

Approved 3-19-84
Date sh

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 14, 1984 in room 423-S of the Capitol.

All members were present except:

Committee staff present:

Emalene Correll, Research
Bill Wolff, Research
Norm Furse, Revisor
Sue Hill, Secy. to Committee

Conferees appearing before the committee:

Senator Paul Feleciano, Jr.
Mark Adams, a hemophilia patient
Dr. William D. Haire, Medical Advisor Greater Wichita Chapter of National
Hemophilia Foundation & Director of Hertzler Clinic
Mr. Jerry Adams, parent of child with hemophilia
Dr. Virginia Tucker, Dept. of Health and Environment
Dr. Joe Hollowell, Dept. of Health and Environment
Wayne Probasco, Kansas Podiatry Association
Elizabeth Carlson, Bd. of Healing Arts
Dr. Charles Hepford, practicing Podiatrist
Dr. Reid Ecton's printed testimony read by Dr. Hepford.
Dr. Donald A. Mahrle, practicing Podiatrist, and Professor of Podiatry.
Gene Johnson, Ks. Community Alcohol Safety Action Project (ASAP)
Mary Ellen Conlee, Registered Lobbyist for city of Wichita.
Dr. Meredith Moore, Pres. of Bd. of National Council on Alcoholism-Topeka Div.
Chris McKenzie, League of Municipalities
Jane Morrissey, Execu. Dir. of National Council on Alcoholism-Topeka Div.
Naomi Wilson, parent of a child with hemophilia.

Visitor's register, (See Attachment No. 1.)

Chairman called meeting to order, and welcomed Rep. Williams back to committee. He has been ill a few days.
Hearings began on SB 640:--

Senator Feleciano spoke to SB 640, in that he first became aware of several problems facing patients and families of patients of hemophilia. The suffering, and the cost of care, etc. He was asked if there might be some solutions, and he then introduced this bill after doing a great deal of research into this issue. (See Attachment No. 2.), for details. He stressed two points, - one that this is a supplemental program. They are not asking the State of Kansas to pay total medical bills for all hemophiliacs, and the second point, unlike other state assistance programs, this one can actually in the long run pay for itself.

Mark Skinner, a hemophiliac spoke to SB 640. He began with noting some advancements that have been developed, i.e., an antihemophiliac factor (AHF) concentrate. This factor concentrate will temporarily replace the clotting factor which is missing in the hemophiliac. He explained how he is able to maintain necessary treatment supplies, and can work without interrupting his regular daily schedules by treating himself at home. This is called home therapy. He then explained the high costs of medication for patients. He said he feels very fortunate to be in a position where the insurance pays about 80% of his medical costs. Many hemophiliacs are not as fortunate. (See Attachment No. 3.), for details of his comments.

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 14, 1984.

SB 640 hearings continue:--

Dr. William Haire, Director of Hertzler Clinic Hemophilia Diagnostic and Treatment center spoke to SB 640 stating that the bill, if approved, would serve to provide assistance to patients with hemophilia in meeting the costs of their medical care that are not covered by Insurance companies, medicare, medicaid, etc. The advantages of the State of Kansas helping subsidize home therapy for these persons would help relieve them from pain and suffering, probably prevent crippling and disabling, and help them to be employable, allowing them to earn a taxable income and keeping them off public assistance roles, etc. (See Attachment No.4.) for details.

Mr. Jerry Adams, a parent of a hemophiliac, Brian Adams who was also present, and a young friend James Wilson also a homophiliac. Mr. Adams spoke to SB 640 in that it would be of great help to families of these patients. He gave background on the disease in his son, the treatments that are necessary in the treatment of hemophilia. How home therapy is so much better for the patient, if it can be made possible at all. The child can continue to go to school and not have to go into the hospital for infusions and rest, etc. He answered questions about how often are infusions necessary, time involved in administering infusions, etc. He displayed a packet of the medication and equipment that is used for these infusions and explained the substance itself. He answered questions from committee.

Dr. Virginia Tucker, Dept. of Health and Environment spoke to SB 640 in regard to the official position taken by the Dept. of Health and Environment. The bill, if approved would provide for care and provision of blood and blood derivatives to those suffering from hemophilia, in helping pay for this care when the families have exhausted financial coverage from their insurance, medicare, medicaid, etc. The Department of Health will administer the program through the Kansas Crippled and Chronically Ill Children program - Section on Genetics. No additional staff would be needed, and the patients care for in this program would be handled the same as others handled in the KCCIC programs. She recommended that SB 640 be recommended favorably for passage. (See Attachment No.5.), for details.

Dr. Joe Hollowell, Dept. of Health and Environment answered questions of committee along with Dr. Tucker, i.e. differences between von Willebrand's disease, and hemophilia, funding, age limits in programs, etc.

Chair noted we would move on to other bills, and return later in meeting to SB 640 if others choose to add to hearings.

SB 530 hearings began:

Wayne Probasco, Ks. Podiatry Association, spoke to SB 530, from a position paper, (see Attachment No. 6.), for details. He explained the reasons for recommending a one-year postgraduate training or post-graduate study program. The printed statement goes into five points they feel are necessary and urge for approval of SB 530.

Elizabeth Carlson, Board of Healing Arts was approached by the Podiatry Association and they did vote for this broadning of education, requiring a residency to achieve licensure in the state of Kansas.

Dr. Charles Hepford, practicing podiatrist in Topeka read printed testimony for Dr. Reid Ecton in Dr. Ecton's absence. (See Attachment No. 7.), for details. This was a very comprehensive statement stating that SB 530 is an act amending the licensure of podiatrists by adding a requirement of a post-graduate training program to the existing law. Their Association feels this added year of experience would greatly increase the clinical experience of the podiatrist prior to the start of his private practice. This extra year of medical experience will have most of its emphasis on hands-on care of patients.

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE,

room 423, Statehouse, at 1:30 A.M./P.M. on March 14, 1984

SB 530 continues:--

Donald A. Mahrle, practicing podiatrist, and he stated for the last 14 years he has taught in residency training programs. Due to the increase in enrollment in podiatry education, which has grown 40% to 50%, and the clinical resources have maintained the same level, the students that are graduating do not have the hands-on experience as in earlier years. This is so vital a need, so we are asking the residency be increased a year, he said, to serve this need. Good clinical experience where there is supervision is very important for these students, and we feel the bill is necessary. He then answered questions from committee and staff.

