Approved: 20-16,1998

MINUTES OF THE Senate Committee on Financial Institutions and Insurance.

The meeting was called to order by Chairperson Don Steffes at 9:00 a.m. on February 10, 1998 in Room 529-S of the Capitol.

All members were present except:

Committee staff present: Dr. William Wolff, Legislative Research Department

Fred Carman, Revisor of Statutes Nikki Feuerborn, Committee Secretary

Mary Ellen O'Brien Wright, Assistive Technology of KS Conferees appearing before the committee:

Jan Naegele, Topeka

Dorothy E. Nary, Lawrence

Jerry Dalstrom, 10th Street Medical, Topeka

Nora Manier, Parsons Nancy Ruoff, Topeka

Ron Hein, American Diabetes Assoc, KS Dietetic Assoc

Robyn Parker, KSNA Marty Glenn, KS Dietetic Assoc. Bob Williams, KS Pharmacists Assoc. Pat Hohman, Diabetes Educator

Representative Becker moved that the minutes of the January 27, and February 2, 3, 4, and 5 meetings be approved. Motion was seconded by Senator Brownlee. Motion carried.

Hearing on SB 509-- Insuring durable medical equipment

Mary Ellen O'Brien Wright, appearing for Assistive Technology of Kansas, asked for the bill which would establish a minimum that health insurance companies must pay annually per individual for durable medical equipment, define durable medical equipment more broadly, and provide power equipment when appropriate (Attachment 1).

Jan Naegele appeared with her daughter Linds who is a nonverbal Cerebral Palsey child before the Committee. She related the expenses associated with her physical disabilities which include physical therapy, occupational and functional therapy, and the purchase of equipment which allow her mobility (Attachment 2). She told of their experiences with an insurance company who limited payment to nonpower wheel chairs, authorized only partial payment for an epson communication device, and denied payment for a full sized van as well as other equipment which was prescribed as necessary for Linds.

Dot Nary, Lawrence, appeared as an individual who has been in a wheelchair for the past ten years and as an advocate for other disabled persons (Attachment 3). She asked that equipment be broadly defined in terms of function for insurance purposes, that policy limits reflect the actual costs of such equipment, and that the decision regarding necessity and type of equipment be made by the patient/health care provider team rather than an insurance administrator or clerk.

Jerry Dahlstrom, owner of Tenth Street Medical Inc., explained the difficulty of providing the right kind of equipment necessary for some patients when a request for such equipment e.g. seating system is denied by an insurance company (Attachment 4) He described some of the 237 steps involved in building such a system for persons who spend 18 hours or more a day in a wheel chair. The cost for this system is \$4,300, lasts about three years, and should be considered as durable medical equipment by insurance companies. The use of such a system prevents pressure problems which result in back, spine, pelvic, and skin injuries.

Nora Manier, Parsons, spoke on behalf of her daughter Jessica who was born with O.I. (brittle bone disease) and has spent her life in a wheel chair (Attachment 5). The cost of her latest power wheel chair has risen to a current cost of \$16,000 of which Blue Select agreed to pay \$2,500 if there was a prescription ordered by her physician. Blue Select did not pay the agreed amount and the total amount was raised through donations and fund raisers at the local level and contributions from United Cerebral Palsy of Kansas, Kansas Society for Crippled Children, St. Francis Foundation, Disabled Children Relief Fund, and the Children's Miracle

## CONTINUATION SHEET

MINUTES OF THE Senate Committee on Financial Institutions & Insurance, Room 529-S Statehouse, on February 10, 1997.

Network. Mrs. Manier said she has spoken before many groups through the years in an effort to provide power chairs to allow mobility for her 14 year old daughter.

Nancy Ruoff of Topeka described the spina bifida condition her son Joshua was born with and the problems which have ensued with inadequate health insurance coverage (Attachment 6). Even though their physician recommened Therapeutic Electrical Stimulation which is used to stimulate and develop muscle strength and growth, the insurance company refused at first to cover the therapy, they eventually offered the parents the alternatives of either waiting a year for the regular DME allowance or paying for the therapy at their own expense. The on-going battles with the insurance company over prescribed treatments by specialists were reviewed. Mrs. Ruoff pleaded with the Committee to make it possible for people with disabilities to take advantage of the latest technology in order to make their lives more productive.

Written testimony was received from:

Marcelle R. Shrake, 1916 SW Wayne Avenue, Topeka (Attachment 7).

Steven and Kristen Cooper, 1424 N. Westfield Ct., Wichita (Attachment 8)

Jane Rhys, Ph.D., Executive Director of Kansas Council on Developmental Disabilities (Attachment 9).

Donna Stevenson, Community Services Director of Community Action, Inc. (Attachment 10).

