

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE

The meeting was called to order by Senator Jan Meyers at
Chairperson

10 a.m. ~~pm~~ on February 23, 1984 in room 526-S of the Capitol.

All members were present ~~except~~:

Committee staff present:

Emalene Correll, Legislative Research Department
Bill Wolff, Legislative Research Department
Norman Furse, Revisor of Statutes office

Conferees appearing before the committee:

Senator Paul Feliciano
Mark Skinner, Administrative Assistant to Senator Paul Hess
Dr. John Cullen, Co-Director of Midwest Comprehensive Diagnostic and
Treatment Center, Bonner Springs
Dr. William Haire, Director, Hertzler Clinic, Halstead
Gerald Adams
Greg Stevens
Barbara Sabol, Secretary, DH&E

Others present: see attached list

SB 640 - Program for treatment of Hemophilia

Senator Paul Feliciano testified in support of SB 640, and stated that unlike most state assisted programs, this one can go on paying for itself, and is a much needed bill, not only for the benefit of hemophiliacs and their families, but it makes good sense for the State of Kansas. Senator Feliciano introduced Mark Skinner, Administrative Assistant to Senator Paul Hess, who testified in support of the bill.

Mr. Skinner distributed testimony to the committee stating that he was a hemophiliac and related some of his experiences and thoughts. He said that the most notable advancement in treatment has been the development of an Anti-Hemophiliac Factor (AHF) Concentrate. This Factor Concentrate temporarily replaces the clotting factor in blood, and he can now infuse the missing clotting factor any time, without interrupting his daily schedule to go to a hospital or clinic. One aspect of home therapy which is extremely important is the cost of health care, as insurance is difficult to obtain at an affordable level. 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. Mr. Skinner related his participation in a program in Kansas City, Missouri. The Midwest Comprehensive Hemophilia Diagnostic and Treatment Center provides yearly analysis and diagnosis, and assists the patient in obtaining the necessary treatment and supplies. Mr. Skinner stressed that it would be helpful if the state could serve as a conduit to help hemophilia patients obtain treatment and necessary medicine, without going outside the state, and said the home therapy program has allowed him to exercise control over his life and participate in a normal lifestyle. (Attachment #1).

Dr. John Cullen, Co-Director of the Midwest Comprehensive Diagnostic and Treatment Center, Bonner Springs, testified in support of SB 640, and outlined what they offer patients in Kansas, where the program has deficits, and why they are asking for assistance. He stated that hemophilia is an inherited condition in which there is a deficiency of protein within the blood. The task of the protein is to help clot the blood, and the severity of the deficiency is what determines the severity of the patient. Dr. Cullen said three areas where they need assistance in funding are: home therapy, carrier detection, and a registry of patients.

CONTINUATION SHEET

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE,
room 526-S, Statehouse, at 10 a.m.~~xxx~~ on February 23, 1984

Dr. William Haire, Director, Hertzler Clinic, Halstead, testified in support of SB 640, and stated that Medicare and Medicaid do not cover hemophilia, and coverage by Blue Cross-Blue Shield depends upon the individual contract.

Gerald Adams testified in support of SB 640. He stated that his son is a hemophiliac and related some of his experiences.

Greg Stevens testified in support of SB 640. He stated that he is a hemophiliac and cited examples of his problems with care and the cost of medical care.

Barbara Sabol, Dh&E, testified in support of SB 640, and distributed testimony stating that this bill provides direct financial assistance for development and provisions of health care of persons with hemophilia. DH&E suggested certain technical clarifications, and recommended that the patients cared for in this program be handled the same way as others in the Crippled and Chronically Ill Children's Program are handled. (Attachment #2). There was discussion concerning funding of the program, and Secretary Sabol felt that to fully implement the provisions of this bill would cost between \$75,000 and \$100,000, based on the type of services set out.

SB 623 - Requiring certain treatment information be given to patients suffering breast cancer

Senator Meyers briefly outlined the bill and said Senator Francisco had expressed concern about not being able to get information about doctors who may be impaired while continuing to practice, and he had submitted an amendment stating "the licensee shall submit to the Board a release of information authorizing the Board of Healing Arts to obtain a report of such examination".

Senator Johnston moved that this amendment be adopted. Senator Ehrlich seconded the motion and it carried.

Senator Johnston moved that SB 623 be reported favorably, as amended. Senator Ehrlich seconded the motion and it carried.