Hearings closed on SB 530:--

Hearings began on SB 539:--

Gene Johnson, Kansas Community Alcohol Safety Action Project Coordinator's Association, spoke to SB 539 as a continuation of their support of DWI legislation. It is our belief, he said, that certification of the Community Alcohol and Drug Safety Action Projects should be the responsibility of the Administrative Judge of each Judicial District with the approval of all the Judges within that district. We feel these Safety Action Projects are an extension of the arm of the court, and is only logical that we answer to that court. (See Attachment No. 8.), for details of his comments. (Also see Attachment No. 9. for a letter from Mr. David Gorrell, President of KCADSAP Coordinators Association), for details. Mr. Johnson answered extensive questioning from committee and staff.

Mary Ellen Conlee, City Mgrs. Office, Wichita, Ks., spoke in support of SB 539, and was representing the City Commission of Wichita she said. They feel the municipal courts are indeed an arm of the Courts, and should not have to be serving both the Courts and the SRS. They feel, she said, this is not a treatment program, but a short probation program. We are dealing here, she said, with a person who has violated the DUI law. They believe, she said, the Court must retain control of this process and that SRS licensing would be an unnecessary step in that it would cause undo paper work and unnecessary challenges to the professionals who run the program. She then answered questions from staff and committee.

Dr. Meredith Moore, Bd. of National Council of Alcoholism, spoke to SB 539, in that if the Alcohol Safety Action Project (ASAP) programs can provide the best services for the community, they must have a single organization which sets the standards, evaluates the Agencies abilities to meet those standards, and prohibit an Agency from functioning if those standards are not met. There are many people involved that are victims of alcoholism, and they need people who know about alcohol treatment. She stressed that alcoholism is a disease. Using an analogy, she said that to say that pre-sentencing evaluation is not part of the treatment is to say that a blood test or x-ray is not part of the treatment that a physician would provide. She urged committee to vote no on SB 539. She then answered questions from committee.

Chris McKenzie, League of Municipalities recommended that SB 539 be voted favorable for passage.

Jane Morrissey, Executive Director of National Council on Alcoholism-Topeka Division spoke in opposition to SB 539. She stated that in certifying a community-based ADSAP, the Administrative Judge is required to determine evaluations, supervision and monitoring required under subsection (a), and further follow up evaluations, (see Attachment No. 10.), for details of her statement. Their Association feels the Judges should not be doing this type of evaluation and follow up. Further, they feel all programs delivering alcohol and drug treatment services should meet the same requirements. She urged committee to vote no on SB 539. She then answered questions from committee and staff.

Hearings closed on SB 539.

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 14, 1984

Chair recognized Mrs. Naomi Wilson, a parent of a hemophiliac child, as she had requested a few minutes to make a statement on SB 640.

Hearings continued again on SB 640:--

Mrs. Naomi Wilson stated her son is now able to be on home therapy for treatment of his disease, hemophilia. He now has to miss only about 30 minutes of class against half a day as was the case before he was able to treat himself using home therapy when infusion is necessary. It is their hope, as parents of those suffering from hemophilia, that children born today and beyond today with this disease won't have as many problems as they have gone through and that the children will not have to suffer all the discomforts that her son has had to suffer. She then explained some of the cost factors with medications that are necessary, and in her son's particular situation, the treatment runs about \$150 to \$200 per day. She told of insurance problems. In many cases the insurance benefits simply run out and people then do not know where to turn. She spoke of many of these children also suffer from emotional and nervous disorders when they see their families dealing with financial problems because of the high cost in treating their hemophilia. She then offered to get informational brochures for committee to study.

Hearings closed on SB 640.

Meeting adjourned at 3:10 p.m.

Date: 3/14/84

GUEST REGISTER
HOUSE
PUBLIC HEALTH AND WELFARE

Please Print

NAME	ORGANIZATION	ADDRESS
KEITH R LANDIS	CHRISTIAN SCIENCE COMMITTEE ON PUBLICATIONS FOR KANSAS	TOPEKA
Jill McBride	United Way	Topeka
Elizabeth W CARISON	Bd of Healing ARTS	"
E. A. Hupford, DPM	Kansas Pod. Assn	Topeka
David A. Mahler, DPM	Kans. Pod. Assn	Topeka
Bill & Lois Deem	Kansas Pod. Assn	S. Mo. Hs.
Shirley K. Cox	KAPA	" " "
Wayne Probasco	Kans Podiatry Assn	Topeka
Michael Flyzik	SRS/ABAS	Topeka
Gene Johnson	KC ASAP Coord Assn	Topeka
M. E. Conlee	City of Wichita	Wichita
Pat Rayls	Interested Party	Topeka
Peggy Rayls	" "	Topeka
Diane Bottorff	K SNA	Topeka
Jane Morrison	NCA	Topeka
Berredith Moore	NCA	"

S.B. 640 Senator Paul Fekciano

Attn #2
3-14-84

I FIRST BECAME AWARE OF THIS ISSUE WHEN I MET MR. GERALD ADAMS, WHO IS HERE WITH US TODAY, AND WHO RELAYED TO ME THE SERIOUS FINANCIAL PROBLEMS HE FACES AS A PARENT OF A HEMOPHILIAC CHILD AND WHO ASKED IF ANY LEGISLATION COULD REMEDY THE PROBLEM.

THE AVERAGE COST FOR A HEMOPHILIAC PATIENT PER YEAR IS \$12,000. CURRENTLY, IN KANSAS, THE FAMILIES OF HEMOPHILIACS ARE REQUIRED TO BEAR A LARGE PART OF THAT COST BECAUSE PRIVATE INSURANCE COVERAGE AND MEDICARE/MEDICAID PLANS COVER ONLY A PORTION OF IT. FEW FAMILIES CAN AFFORD SUCH EXPENDITURES IN ONE YEAR LET ALONE ON A YEARLY BASIS.