Jennifer Schwartz, 3004 West 30th Court, Lawrence (Attachment 11)

Sharon Huffman, Commission on Disability Concerns, DHR (Attachment 12)

Jeff Drake, 7901 West 91st Terrace, Overland Park (Attachment 13) Glen W. White, Ph.D., 416 Nancy Court, Lawrence (Attachment 14)

Josie Torrez, Families Together, Inc., Topeka (Attachment 15)

Shannon M. Jones, Statewide Independent Living Council of Kansas, Topeka (Attachment 16)

Michael Byington, Director, Envision Governmental Affairs Office, Topeka (Attachment 17) Steve Richardson, Topeka Independent Living Resources Center, (Attachment 18)

The hearing was continued. The opponents to the bill will be heard on Monday, February 16, 1998.

Hearing on SB 386--Insurance coverage for diabetes

Ron Hein, legislative counsel for the American Diabetes Association and the Dietetic Association of Kansas, spoke on behalf of the organizations he represents and for himself as a diagnosed diabetic for 18 years (Attachment 19). He explained that this bill would require health insurance companies to offer first dollar reimbursement for diabetes self-management supplies and education. Diabetes nationwide accounts for one of every seven healthcare dollars spent costing \$138 billion annually. The management of the disease is based upon up front knowledge and control through education. Mr. Hein stated that insurance executives need to be educated about diabetes. Even though with the passage of this needed legislation there would be a slight increase on the front end, health costs could be dramatically reduced in the future.

Robyn Parker, Kansas State Nurses Association, informed the Committee that there has been an increase of 50% in dollars spent on diabetes and related complications in the past five years (Attachment 20). She stated that only preventive treatment can improve the quality of life for diabetes patients and substantially reduce health care costs. There is no cure for the disease, only management. She read from a letter prepared by Dr. James A. Mack of Wichita which explained some of the procedures diabetics must use in the management of their disease.

Marty Glenn, Co-Chair for Legislative Affairs of the Kansas Dietetic Association, spoke from a dietitians viewpoint on the management of diabetes (Attachment 21). He related the number of health problems that occur due to the lack of nutritional education provided to diabetics and how their lives could be improved with the proper prevention.

Bob Williams, Kansas Pharmacists Association, spoke on the necessity of an entire health team being involved in the education and treatment process of diabetes under health insurance coverage (Attachment 22). Many states have already passed such legislation or are investigating the need for such mandates.

Patricia Hohman, a registered nurse with a Masters Degree in nursing and a certified diabetes educator, spoke from personal experience as a diabetic and an educator of diabetics (Attachment 23). There are 81,000 diabetics in Kansas who require education and supplies in order to manage their disease and to keep it from progressing. Insurance coverage for such people is a small price to pay to avoid the high cost of blindness, kidney failure, and/or amputation.

The hearing was continued until Monday, February 16 when opponents to the bill will be heard.

The meeting was adjourned at 10:00 a.m. The next meeting is scheduled for February 11, 1998.

## SENATE FINANCIAL INSTITUTIONS & INSURANCE COMMITTEE GUEST LIST

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## SENATE FINANCIAL INSTITUTIONS & INSURANCE COMMITTEE GUEST LIST

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Katchen Olsen	CC Barkers ASSN.
John Bishop	ADA
Mutt Goddard	HCBA
Brad Sarvot	BCBS
LARRY FROE/10/4	Bd of PhARMACY
Vida Schmidt	Bolof Pharmacy
Took Mirans	Ks. Roxmacists Assoc
Kevin Davis	Am. Family Drs
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## SENATE FINANCIAL INSTITUTIONS & INSURANCE COMMITTEE GUEST LIST

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Assistive Technology For Kansans

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# Testimony Presented to the Senate Financial Institutions and Insurance Regarding Senate Bill 509 By Mary Ellen O'Brien Wright February 10, 1998

I am Mary Ellen O'Brien Wright with Assistive Technology for Kansans and I am here today to testify in favor of Senate Bill 509, which will establish a minimum that health insurance companies must pay annually per individual for Durable Medical Equipment (DME), define DME more broadly, and provide power equipment when appropriate.

The need for DME on the part of someone with a disability is essential, not a mere convenience. Some of the reasons children and adults use DME include increased functioning, preventing further deterioration, and/or replacing or alleviating the malfunction of a body part. Few, if any of us, would choose to use DME in the absence of an illness, injury or permanent disability. Private insurance is one source of funding for DME, a source for which individuals pay for themselves, through their employer, or a combination of both, by paying health insurance premiums. This is done in the hope of having adequate health care coverage in the event it is needed. Adults with disabilities and families with children with disabilities have brought it to our attention that adequate DME coverage is not always available through private health insurance.

Some health insurance companies avoid paying for DME by establishing annual policy limits per individual that are so low that it may not even cover one piece of equipment. They may choose to refuse to provide certain equipment even in the presence of a medical condition and when medically appropriate. Annual policy limits vary, but an average figure is \$1,000. The cost of DME needed by children and adults with severe disabilities or chronic illness may easily exceed these policy limits.

