Health and Environment. The services provides families in Kansas with genetic counseling and diagnostic services as well as information about birth defects and genetic diseases. Services are provided at the Medical Center sites in Kansas City and Wichita and at 6 outreach satellite clinics.

HOW COMMON ARE GENETIC DISORDERS?

- 5-7% of all pregnancies result in children with major or minor birth defects, many of which are genetic
- More than 2000 genetic disorders are known, some are rare, others occur more frequently
- One in 200 infants is born with a chromosome abnormality
- 33% of children's admissions to pediatric hospitals are for conditions wholly or partly genetic in origin
- 5-10% of all individuals will develop a genetically related disorder during their lifetimes

Fiscal Note
1988 Session
March 16, 1988

Bill No.

The Honorable Marvin Littlejohn, Chairperson
Committee on Public Health and Welfare
House of Representatives
Third Floor, Statehouse

Dear Representative Littlejohn:

SUBJECT: Revised Fiscal Note for House Bill No. 2464 by Committee on
Public Health and Welfare

In accordance with K.S.A. 75-3715a, the following fiscal note concerning
House Bill No. 2464 is respectfully submitted to your committee.


House Bill No. 2464 creates the Dieticians Licensing Act and requires that a person must be licensed by the Secretary of Health and Environment in order to practice dietetics in Kansas. The bill creates and establishes qualification requirements for a five-member advisory board on dieticians, whose members are to be appointed by the Governor. The Secretary of Health and Environment is authorized to implement the act, including establishment of: a code of ethics; standards to determine the qualifications and fitness of applicants; standards for approval of education programs; procedures for examining license applicants; procedures for receipt and response to complaints; and procedures for issuance, reissuance, revocation, suspension or denial of licenses. Further, the bill establishes basic educational and experience requirements to qualify for a license. In addition to issuance of licenses that will have an effective period of two years, the Secretary also is authorized by the bill to issue provisional permits to practice dietetics. The Secretary is to establish application and renewal fees sufficient to cover the costs of administering the requirements of the bill. All receipts from such fees would be deposited into the State General Fund at least monthly.

The Department of Health and Environment estimates that it would require two new positions--an Administrative Officer II and a Secretary I--and \$91,731 to implement the requirements of House Bill No. 2464 in FY 1989. Of the total, approximately \$47,400 would be for salaries and wages and the remainder, for other operating costs. The FY 1989 amount includes \$25,000 in contractual services to evaluate university educational programs, a cost which would be incurred periodically but not necessarily annually. The entire cost of administering the licensing program would be financed from the State General Fund. However, receipts to the State General Fund would increase by an offsetting amount through collection of application and renewal fees. Because the basic license duration is two years, however, receipts and expenditures would balance over a two-year timeframe and not necessarily annually.

*Attn #8
3-21-88
PAXW*

Any expenditures or receipts resulting from passage of House Bill No. 2464 would be an adjustment to the amounts contained in the FY 1989 Governor's Budget Report.

Sincerely,


Michael F. O'Keefe
Director of the Budget

MFO:JJ:dlf

cc: Dr. Stan Grant, Department of Health and Environment

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