OTHER STATES HAVE ESTABLISHED PROGRAMS SUCH AS THE ONE PRESENTED HERE. THIS PIECE OF LEGISLATION HAS BEEN MIRRORED AFTER THE MISSOURI "PAYER OF THE LAST RESORT" STATUTE.

CURRENTLY THERE ARE 66 HEMOPHILIA PATIENTS DOCUMENTED IN THE STATE OF KANSAS AS THE EXPERTS I HAVE HERE WITH ME WILL TESTIFY, THE ANNUAL FISCAL COST IS ESTIMATED TO BE BETWEEN \$75,000 - \$100,000.

I WANT TO POINT OUT TWO IMPORTANT POINTS TO THIS BILL AND THEN I WILL LET THESE OTHER PEOPLE SHARE THEIR INFORMATION.

Attn #2
3-14-1984

FIRST, THIS IS A **SUPPLEMENTAL** PROGRAM. IN OTHER WORDS, WE'LL NOT BE ASKING THE STATE OF KANSAS TO PAY THE TOTAL COSTS OF MEDICAL BILLS FOR ALL HEMOPHILIACS. THE STATE OF KANSAS ONLY STEPS IN AND PAYS MONEY **AFTER** PRIVATE INSURANCE COMPANIES AND FEDERAL PROGRAMS HAVE BEEN EXHAUSTED BY THE HEMOPHILIA PATIENT.

SECOND, AND PERHAPS MOST IMPORTANT OF ALL IS THAT, UNLIKE OTHER STATE ASSISTANCE PROGRAMS, THIS ONE CAN ACTUALLY IN THE LONG RUN PAY FOR ITSELF.

IF A HEMOPHILIA CHILD CANNOT AFFORD TO RECEIVE THE MEDICATION NECESSARY TO DEAL WITH A CHILDHOOD BLEEDING INCIDENT, THEN SEVERE DAMAGE IS INCURRED TO THE BODY USUALLY IN THE FORM OF CRIPPLING. A CRIPPLED CHILD GROWS UP TO BE A CRIPPLED ADULT WHO INEVITABLY ENDS UP ON THE STATE WELFARE PROGRAM.

HOWEVER, IF A HEMOPHILIA CHILD DOES RECEIVE THE PROPER "FACTOR 8" MEDICATION WHEN NEEDED, HIS BODY REMAINS HEALTHY AND THE INDIVIDUAL GROWS UP TO BE AN **EMPLOYABLE** ADULT WHO DOES NOT HAVE TO GO ON WELFARE TO SUPPORT HIS FAMILY.

IN SUMMARY THIS IS NOT ONLY A MUCH-NEEDED BILL FOR THE BENEFIT OF HEMOPHILIA'S AND THEIR FAMILIES, BUT IT ALSO MAKES GOOD ECONOMIC SENSE FOR THE STATE OF KANSAS.

PAGE 3

I CAN TAKE QUESTIONS NOW, HOWEVER, I THINK WHAT THE REST OF THE CONFEREES HAVE TO SAY WILL BE EXTREMELY EDUCATIONAL AND INFORMATIVE AND MAY ANSWER ANY QUESTIONS YOU HAVE. IF YOU HAVE FURTHER QUESTIONS AFTER THEY ARE FINISHED, I WILL BE GLAD TO ADDRESS THEM. THANK YOU.

~~Attm #2~~
~~3-11-84~~

Hemophilia Facts

1. Hemophilia is the most common and serious congenital coagulation (inability to clot) disorder of human blood. The coagulation defect is a deficiency of one or more factors required to clot blood.
2. Incidence: 1:10,000 to 1:20,000 population. Translated to the population of Kansas, there should be 60 to 125 cases. At the present time between 61 - 68 have been identified.
3. Types of hemophilia
 - a. Classical hemophilia (Factor VIII deficiency) - most common type - 80% of cases
 - b. Christmas disease (Factor IX deficiency) - 15% of cases
 - c. von Willebrand's disease (Deficiency of platelet adhesiveness and Factor VIII)
4. Genetics
 - a. Both classical hemophilia (Factor VIII deficiency) and Christmas disease (Factor IX deficiency) are sex linked. Only males have the disease. Mothers who carry the abnormal "x" chromosome pass it on to 50% of their male offspring.
 - b. von Willebrand's disease occurs in both males and females. It is considered to have dominant transmission of an abnormal gene. In other words, if either parent gives them the abnormal gene the individual will have the disease.
5. Clinical manifestations -
 - a. Classical hemophilia and Christmas disease
 1. Develop uncontrolled bleeding with trauma into joints, muscle, gums, intracranial, and other organs.
 2. Spontaneous bleeding particularly into joints and muscle
 3. Following treatment may develop contractures of joints or muscle which will require physical therapy or surgery
 - b. von Willebrand's disease is not as severe a disease
 1. Develop nose bleeds, bleeding from gums, oozing from cuts, bleeding into joints
6. Treatment to correct the deficiency is present in the following:
 - a. Factor specific cryoprecipitate
 - b. Factor specific concentrate

~~Attm #2~~

- c. Fresh frozen plasma
 - d. Fresh blood
7. Treatment situations
- a. Patients or parents must be taught early signs and symptoms of bleeding and the need for early treatment.
 - b. Preventive dental care is important. Preceding factor replacement may be required to prevent bleeding.
8. Reason for support of home therapy
- a. Patient can be taught how to give coagulation Factor replacement
 - b. Treatment can be initiated early therefore avoid the serious complications of the hemorrhage
 - c. A Federal grant administered by Children's Mercy and St. Luke's hospital in Kansas City helps with patient training for home therapy but does not pay for purchase of coagulation Factors or infusion supplies
 - d. Since early treatment can be achieved, absenteeism from both school for children and work for adults can be markedly reduced.