I would like to address the fiscal note prepared by the staff of the Insurance Commissioners Office, particularly the fiscal impact information provided by Blue Cross Blue Shield of Kansas. I know it must be of as much concern to you as it is to me. Blue Cross Blue Shield of Kansas would have you believe that, if the minimum were increased to \$10,000, their cost increase would be \$24.04 per person per month. Preferred Plus of Kansas indicates that the increase would be \$0.86 to \$0.98 per person per month, a not unreasonable amount. And the Kansas Department of Health and Environment, the only objective source available, indicates an increase of just \$0.84 per individual per month. Once again, not unreasonable. Given the range of these numbers, and taking the level of objectivity into consideration, I believe the figures provided by Blue Cross Blue Shield of Kansas should be viewed with great skepticism.

I would also like to bring your attention to the attached letter provided by Blue Cross Blue Shield of Kansas last September, with figures based upon a \$5,000 annual minimum per person. At that time they indicated that the increase per individual per month would be \$0.10. Perhaps increasing the minimum from \$5,000 to \$10,000 may not mean that you can double \$0.10 to \$0.20. It tests all credulity, however, for the monthly increase to escalate so dramatically from \$0.10 to \$24.04 per person per month. Note, too, that with an annual minimum coverage of \$5,000 Blue Cross Blue Shield of Kansas states that the program will cost "approximately \$180,000 a year", while a \$10,000 annual minimum increases total

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annual costs to "more than \$79 million dollars"! Although I am not a mathematician, even I recognize that this math just does not add up.

The kind of DME Blue Cross Blue Shield of Kansas chose to determine their figures is an issue as well. Using just one example, they indicate that 6.81% of their population has arthritis, and the DME purchased for them is a Whirlpool/Jacuzzi. While I do not doubt that they purchase such items for people with arthritis, I find it hard to believe that all, or even a majority of their consumers with arthritis are receiving Whirlpool/Jacuzzis. In my twenty-one years of working in the field of disabilities, the DME I see on a regular basis includes hearing aids, walkers, wheelchairs, scooters, communications boards, etc., and not such items as Whirlpool/Jacuzzis or personal computers with software. If Blue Cross Blue Shield of Kansas has difficulty identifying what type of DME is used by people on a regular basis, I question how they can project their costs accurately. Perhaps if their figures were based on DME most people with disabilities use on a regular basis, their figures might be more realistic.

When DME is inadequately covered by health insurance companies assistance is frequently sought from taxpayer supported programs such as Medicaid, Medicare, Vocational Rehabilitation or non-profit organizations. This shifts the cost of funding DME onto public programs rather than for-profit health insurance companies. Inadequate DME coverage can also lead to increased physical deterioration and dependence. Debilitation and lack of independence places a heavier burden on caregivers, resulting in institutionalization, particularly nursing home placements. Once again, the financial burden falls on the public sector. And the cost of nursing home placement is much higher than the cost of the DME necessary to maintain and/or improve functioning and independence.

The financial impact of having a disability or a family member with a disability can be staggering. Those individuals and families who attempt to keep abreast of the costs find that funding DME is a major financial hardship. In addition to paying for health insurance premiums, they must also pay for DME costs beyond the policy limit as well as for uncovered items. People often call the Assistive Technology for Kansans project seeking funding for DME. One of the few options available is to ask for assistance from civic organizations that sometimes provide such financial assistance. Few of us here today would want to be asking for this kind of assistance for ourselves or a family member on a regular basis. Yet this might be the only recourse for an individual needing the equipment, or whose child needs the equipment.

Insurance companies who provide adequate DME for their consumers have nothing to fear from this bill. Only those who provide the bare minimum of DME coverage, and consequently inadequate coverage, will find this bill objectionable. By recommending the passage of Senate Bill 509 I ask that you look past this smoke screen of grossly inflated costs provided by one insurance company and place the responsibility of payment for DME where it belongs, on health insurers who collect premium payments to cover such services. Representatives of health insurance companies will have ample opportunity to discuss this matter with you during the next few weeks of this legislative session. Due to time limitations, only two individuals will be given that opportunity today. I ask that you please read the testimony of all of the others in order to fairly and equitably hear both sides of this story.

Thank you for the opportunity to bring this issue before you today.



An Independent Licensee of the Blue Cross and Blue Shield Association

1133 SW Topeka Boulevard Topeka, Kansas 66629-0001 Local Corporate Phon (913) 291-7000

Corporate 800 Number - (800) 432-0216

July 29, 1997

Mr. Jay Rogers Accident and Health Division Kansas Insurance Department 420 S.W. 9th Street Topeka, KS 66612-1678 AEGE, VED Julia 124 Filia List 142 Desiring

RE: ASSISTIVE TECHNOLOGY FOR KANSANS

Dear Mr. Rogers

You requested information concerning the potential financial impact on assistive technology, including durable medical equipment, orthotics and prosthetics if cost caps were increased from \$2,500 to \$5,000.