SB 658 - Issuance of marriage license, eliminating waiting period and establishing time limit for use of license

Senator Ehrlich moved that SB 658 be reported favorably. Senator Hayden seconded the motion. The motion failed.

Senator Bogina moved that SB 658 be amended by striking the removal of the 3-day waiting period, and leaving in the other factors. Senator Chaney seconded the motion. The motion carried.

Senator Johnston moved that SB 658 be reported favorably, as amended. Senator Ehrlich seconded the motion and it carried.

The meeting was adjourned.

SENATE
PUBLIC HEALTH AND WELFARE COMMITTEE

DATE 2-23-84

(PLEASE PRINT)
NAME AND ADDRESS

KETHN R LANDIS

Jim McBride

Janet Reinsel

Virginia L. Tucker, M.D.

Paul Adams

Sophie George

Marilyn Adams

Brian Adams

Paul Adams

GREG STEVENS

William D. Haive

KAREN McCLAIN

Sandy Kasse

Don Stute

JOHN CULLEN M.D.

PAT SCHAFFER

Marilyn Bradt

Deane Bottorff

John Stahl

John Stahl

Leggy Kaye

Inoague Hughes

Carl Reimithanner

M. Hoover

JOE HOLLOWELL

ORGANIZATION

CHRISTIAN SCIENCE COMMITTEE
ON PUBLICATIONS FOR KANSAS

United Way of Topeka

Washburn Univer Nsg School

KDHE

Senator Hays

Senator Silcove

Greater Wichita Chapter ^{Natl Hemophilia} _{Foundation}

GREATER WICHITA CHAPTER ^{NATL. HEMO.} _{FOUNDATION}

Hertzler Clinic (Imp. Hemophilia Center)

Wich. Chap. Nat'l Hemophilia

SEN. FELECIANO'S LEG, INTERN

PTLN

Bd of Health, Art

FEDERAL HEMOPHILIA CENTER

CHILDREN'S MERCY HOSP.
BUDGET

KINH

KSNA

KDHE

KAPS

Mother of son with Hemophilia

private citizen

Ks Dental Assn

Topeka Central Hospital
KDHE Topeka

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 HEMORAHAGING 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 VENI-PUNCTURE. 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 TREAT-MAENT, JUST THIS PAST DECEMBER I HAD SURGERY ON MY RIGHT ELBOW. IF HOME THERAPY AND AHF WOULD HAVE BEEN AVAILABLE WHEN I WAS

Alch. 1

A CHILD, THE DETORINATION OF MY RIGHT ELBOW JOINT WHICH NECESS-
ITATED 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 IN-
SURANCE 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 IN-
DUSTRY 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 FOR-
TUNATE AS ME. 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

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.

KANSAS DEPARTMENT OF HEALTH AND ENVIRONMENT

TESTIMONY ON SENATE BILL NO. 640

PRESENTED FEBRUARY 23, 1984

SENATE PUBLIC HEALTH AND WELFARE COMMITTEE

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

Background Information:

Senate Bill 640 provides direct financial assistance for development and provisions of health care for persons with hemophilia. You will hear much today about the problems of hemophilia, and the potential for preventing many of the handicapping physical and mental complications of this disease. The cost of adequate care is high and can be a serious burden to many families. It becomes extremely important to assure to persons with hemophilia that a statewide program exists to support the various needs of patients who do not have other sources of support. This bill uses state resources in addition to private and federal resources to accomplish that.

The Department of Health and Environment will administer this program and plan to assign that responsibility to the Crippled and Chronically Ill Children's Program - Section on Genetics. The case management procedures used by the Crippled and Chronically Ill Children's Program could be easily adapted to administer the hemophilia program.

It is our understanding that certain technical clarifications are being considered:

- 1. Secretary of the Department of Health and Environment should be used rather than Director of Health throughout the bill.
- 2. Strike "and private charitable assistance programs" in line 0034 and "and private and charitable assistance programs", in line 0039.
- 3. Stroke beginning with "or participate" line 0050 through "hemophiliac patients" in line 0053.

There should be rule making authority. Funding for this bill has not been included in the Governor's budget; however, no additional staff needed should the development and treatment costs become available. We would recommend that the patients cared for in this program be handled the same way as others in the Crippled and Chronically Ill Children's Program are handled.

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