Study reported in the New England Journal of Medicine at the University of Rhode Island demonstrated the advantage of institution of a home treatment program compared to cost of hospital admissions, emergency room and walk-in-clinic visits

Table 3. Costs of Hemophilia Treatment

CATEGORY	CONTROL YEAR		PROGRAM YEARS	
	1977	1978	1979	1980
No. of patients in program	23	38	42	43
All hospital admissions (\$)	\$90,834	\$39,149	\$101,755	\$102,798
All admissions for bleeding episodes only (\$)	45,590	12,252	23,260	10,281
Emergency-room and walk-in-clinic visits (\$)	21,152	19,196	4,017	7,867
Total service costs for bleeding episodes only (\$ per patient)	2,902	828	649	422
Total cost of clotting factor, all patients (\$)	158,879	267,497	406,259	317,114
Average cost of clotting factor (\$ per patient)	7,222	7,039	9,673	7,375
Total medical costs (\$ per patient) *	\$11,777	\$8,575	\$12,191	\$9,948

* Costs of all hospital admissions, emergency-room and walk-in-clinic visits, and clotting factor divided by the number of patients in the program.

*Attn. #3
3-14-84*

THANK YOU FOR THE OPPORTUNITY TO ADDRESS THE COMMITTEE. TO DAY I AM HERE AS AN INDIVIDUAL. I AM PLEASED TO HAVE THIS OPPORTUNITY TO SUPPORT SENATE BILL #640. AS SOME OF YOU MAY KNOW I HAVE HEMOPHILIA. THEREFORE, I WOULD LIKE TO TAKE THIS TIME TO SHARE WITH YOU SOME OF MY EXPERIENCES AND THOUGHTS.

DURING MY LIFETIME THERE HAVE BEEN MANY MAJOR ADVANCES IN THE TREATMENT OF HEMOPHILIA. THE MOST NOTABLE ADVANCEMENT HAS BEEN THE DEVELOPMENT OF AN ANTIHEMOPHILIC FACTOR (AHF) CONCENTRATE. THIS FACTOR CONCENTRATE WILL TEMPORARILY REPLACE THE CLOTTING FACTOR WHICH MY BLOOD IS MISSING. WITH THE CONCENTRATES CAME THE HOME-CARE OR SELF-INFUSION PROGRAM. SELF-INFUSION HAS ALLOWED ME TO SHORTEN THE INTERVAL BETWEEN THE ONSET OF HEMORRHAGING AND TREATMENT. ADDITIONALLY, I CAN NOW INFUSE THE MISSING CLOTTING FACTOR AT HOME, SCHOOL, OR WORK WITHOUT INTERRUPTING MY DAILY SCHEDULE TO GO TO THE HOSPITAL OR CLINIC. WITH THIS PROGRAM, I MAINTAIN ALL THE SUPPLIES, EVALUATE TREATMENT, CALCULATE DOSAGES, AND PERFORM THE VENIPUNCTURE. EARLY INFUSION CAN PREVENT COMPLICATED JOINT PROBLEMS AND MINIMIZE PAIN AND SWELLING WHICH ACCOMPANIES THE JOINT AND MUSCLE BLEEDING. FURTHERMORE, EARLY INFUSION CAN REDUCE THE NUMBER OF INFUSIONS NEEDED TO CONTROL A BLEEDING EPISODE.

ONE ASPECT OF HOME THERAPY WHICH IS EXTREMELY IMPORTANT TO A PERSON WITH HEMOPHILIA IS THE COST OF HEALTH CARE. AS YOU CAN GUESS HEALTH INSURANCE IS DIFFICULT TO OBTAIN AT AN AFFORDABLE LEVEL. TO GIVE YOU AN EXAMPLE OF THE COST OF TREATMENT, JUST THIS PAST DECEMBER I HAD SURGERY ON MY RIGHT ELBOW. IF HOME THERAPY AND AHF WOULD HAVE BEEN AVAILABLE WHEN I WAS

*Attn. #3
3-14-1984*

*Attn. #3
3-14-84*

A CHILD, THE DETORINATION OF MY RIGHT ELBOW JOINT WHICH NECESSITATED THE SURGERY, COULD HAVE BEEN AVOIDED. THE PREVENTATIVE CARE AND RAPID TREATMENT AVAILABLE TODAY COULD HAVE PREVENTED THE MANY COMPLICATIONS. FOLLOWING THE SURGERY I WAS DOING HOME THERAPY FOR SEVERAL WEEKS. IN ADDITION TO THE APPROXIMATE 28,000 UNITS OF AHF WHICH I USED IN THE HOSPITAL, I USED ANOTHER 21,000 UNITS DURING FOLLOW-UP HOME THERAPY. EACH UNIT COSTS APPROXIMATELY \$.11/UNIT. $21,000 \times .11 = \$2,300.00$. MY INSURANCE COVERS 80% OF THE COST OF OUTPATIENT DRUG COSTS. THIS STILL LEAVES A SIZABLE AMOUNT TO COME UP WITH AFTER INSURANCE WHEN YOU CONSIDER THAT THE EXPENSE IS NOT A ONE TIME OCCURRENCE, BUT IS CONTINUOUS YEAR AFTER YEAR, THE COSTS MOUNT QUICKLY. I AM FORTUNATE TO BE IN A POSITION WHERE I CAN COME UNDER A GROUP POLICY WHICH ALLOWS FOR PAYMENT OF OUTPATIENT DRUG COSTS, AS MANY DO NOT TODAY, INCLUDING MEDICARE AND MANY BLUE CROSS/BLUE SHIELD POLICIES.

THE HOME THERAPY ALLOWS THE PATIENT AND THE HEALTH CARE INDUSTRY TO AVOID THE COSTS OF REPEATED AND NEEDLESS TRIPS TO THE HOSPITAL TO RECEIVE AN INFUSION. SINCE I RECEIVE MY AHF DIRECTLY, I AVOID PHARMACY COSTS, COSTS FOR MEDICAL PERSONNEL, EMERGENCY ROOM COSTS, REPEATED LAB TESTS, TIME LOST FROM WORK, AND MANY MORE INCIDENTAL COSTS WHICH CAN ADD HUNDREDS OF DOLLARS TO THE COST OF CARE. MANY PATIENTS OF HEMOPHILA ARE NOT AS FORTUNATE AS I. ONE INJURY OR A LONG DISABILITY CAN CAUSE A FINANCIAL CRISIS. MANY PATIENTS REQUIRE DAILY INFUSIONS THROUGHOUT THE YEAR WHICH WOULD INCREASE THEIR COSTS MANY FOLD ABOVE MINE. THAT IS WHERE SB #640 CAN HELP. IT WOULD BE HELPFUL IF THE STATE COULD SERVE AS A CONDUIT TO HELP

*Alt. # 3
3-15-84*

HEMOPHILIA PATIENTS OBTAIN TREATMENT AND THE NECESSARY MEDICINE. NOT ONLY CAN THE COSTS TO THE PATIENT BE REDUCED BUT THE COSTS TO SOCIETY AS A WHOLE, IN A TIME WHEN HEALTH CARE COSTS ARE SKYROCKETING.