We have reviewed data for one of our benefit options that limits the payout for durable medical equipment and based on this data the additional cost to increase the maximum payout from \$2,500 to \$5,000 would be:

Single Contract:

\$0.10 per contract per month

Family Contract:

\$0.22 per contract per month

For this particular benefit program, the additional cost would be approximately \$180,000 a year.

If you have any questions concerning this information, do not hesitate to contact me.

Sincerely,

Joseph S. Kun

Special Projects Actuary

Actuarial Research Department

JSK:jk

My name is Jan Naegele - this is my daughter Linds. Linds has had CP since birth due to a traumatic labor/deliver. My ex-husband and I both work and have carried health insurance as long as we can remember.

Mary Ellen asked us to speak today because of our extensive experience over the years with DME's and health insurance.

First of all I'd like to clarify that Linds is quite a healthy girl. She has yet to be admitted to the hospital since birth other than a less than one day test. She is normal to above normal cognitively. Due to her CP she is nonverbal and has physical difficulties necessitating types of DME to allow for mobility and physical therapy and function in daily living - such as bathing and toileting and also to help prevent physical deformities and health problems related to the affects of Cerebral Palsy.

The struggles and challenges in life with a disability are enormous. Generally we have no time to spendon any one issue or we find they pile up. But, we as parents feel it is important you are aware of what we go through as we have found many people have no idea and waiting to find out until you have a loved one with asymetrical upper body control - necessitating a power wheelchair and finding your health insurance policy has written this medically necessary equipment out of their policy and will only allow the price of a non-power chair which may be a fraction of the cost of the power unit may prove quite a difficulty for your family. Though you most likely as we will find yourself knowing exactly where the priorities lie in the needs of your child. Thus borrowing endless amounts of money to pay for DME which is a medical need which was what we always thought we carried health insurance for.

I'd like to give a few examples of our experiences---

(some dates and amounts are approximations as I did not take the time to retrieve all our records)

Linds' first power wheelchair was purchased in 1989-90. To our disbelief the power-wheelchair was written out of our health insurance policy - Thus our health insurance responded stating they would pay the price of a nonpower wheelchair . The price quoted by the health ins. co. they would allow for the nonpower wheelchair was "way low" according to Linds' Physical Therapist at the time. Thus I wrote to the Insurance Commissioner who agreed and the health ins. co. increased their allottment for the nonpower wheelchair slightly after which we approached a few agencies regarding funding - found one agency who offered \$1000.00 toward the power wheelchair and were humiliated by another who told us we needed to be poverty level to expect funds from them - Henceforth my then husband and I decided to make payments on the remaining balance which was around \$4000.00 and became wary of approaching agencies for funding in the future.

Our next purchase was Linds' epson communication device. The price was around

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\$5,400.00 - The health insurance company denied coverage. We approached the one agency we had faith in - They again offered \$1000.00 toward the cost of the device - Thus we borrowed the remaining approx. \$4,400.00.

At this point a fellow Hays resident caring for his disabled loved one, approached my father and said to tell us not to even try - meaning to keep up financially because as he said "it will take you down - there is no way to keep your head above water."

Linds was ready for an updated communication device around 2 years ago. We did not submit this one as we were certain it again would be denied.

As a family before our divorce in 1993, we purchased a full sized van our of necessity to transport the wheelchair - which we certainly would not have purchased if not out of necessity.

Our latest dealing with health insurance was the purchase of Linds' current power - wheelchair July 8th of 1997. The total cost of the power- wheelchair was \$10,796.98. We as a family were required by the provider to pay approx. 50% of the total cost upfront before the provider would order the power wheelchair - so we borrowed \$5000.00. Our health insurance company had written power wheelchairs out of their policy - thus allowed \$817.08 which was their allowance for the price of a non-power wheel chair. Our health insurance co. allowed \$920.00 for the power tilt on the wheelchair which allows Linds to tilt the wheelchair to help prevent pressure sores and skin breakdown. Once again left with an enormous balance of \$9,059.00 either to pay ourselves or start phoning agencies looking for funding. This time the same agency who in the past offered \$1,000.00 to help with equipment offered \$5000.00 which was a wonderful substantial amount. Thus leaving us as a family with a balance of \$3,816.80.

My goal in speaking today was to make you aware of some of the things we go through due to health insurance companies being allowed to "write out" certain DME from their policies. My hope would be that medically necessary Durable Medical Equipment such as the power wheelchair be covered by health insurance coverage so that we as many of you who carry health insurance could begin to meet our children's health care needs through our health insurance.

## Testimony in Support of Senate Bill No. 509, 2/10/98 Proposed Durable Medical Equipment Bill

Senator Steffes and members of the Senate Financial Institutions and Insurance Committee, my name is Dot Nary and I live at 1801 Maple Lane, Lawrence, KS. I am a graduate student and research assistant at the University of Kansas. I've been a wheelchair user for about ten years. For the last twelve years, I have worked as a peer counselor and advocate for people with disabilities. Thank you for the opportunity to speak this morning on behalf of Senate Bill 509.

One of the most persistent and serious problems faced by people with disabilities who work is the limitations in coverage imposed by private insurance companies, particularly in the area of durable medical equipment. While this equipment is no more expensive than many medical procedures, insurers have traditionally seen this as an area where they could successfully restrict benefits.

From the perspective of persons with disabilities, several points are very clear:

- 1. For purposes of insurance coverage, equipment must be broadly defined in terms of function, in order to address and support the wide range of disabilities and functional limitations;
- 2. Policy limits should not be set to save insurance company dollars, but must realistically reflect the actual costs of such equipment and its typical longevity;
- 3. The patient/health care provider team is best equipped to make decisions about whether and/or what type of durable medical equipment is needed. These decisions should not be arbitrarily made by an insurance administrator, or worse, an insurance clerk.

My chairs cost about \$2500 and last for about three years of intensive use. This lightweight chair gives me the ability to move about quickly and efficiently, with a minimum of maintenance and breakdowns, and with a minimum of wear and tear on my joints. My pressure-relieving seat cushion costs about \$350, lasts about the same length of time, and allows me to sit for an average of 18 per hours a day. It prevents me from getting pressure sores, one of which can cost up to \$90,000 in medical services, equipment and supplies to heal. This chair and cushion allow me to be a reliable employee, attend classes, keep house, recreate, volunteer in the community, and engage in physical fitness activities, just as a non-disabled person does.

When I obtained this equipment, I was covered by an insurance plan with liberal durable medical equipment benefits that covered most, but not all, reasonable needs. I am now covered by an HMO that imposes a limit of \$1000 dollars per year on equipment. The policy does not allow the amount to be carried into the next year if it is not used. Therefore, in any calendar year, I can get less than half the amount of a wheelchair paid for, even though I am paying the same insurance premiums as anyone else. To me, this is like saying, yes, we will cover your open heart surgery but only up to \$1000.

When I first started to use a wheelchair, I worried about how I would continue all of my activities as a wheelchair user. Now, I know that I can do just about anything that I could do

Senate IDI D attachment 3 2/10/98 when I walked but I worry whether I'll be able to get the right kind of equipment that I need when I need it, so that I can remain active.

For my colleagues and friends with other more involved types and levels of disability, durable medical equipment may allow them to negotiate the community in a power chair, communicate with an assistive communication device, or access the benefits of other cutting edge technology for a variety of other very functional and necessary purposes.

My generation is one of the first in which those born with spina bifida, my disability, have both survived and thrived. We are the first generation to benefit from civil rights legislation, including the Americans with Disabilities Act, that guarantees equal access to the workplace, public accommodations and transportation. And we must be the first generation able to work, achieve and contribute to society unhampered by artificial, capriciously imposed insurance limitations that prevent us from accessing technology that supports us, enhances our lives and abilities, and is vital to our continued functioning and health. Therefore, I ask you to support S. B. 309.

Respectfully submitted,

Dorothy E. Nary

### Jerry Dahlstrom ATS, CRTS

Upon founding Tenth Street Medical Inc. over seven years ago Jerry Dahlstrom made a commitment to provide the best rehabilitation equipment and services in Kansas. Through hard work and Tenth Street's reputation as a quality rehabilitation products provider, the company has grown to 20 employees including a seating division with 5 professionals.

Though Jerry's main duties currently rest with providing strategic and tactical direction for the company, he is still very involved with Tenth Street's customer list. Jerry has attended over 250 hours of training in advanced principles of seating and positioning, led Tenth Street's effort in purchasing diagnostic technology, and works diligently to stay current on the most appropriate equipment in our marketplace today. Jerry has a demonstrated expertise in of all varieties of durable medical equipment. That expertise was recently reflected in Jerry's successful completion of RESNA's (Rehabilitation Engineering Society of North America) Assistive Technology Supplier (ATS)/Certified Rehabilitation Technology Supplier (CRTS) qualification standards.

Jerry's influence in Kansas has extended far beyond the reach of Tenth Street Medical. In a cooperative effort with Kansas Neurological Institute, Washburn University and the Capper Foundation Jerry helped bring a Seating and Mobility Center to Topeka. Jerry's collaborative skills and vision have also set the groundwork for a degree in Rehabilitation Technology with Washburn University. The degree program is in Washburn's approval process, and would be the first campus based degree program of its kind in the United States.

In yet another collaborative effort, Jerry serves as the President and co-founder of Heartland Rehabilitation and Health Management (HRHM). HRHM serves as a network for independent alternate site health care providers in Kansas. HRHM's subsidiary company Heartland Homecare Services provides pharmaceuticals and meet the equipment needs of people throughout Kansas with developmental disabilities.