FOR THE PAST SEVERAL YEARS I HAVE BEEN PARTICIPATING IN A PROGRAM IN KANSAS CITY, MISSOURI, WHICH WORKS WITH THE MISSOURI PROGRAM WHICH THIS BILL IS PATTERNED AFTER. THE MIDWEST COMPREHENSIVE HEMOPHILIA DIAGNOSTIC AND TREATMENT CENTER PROVIDES A YEARLY ANALYSIS AND DIAGNOSIS FOR CONTINUING RESEARCH AND PATIENT EVALUATION AND EDUCATION. THIS PROGRAM ASSISTS THE PATIENT IN OBTAINING THE NECESSARY TREATMENT AND SUPPLIES. SINCE THIS TYPE OF INFORMATION IS NOT AVAILABLE LOCALLY OR IN KANSAS, I HAVE BEEN FORCED TO GO OUTSIDE THE STATE.

THROUGH THE RESPONSIBILITY WHICH COMES WITH THE HOME THERAPY PROGRAM, I HAVE BECOME MORE KNOWLEDGEABLE ABOUT THE CARE AND TREATMENT OF HEMOPHILIA.

IN CONCLUSION, I WOULD LIKE TO SAY THE HOME THERAPY HAS ALLOWED ME TO BE INDEPENDENT AND CONFIDENT IN THE CARE AND TREATMENT OF MY DISEASE. THE HOME THERAPY PROGRAM HAS ALLOWED ME TO EXERCISE CONTROL OVER MY LIFE AND PARTICIPATE IN A NORMAL LIFESTYLE.

I ENCOURAGE YOUR FAVORABLE CONSIDERATION OF THIS PROPOSAL. I WOULD BE HAPPY TO ANSWER ANY QUESTIONS.

SU
Y
W. WELCH, M.D.
A. DEAN BURNETT, M.D.
GENE E. MARSH, M.D.

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JOHN H. KOHLER, M.D.

HEMATOLOGY
WILLIAM D. HAIRE, M.D.

GASTROENTEROLOGY
KENNETH KIMMEL, M.D.

GYNECOLOGY
COLIN BAILEY, M.D.
H. RANDOLPH WILSON, M.D.

PSYCHIATRY
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DAN MONTGOMERY, M.D.
GARY M. SELTMAN, M.D.
WILLIAM E. PAPINEAU, PH.D.
LORRAINE E. GALLE, M.S.W.
R. L. SIEBERT, M.S.W.

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WILLIAM A. WALKER, M.D.

BUSINESS ADMINISTRATION
JOHN A. POLSON
TERRY L. RHODES
MOYER W. BUNTING

*Attn. #4
3-14-84*

What does this bill provide?

This bill provides assistance to patients with hemophilia in meeting the costs of their medical care that are not covered by other payors (insurance companies, Medicare, Medicaid, etc.).

What items are included in these costs?

With Kansas patients, these items are almost entirely the blood clotting factor, needles, syringes (and other transfusion equipment) and medications necessary for home (outpatient) treatments. Most patients currently have access to other payors for costs incurred with in-hospital treatment.

What is involved in home therapy of hemophilia?

Transfusion of blood clotting factor by the patient or his family immediately after bleeding begins - wherever and whenever this is necessary.

Why would the State of Kansas want to subsidize home therapy of hemophilia?

- 1) The fact that medically, this form of therapy provides more prompt relief of the pain and suffering caused by acute bleeding episodes and delays (and probably prevents) the crippling, disabling and occasionally fatal complications of the only other available alternative - inpatient/hospital based therapy.
- 2) The fact that financially, home therapy generates income for the State.
 - by improving the employability of hemophiliacs, allowing them to earn a taxable income and keeping them off public assistance roles. These two areas alone would probably result in more income to the State than it would cost to subsidize home care (using published national statistics on this aspect of home therapy).
 - by improving rates of hospitalization of hemophiliacs (often paid for by the State if the patient is unemployed).
 - by freeing parents, spouses or other family members to enter the work force and earn taxable income.
- 3) The fact that home therapy can be expensive - often too expensive for private resources alone, even with current rates of insurance coverage. This makes some patients have to forgo home therapy or turn to the State for help.

Respectfully submitted,

William D. Haire MD

Medical Advisor Greater Wichita Chapter of
the National Hemophilia Foundation
Director, Hertzler Clinic Hemophilia Diagnostic
and Treatment Center

*attn. #4
3-14-1984*

TESTIMONY ON SENATE BILL NO. 640

Presented February 23, 1984

Senate Public Health And Welfare Committee

This is the position taken by the Midwest Comprehensive Hemophilia Diagnostic and Treatment Center.

Background Information

The Hemophilias are inherited conditions in which there is a deficiency of a blood protein which is necessary for normal blood clotting. Depending on the severity of the deficiency, patients may have prolonged bleeding from trauma, repeated hemorrhage into joints with normal everyday activity or even have spontaneous bleeding while at rest. The treatment of hemophilia has changed dramatically in the last 20 years. In the early part of this century bed rest and pain control were the only therapeutic modalities available. People affected with hemophilia usually died in childhood or as young adults. Following World War II blood transfusions made replacement of the missing blood protein possible. Patients were hospitalized frequently and for extensive periods to receive large quantities of blood to stop bleeding. Intracranial hemorrhage was the most common cause of death. However, the cycle of bleeding into a joint, developing a thickened joint lining (the synovium), which then led to more bleeding ultimately led to crippling deformities. Prolonged hospitalization led to school absenteeism and failure. Although patients now survived to adulthood they were frequently unemployable, dependent on hospitals for survival, and suffered from low self esteem. The second leading cause of death among hemophiliacs was now suicide.