Senate FD J actachment 4 3/10/98 TO: THE COMMITTEE ON FINANCIAL INSTITUTIONS AND INSURANCE

FROM JERRY DAHLSTROM, ATS CRTS

PRESIDENT, TENTH STREET MEDICAL, INC.

1710 SW 10TH STREET TOPEKA, KANSAS 66604 PHONE: 785/234-3322

RE: SECTION U.S.A. 1997 SUPP. 40-1909

SENATE BILL No. 509

Durable medical equipment (DME) tends to be mobility equipment and otherwise life enhancing equipment. DME aids individual Kansans with disabilities to be healthier and more productive. DME allows Kansans to remain mobile, positively impact their community and remain a lesser tax burden to their fellow Kansans.

The largest users of DME are our senior and elderly populations. Therefore, it is important to note that DME converge offered by Medicare amounts to 5 percent (5%) of the annual Medicare budget. Medicare DME coverage is some of the best available.

As we look at younger and younger segments of the Kansas population, the need for DME diminishes. Our funding sources become private insurance, state funds and individual resources.

When illness or injury occurs within our younger population, the extremely low DME limits which the state of Kansas allows third party payors to establish can financially devastate families. The current lack of funding increases the tax burden of all Kansans.

If any business is going to operate within the confines of the borders of the State of Kansas and be regulated by the State of Kansas it should as well be responsive to the needs of Kansas citizens.

Cutting corners and trimming dollars is not going to bring mobility back to the lady who suffered the spinal cord injury when the drunken driver crossed the center line. Her insurance company is allowed, by the State of Kansas, to offer an insurance package, through her employer, with a One Thousand dollar (\$1000.00) DME annual limit. She needs Thirty Thousand dollars plus (\$30,000.00) for mobility and life enhancing equipment.

The DME needs of our citizens are rare and a small fraction of our total health care dollars. It is time for Kansans to start taking care of Kansans; to increase our tax base through mobility and looking forward to a brighter future for our citizens. Insights into the individual experience are placed very well into perspective by Mr. Jeffery LeHane. His observations are included.

TO: THE COMMITTEE ON FINANCIAL INSTITUTIONS AND INSURANCE

FROM: JEFFREY LEHANE RESPISERV INC. 300 SW BLVD. KCKS 66103

RE: SECTION K.S.A. 1997 SUPP. 40-1909 SENATE BILL No. 509

I'M PROVIDING THIS MEMO TO SUPPORT THE PROPOSED CHANGES IN THE LEGISLATION.

I HAVE 7 YEARS OF EXPERIENCE IN PROVIDING MEDICAL EQUIPMENT.

WHEN A CUSTOMER DISCOVERS THEY DO NOT HAVE ENOUGH COVERAGE FOR BASIC MEDICAL EQUIPMENT, IT IS USUALLY AFTER THE NEED HAS ARISEN. THE PROBLEM IS AS FOLLOWS:

- THE GENERAL PUBLIC DOES NOT HAVE THE KNOWLEDGE OF INSURANCE AND THE HEALTH CARE NECESSARY TO FORECAST THE NEED FOR MEDICAL EQUIPMENT COVERAGE.
- 2. THE COMMON OCCURANCE IS THE INSURED DEVELOPS HOSTILITY TOWARDS THE INSURACE CARRIER AND THE EMPLOYER FOR FAILING TO COVER EQUIPMENT.
- 3. IN CASES WHERE COVERAGE WAS NOT AVAILABLE, THERE IS USUALLY EXTREME HARDSHIP TO THE INSURED AND THE INSURED'S FAMILY.
- 4. MOST EMPLOYERS WILL PROVIDE COVERAGE WHEN THEY DISCOVER THEIR POLICIES FAIL TO COVER NEEDS OF EMPLOYEES.
- 5. IF THE EMPLOYER AGREES TO CHANGE A POLICY, IT IS TO LATE TO HELP THE INDIVIDUAL THAT IDENTIFIED THE NEED.

IT WOULD BE IN THE BEST INTEREST FOR THE INSURANCE COMPANIES AND THE EMPLOYERS OF THE STATE TO PROVIDE THE COVERAGE PROPOSED.

HME NEWS REPORTED IN 1996 THAT 10,000 PEOPLE WERE EMPLOYED IN PROVIDING MEDICAL EQUIPMENT IN KANSAS. ALL IN THE MEDICAL EQUIPMENT INDUSTRY ARE WATCHING AND WOULD SUPPORT THE PROPOSED CHANGES IN THIS LEGISLATION.

JEFF LEHANE

Jml/JML

I am here today to urge you to consider Senate Bill Number 509. My name is Nora Manier. I'm a single parent with two daughters. ChRinda is a senior at K-State University and Jessica is a 14 year-old 8th grader at Parsons Middle School. I've worked at Parsons State Hospital and Training Center for 23 years.