In 1966, the missing blood protein became available as a factor concentrate. This allowed therapy to be given as an outpatient in doctor's offices and emergency rooms. As more was learned about the use of factor concentrates, families were educated about the disease and proper treatment. This made home therapy a possibility. Home therapy allowed early treatment for

trauma making it possible to delay and even prevent the cycle of bleeding and rebleeding which led to the devastating joint destruction and crippling. Home therapy has been known to create a healthier patient and family. Healthier with respect to musculoskeletal deformities, emotional well being and intellectual development. The improved attendance at school and decreased incidence of brain damage from intracranial hemorrhage brought about by prompt home therapy eventually leads these patients into adulthood as employable contributory members of society. Unfortunately, not all hemophiliacs can afford such home therapy. A state hemophilia program is needed to help with the financial burden.

A Full Hemophilia Program

A complete hemophilia program has the following six components:

1. Identification of patients through a registry.
2. Classification of the patients according to severity.
3. Comprehensive evaluation annually by a Center with expertise in hemophilia. This includes hematologist, orthopedic surgeons, dentists, geneticists, physical therapist, social workers and a nurse specially trained in hemophilia.
4. Education of the patient, family, local physician and medical community to provide day to day care.
5. A home therapy program which provides record keeping, necessary infusion supplies including factor concentrate, education of proper technique, periodic review of performance, and consultation with the Comprehensive Center for the family and local physician.

6. Carrier detection and genetic counseling of sisters and daughters of hemophiliacs.

The Federal Hemophilia Program

The Midwest Comprehensive Hemophilia Diagnostic and Treatment Center has received federal funding to provide comprehensive evaluations for patients with hemophilia from the western half of Missouri and all of Kansas. Funding has been provided for education for home therapy and telephone consultative services for local physicians. A full time nurse specialist trained in hemophilia is funded by this grant. Monies are available for educational symposia throughout the service area. The total amount for these services for Kansas residents is \$35,000 to \$40,000 per year for the present grant. Carrier detection services are also available.

What is needed in a Kansas State Hemophilia Program?

1. The establishment of a registry for Kansas residents with hemophilia.
2. Funding for a home therapy program which will assist patients with expenses of supplies and factor concentrates.
3. Funding for carrier detection and genetic counseling for sisters of hemophiliacs and daughters of hemophiliacs.

Testimony presented by John W. Cullen, M.D.
Co-Director of the Midwest Comprehensive Hemophilia Diagnostic
and Treatment Center

2/23/84

Attn. #5
3-14-84

KANSAS DEPARTMENT OF HEALTH AND ENVIRONMENT

TESTIMONY ON SENATE BILL NO. 640

PRESENTED MARCH 14, 1984

HOUSE PUBLIC HEALTH AND WELFARE COMMITTEE

This is the official position taken by the Kansas Department of Health and Environment:

Senate Bill 640 provides a mechanism for care and provision of blood and blood derivatives to persons suffering from hemophilia, a serious genetically determined deficiency of factors necessary for the coagulation of blood. Males receive the abnormal gene from their mother which results in deficiency of Factor VIII, the coagulation factor responsible for 80% of cases of hemophilia. Deficiency Factor IX, also sex linked in its transmission, and von Willebrand's disease, not sex linked, account for the majority of other hemophilia cases.

In addition to provision of direct care to patients, it promoted educational programs for physicians, dentists, hospitals, public health departments, families of patients and the public concerning the disease of hemophilia, its complications and the efficacy of early treatment and value of home therapy.

Direct support for care, blood, blood derivatives, and concentrates of deficient coagulation factors will be available to patients who have exhausted financial coverage from insurance, medicare, medicaid and other government assistance programs. The Department of Health will administer the program through the Kansas Crippled and Chronically Ill Children (KCCIC) program - Section on Genetics. At the present time KCCIC program provides care for hemophiliacs who have developed orthopedic complications of the disease. The addition of direct case management of care and provision of agents early in the course of the disease could be easily adapted to KCCIC program. No additional staff are needed should the development and treatment costs become available. The patients cared for in this program will be handled the same as others handled in the KCCIC program.

Funding for this bill has not been included in the Governor's budget.

Department's Position:

We recommend that Senate Bill 640 be recommended favorably for passage.

Presented by: Barbara J. Sabol, Secretary
Kansas Department of Health and Environment

Attn. #5
3-14-1984

Attn. # 6
3-14-84

Position of the Kansas Podiatry Association
Relating to Postgraduate Study; Amending K.S.A. 1983
Supp. 65-2003 Repealing the Existing Section

During the last several years members of the KPA have discussed the possibility of requiring one year of postgraduate study before practicing podiatry in the state of Kansas. At the present time a graduate of an accredited podiatry college may enter practice without any formal postgraduate study; however, there are several states that do require a year of postgraduate study before practicing. At the 1983 fall meeting of the KPA, the general membership voted unanimously to add to the existing requirement a one-year postgraduate study requirement. This would require an incoming podiatrist to show that he/she has a minimum of one year of postgraduate podiatry study.

The reasons for recommending a one-year postgraduate training or postgraduate* study program are as follows:

1. To increase clinical experience and competence.
2. To further prepare for the management of podiatric conditions and diseases as they are related to systemic diseases in the lower extremities.
3. To further prepare for the prevention and control of podiatric conditions and diseases.
4. To further prepare for the treatment of conditions with mechanical and rehabilitative methods.
5. To bridge the gap between formal degree training and totally independent practice.

*This most likely will be an APA approved residency program. If a candidate applies for a residency and is unable to get one, but wants to practice in Kansas, the KPA, through the approval of the Board of Healing Arts, would establish a preceptor program sponsored by or supervised by an accredited podiatry college.