Jessica was born with O.I. or Brittle Bones, and she has never walked. Ten years ago when Jessica got her very first power, wheel-chair the cost was 6,500. Our hometown of Parsons, Ks. raised all of the money except 1,000. The old Cripple Children's Program now called Services for Children with Special Health care Needs provided the last 1,000 to cover the cost of the power, wheel-chair.

Jessica had to prove that she could operate a power car. A video was made of Jessica turning the car right then left, going forward and then backwards. They thought a child of four years old would not be capable of doing this, but after the viewing we received the donation.

Last February, both wheels came off of Jessica's old power, wheel-chair that she had used for nine years. We were not able to get parts any more and the electric system had a short in it. This was quite amazing for any power wheel-chair.

It was now time to look for a new power, wheel-chair plus funding. The first call I made was to my insurance company, Blue Select. I was told the company could give as much as 2,500 on a power, wheel-chair because that is the amount that would match what a manual wheel-chair would cost. I was told that the only thing I needed to send them was a RX from Jessica's doctor stating a need.

Senate IDeD Attachment 5 This was sent but Jessica was denied. Once again I called Blue select and went through the process again but this time I wrote a letter about my child saying that she is a very active child who is on the Honor Roll, is a member of student council and she also participates in the school plays and she is also a Girl Scout. Jessica wants to be a Doctor when she grows up so that she can help others.

Jessica's new red power wheel-chair cost 16,000. I was assisted with funding applications from the Kansas Assitive Technology Project and Southeast Kansas Independent living.

Jessica received all the funds except the 2,500 from Blue Select. Jessica's classmates gave her a fund-raiser and they were able to raise 2,500 that Blue Select did not send. As of today I've received no answer as to why my claim was denied.

## **Funding Breakdown for Jessica Moss**

United Cerebral Palsy of Kansas
 The Kansas Society for Crippled Children
 St. Francis Foundation
 Soroptimist International
 Disabled Children Relief Fund
 Parsons Student Council
 Contribution: 5,000.00
 Contribution: 250.00
 Contribution: 2,500.00
 Contribution: 2,500.00
 Contribution: 2,500.00
 Contribution: 5,000.00
 Contribution: 5,000.00
 Contribution: 5,000.00
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 Contribution: 5,000.00

## Testimony in favor of passage of Senate Bill No. 509

I wish to testify in favor of Senate Bill No. 509. This bill is necessary for the following reasons:

- 1. To provide the opportunity for individuals with disabilities to reach their full potential
- 2. To bring insurance coverage for DME up-to-date with inflation, technology, and price increases
- 3. To require to insurance industry to accept and cover physician-prescribed DME (including power wheelchairs and scooters) when necessary.

Three years ago, my son Joshua was born with spina bifida, a birth defect in which the spinal column has not closed properly during formation. In Joshua's case, this resulted in limited sensation and muscle control in his upper legs and no sensation or muscle development in his lower legs. Joshua has a shunt to control excess fluid in his brain, and is also on a regular catheterization schedule to maintain the health of his bladder and kidneys. In addition to being the mother of a child with a disability, I am also a founding member of the Spina Bifida Group of Topeka and serve on the Assistive Technology for Kansans Task Force. I wish to share some experiences and stories with you today to help you understand the importance of the passage of Senate Bill No. 509.

Joshua is currently three years old and is enrolled in the early childhood development program in our school district. His primary means of mobility include crawling, using a manual wheelchair, and walking with a walker and the aid of full-leg braces. My husband and I are committed to helping Joshua achieve his full potential. We are fortunate enough to have health insurance, some families are not. Even with insurance, however, there are often times the coverage falls far short of the need, especially in the area of durable medical equipment exclusions and coverage limits.

Joshua received his first wheelchair and walker in December, 1996. The walker was received on time, but due to delays at the manufacturer, the wheelchair was not received until the first day of our 1997 insurance plan coverage year. His first wheelchair, received when he was just over two years old, cost approximately \$2,000, just under our insurance plan's annual DME limit. It is not uncommon for a child's first wheelchair to cost anywhere from \$2,000 - \$3,500 for a manual chair.

At that same time, we chose to pursue an additional form of treatment for Joshua known as Therapeutic Electrical Stimulation (TES) which is used to stimulate and develop muscle strength and growth. A battle ensued with our insurance company who refused to accept our specialist's recommendation that our son pursue this therapy. Eventually, our insurance company agreed to coverage for our son (the same week they refused coverage for this treatment for another family with a child who has the same diagnosis and insurance plan as we do). However, the equipment needed to pursue this therapy was considered DME. Now we had a choice to pursue the therapy

Senate FSS D attachment 6 2/10/98 and absorb most of the \$1,500 cost ourselves, or to wait an entire year and hope we would not have additional DME expenses in the following coverage year. In order to give Joshua the most benefit, we had no choice but to pursue the therapy at our own cost.