Wayne Probasco

Attn. # 6
3-14-1984

KANSAS PODIATRY ASSOCIATION

615 S. TOPEKA AVE., TOPEKA, KANSAS 66603

913-354-7611

*Attn. #7
3-14-84*

Presentation

before the

Health and welfare Committee

on

S.B. 530

Post-graduate study for podiatrists

T. Reid Ecton, D.P.M.
8901 W. 74th
Shawnee Mission, KS 66204

*Attn. #7.
3-14-1984*

Chairman and members of the committee, I am Dr. Reid Ecton , a practicing podiatrist from Shawnee-Mission, Ks. I am here to speak for Senate Bill #530 which is an act amending the licensure of podiatrists, by adding a requirement of a post-graduate training program to the existing law. Podiatry is that profession of the health sciences which deals with the examination, diagnosis, treatment, prevention, and care of conditions and functions of the human foot by mechanical, medical and surgical methods. Podiatrists receive their professional education at one of six Colleges of Podiatric Medicine accredited by the Council on Podiatric Education of the American Podiatry Association. The Council is recognized for this purpose by the U.S. Office of Education and the National Commission on Accrediting. The Colleges are located in Chicago, Cleveland, New York City, Philadelphia, San Francisco, and Des Moines. The Des Moines College is part of the Iowa University of Osteopathic Medicine and Health Sciences. All Colleges award the degree of Doctor of Podiatric Medicine (DPM) to candidates who have successfully completed the formal four year program. All applicants to podiatry schools are required to have completed the Medical College Admissions Test (MCAT). Increasing emphasis is placed on the health of the body as a whole--not the feet alone-- with many of the requirements and electives the same as those offered by medical schools, but with special emphasis on the lower extremity.

The podiatrist shares with the medical doctor, the osteopathic physician, and the dentist the most important characteristic of a member of a health profession: the legal right to make, and act upon his own independent medical judgement. With this right developed the concurrent requirement for regulation to insure the public an appropriate level of competence for these as for all other health professionals. Kansas in addition to requiring specific examination of subject matter, has also required a stipulated number of hours of participation in approved post-graduate programs as a condition for license renewal. These provisions are welcomed, indeed encouraged, by the profession to assure continuing competency of the podiatrist. Along with the privilege of independent practice goes the responsibility to demand well educated practitioners of podiatric medicine. In addition to undergraduate and graduate podiatric education as current requirements of the State Board of Healing Arts law we feel that the addition of a one year clinical experience (residency) should also be required. This one year experience is now required of all medical and osteopathic license applicants. A number of states have seen the reason of this mechanism and have amended their laws to require this clinical year for licensure in podiatric medicine.

This recommendation is based upon several points.

Upon completion of a formal podiatric medical education this

extra year would increase the clinical experience of the podiatrist prior to the establishment of his private practice. This one year training program would further prepare the graduate podiatrist for an awareness of the correlation between foot problems and the general health and well-being of the total patient. This training would allow the resident to increase his independent ability of clinical podiatric conditions and their treatment with the assistance and supervision of teaching and practicing podiatrists and physicians. This extra year of medical experience with most of its emphasis on hands-on care of patients ~~is the~~ would provide experience and training necessary for the exercise of the skills, attitudes, and appropriate judgement required in the professional practice of podiatric medicine and surgery. It is also the bridge between formal academic training and independent practice. Post-graduate residency programs for the podiatrist exist in a growing number of teaching hospitals. Currently there are podiatric residency programs in 136 teaching hospitals in 30 states. in addition, several affiliated Veterans Administration hospitals provide podiatric residency programs. The Council on Podiatric Education sets as its goal for a residency program the following: "Rotating podiatric residency programs shall provide podiatric and medical rotations with a view toward preparing the resident for a position in total community

podiatric health care delivery or entry into advanced education in a special medical area."

This request in increased educational requirements for state licensure is designed to provide a more competent podiatric practitioner in the areas of mechanical, medical and surgical care to meet the 1984 standards of care and needs of Kansans.

Thank you for your attention.

*Attn. #8
3-14-84*

Testimony on S.B. 539

Public Health & Welfare

March 14, 1984

My name is Gene Johnson and I represent the Kansas Community Alcohol Safety Action Project Coordinator's Association. Our membership consists of 27 organizations serving all of the Judicial Districts in the State of Kansas. Our organization meets on a quarterly basis throughout the year to discuss mutual problems and to update our efforts to provide the highest attainable service to the courts and clients we serve.

We support S.B. 539 as a continuation of our successful efforts the past two years in supporting DWI legislation. It is our belief that certification of the Community Alcohol and Drug Safety Action Projects should be the responsibility of the Administrative Judge of each Judicial District with the approval of all the Judges within that district. This allows a great deal of local input into each community's efforts to reduce alcohol related crashes. We must remember, those offenders have admitted to, or been convicted of a very serious crime against our society. That crime being driving under the influence of alcohol and/or drugs. We feel that the Alcohol and Drug Safety Action Projects are an extension of the arm of the court, therefore, it is only logical that we answer to that court.

Our association in the 1983 session supported H.B. 2132 on the basis that each Judicial District would certify the program or programs within their district. We find that a large number of those Judicial Districts have chosen to perform their own certification process.

The reason we are testifying before this committee is that shortly after the legislature adjourned, a request was presented to the Attorney General from the general counsel

*Attn. #8
3-14-1984*

Attn: 8
3-14-84

of Social Rehabilitation Services for an opinion of whether the Alcohol and Drug Safety Action Project was subject to licensing under K.S.A. 65-4001 and 65-4601. This legislation had been passed in the 1972 session. The Attorney General's opinion was that all Alcohol and Drug Safety Action Projects would have to be licensed regardless of whether the Administrative Judge had already granted them a certification. This opinion set aside most of the objectives that were contained in Sub. H.B. 2132 which passed by a large majority last session.

Now, based on this opinion, all Alcohol and Drug Safety Action Projects must be certified by either the Administrative Judge or the Secretary of Social Rehabilitation Services and licensed by the Secretary of Social Rehabilitation Services. We do not believe that it was the intent of the legislature to require both certification and licensing of these programs.

Our membership supports the passage of S.B. 539 unanimously in our continuing efforts to stop the murder and mayhem on our streets and highways by the drinking driver.

Thank you.

Respectfully,


Gene Johnson

ASAP

*Attn. #9
3-14-84*



ALCOHOL SAFETY ACTION PROJECT

TO ASSIST IN REDUCING ALCOHOL-RELATED ACCIDENTS
Telephone: 316-232-9100 • 104 West 4th • Pittsburg, Kansas 66762 • Home Office
Telephone: 316-331-7638 • 311 East Main • Independence, Kansas 67301
Telephone: 316-431-4060 • Memorial Building • Chanute, Kansas 66720

RICHARD D. LOFFSWOLD
Administrative Judge
Project Director

E. DAVID GORRELL C.A.C.
Coordinator

BARRY A. HEITMAN
Coordinator

March 9, 1984

The Honorable Marvin L. Littlejohn
Chairperson
Public Health & Welfare Committee
Kansas House of Representatives
Room 422-S
State Capitol Building
Topeka, Kansas 66612

Dear Representative Littlejohn:

SUBJECT; Senate Bill #539

As President of the Kansas Community ADSAP Coordinators Association representing ADSAP Programs throughout the State of Kansas, I am writing to express KCADSAP's support for Senate Bill #539.

This bill, which incidentally was favored with a 40-0 passage vote in the Senate, will exempt community-based ADSAP Programs certified under K.S.A. 8-1008 and amendments thereto from licensing under the alcoholism and intoxication treatment statutes namely K.S.A. 1983 Supp. 65-4003.

Your statewide ADSAP Programs are dedicated to reducing alcohol related accidents and removing the drinking driver from our streets and highways. This has been and is a tremendous challenge and undertaking. We have made noticeable strides toward these goals under "local control".

The individuals we service have violated the laws of the State of Kansas and must atone for that indiscretion as provided for by the Kansas Statutes. We are not in place to coddle people but instead strive to prevent future violations that can and may cause death.

*Attn. #9
3-14-1984*



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Bill #539

The Kansas Community ADSAP Programs are by legislative intent, responsive to the needs of Kansas Courts and were never intended to replace the alcohol and drug abuse counseling services as offered by most mental health centers.

We submit that licensure by ADAS/SRS is not necessary and constitutes an unnecessary burden upon the ADSAP Programs. We happen to believe that Kansas Administrative Judges are quite capable of providing all guidance and supervision necessary for ADSAP Programs.

PLEASE REMOVE ADSAP FROM ADAS/SRS LICENSING.

Yours very truly,

E. David Gorrell, C.A.C.
President
KCADSAP Coordinators Association

EDG/pr

cc: Mr. Gene Johnson
KCADSAP Legislative Coordinator

*Attn # 10
3-14-84*

Testimony before Public Health
and Welfare Committee
March 14, 1984

Jane Morrissey -

I am the Executive Director of the National Council on Alcoholism--Topeka Division. I am here to oppose S.B. 539.

As you weigh the pro's and con's of this issue, I would like you to consider these facts.

Pursuant to K.S.A. 8-1008, as amended by 1983 Substitute for House Bill 2132, community-based alcohol and drug safety action programs are authorized to perform a variety of services relating to persons who have been arrested for the offense of driving while under the influence of alcohol. These services include pre-sentence evaluations of persons who had been convicted of a violation of K.S.A. 8-1567, supervision of such persons following their sentencing, and if they were required to complete an ADSAP or an abuse treatment program, or any combination of such services.

*Attn # 10
3-14-1984*

Under sub-section C, pre-sentence evaluation is addressed specifically, and

I quote:

"The pre-sentence alcohol and drug evaluation report shall contain an evaluation concerning the defendant's prior traffic record, characteristics and history of alcohol or drug problems, and the amenability of the defendant to education and rehabilitation. The pre-sentence alcohol and drug evaluation report shall include a recommendation concerning the alcohol and drug driving safety education and treatment for the defendant. The pre-sentence alcohol and drug evaluation report shall be prepared by a program which has demonstrated practical experience in the diagnosis of alcohol and drug abuse."

In order to perform this evaluation, the agency delivering the service delivers a treatment service as defined by K.S.A. 1982 Supp. 30-31-2, quote:

"diagnostic and referral services to persons who have a present or past history of alcohol or drug abuse. The services are provided through the provision of medical, dependency, social, and psychological assessments and the development of a plan to provide those services."

Pre-sentence evaluations are crucial in making the best possible recommendation for the defendant, and certainly are a part of the alcohol treatment care continuum.

In our agency in 1983, 913 people who were convicted or pled guilty to DWI, were evaluated. Out of those 913 clients, 233 of those evaluated were diagnosed as suffering from the illness of alcoholism. 240 of those evaluated were diagnosed as problem drinkers.

Alcoholism is a disease and has set symptomology. One of the symptoms is denial. 90% of those diagnosed were not obvious alcoholics or problem drinkers.

Our agency also saw 440 people referred to our ADSAP programs who were diagnosed social drinkers. These people under law participated in an alcohol information school.

In certifying a community-based ADSAP, the administrative judge is required to determine that the program is capable of providing the following:

"(1) The evaluations, supervision and monitoring required under subsection (a); (2) the alcohol and drug evaluation report required under subsection (c) or (d); (3) the follow-up

duties specified under subsection (c) or (d) for persons who prepare the alcohol and drug evaluation report; and (4) any other functions and duties specified by law." (K.S.A.8-1008(b)."

The statute contains no other requirements, either as to the qualifications of the individuals running the program or the facilities or procedures employed in any education or treatment activities.

The argument has been offered that these are court programs and that the courts should be allowed to run them. The fact is that three programs in the state of Kansas are "court programs." These are located in Overland Park and Wichita. The rest of the ADSAP programs are operated out of mental health agencies, local alcohol and drug councils, and, in a few cases, some free-standing, single-purpose agencies who contract with the courts to perform services for the court.

In summation, all of us in the alcoholism prevention, education, and treatment services feel strongly that a priority is a high quality of services be provided to citizens of Kansas who have alcohol or other drug problems. In order to deliver quality services, all the programs delivering alcohol and drug services must meet the same requirements. State licensure provides the opportunity for us not only to strive for, but to meet, uniform standards of operation.

I urge you to vote NO on S.B. 539.