This is just one example of the choices that families face in trying to maximize the abilities of their disabled children without sacrificing their family's ability to live. I have personally battled on multiple occasions with our insurance company to receive coverage for treatment that was approved and recommended by the specialists who know and work with our son, but was determined to be "not necessary" by our insurance company.

Another factor addressed in this bill is the rising cost of DME, with no corresponding rise in the DME limits. One of our durable medical equipment vendors that I spoke with stated that the price increases that the industry has seen in the past 10-20 years have resulted not only from inflation but from the technology that has been developed and is allowing people with disabilities to become more active and productive citizens than ever before. This is a benefit to all of society.

It angers me to see children whose only opportunity for mobility is through the use of a prescribed electric wheelchair be told they are only worth the cost of a manual wheelchair. I have also met those who need hearing aides, or augmentative communication devices and are told these are not covered services. Their families are forced to do without, or raise the money elsewhere. These children face the challenge of overcoming a disability every day of their lives. You and I have no idea what that is like. Once-in-awhile we are inconvenienced with a twisted ankle or bad back which does not allow us to move as quickly as we would like. Or we experience a bad cold which clogs our ears making it difficult to hear, or laryngitis for a day or two which keeps us from being able to talk and communicate with others. These children face these challenges every day of their lives. Imagine being told that the technology is available to help ease this challenge and to create new opportunities, only to be told it is only partially covered, or is not covered at all. Imagine being told that it is not considered "medically necessary" for you to be able to accomplish things such as walking, listening, or communicating.

In closing, I would challenge each of you as you leave today to stop and think as you stand up from your chair, and walk into the rest of your life. Think of those in this room who will never experience that feeling, those whose life is dependent upon DME simply to be able to get from here to there. Stop and thank your Creator that you have been blest with the ability to walk, to hear a small child whisper a secret in your ear, and to be able to say, "I love you" to the people that matter the most to you.

Individuals with disabilities are priceless. They have the ability to change the world, if the world will give them the chance. You have the opportunity through the approval of Senate Bill No. 509, to give them that chance.

Respectfully submitted,

Nancy T. Ruoff 5820 NE Shaffer Road Topeka, KS 66617 (785) 286-4419

#### TESTIMONY IN SUPPORT OF SENATE BILL NO. 509

I, Marcelle Shrake, support the passage of Senate Bill 509 with regards to increasing the limit of durable medical equipment allowance to \$10,000 per calendar year due to the following example.

A wheelchair necessary for my two-year old son was purchased for \$3,800 with a \$500 write-off leaving a balance of \$3,300. The primary insurance (Blue Cross & Blue Shield of Kansas) paid \$2,500 which left a balance of \$800. Our secondary insurance (United Healthcare) paid \$680 or 85 percent which resulted in \$120 of out-of-pocket expense. This used up the allowance for the year and forced me to put off purchasing a walker and the therapeutic electrical stimulation program (an approximate total of \$2,700) which were indicated as medically necessary by our primary care physician through the Spina Bifida Clinic at Children's Mercy Hospital in Kansas City, Missouri.

I don't feel that my ability to pay for equipment that will enable my son to walk, should be held hostage by an outdated monetary limitation on durable medical equipment. The \$10,000 durable medical equipment allowance being proposed is much more realistic considering the cost of even the simplest equipment available today. It is obvious that \$2,500 will not even buy a wheelchair for a two-year old child. My son's access to the necessary equipment that will enable him to overcome or even adapt to his disability is being arbitrarily denied due to this allowance. As his parent and advocate, I am being put in the awkward position of delaying my son's progress, because I cannot afford what he needs, when he needs it.

At issue is access to the equipment, not whether the equipment is worth what it costs. I respectfully ask this body to grant my son access to the equipment he needs by recommending the passage of this bill.

Marcelle R. Shrake 1916 SW Wayne Ave. Topeka, KS 66604-3139

> Senate II. I Ottachment 7 2/10/98

## February 9, 1998

To whom it may concern,

Please allow us to introduce ourselves. We are Steve and Kristin Cooper from Wichita. We are writing to you to solicit your support for Senate Bill 509, introduced by Mary Ellen O'Brien Wright. While we are confident that the passage of Bill 509 would provide a tremendous financial relief to the many citizens of Kansas facing various mental and physical disabilities, we can only testify about how it would positively effect our family.

On April 19, 1995, our daughter Karlee was born missing her right hand and the majority of her right forearm. There is no medical explanation for her particular condition, it is simply termed a "failure of formation". Obviously we had many questions concerning Karlee's future; Would she be able to function independently? How would she be accepted by her peers? What could we do to help? You only need to quickly review your daily activities and how many require the use of two hands to understand how serious our fears were.

After several months of researching different options in prosthetics, we learned about a device called a myoelectric hand. It consists of a motorized hand mounted to a synthetic forearm which opens and closes by sensing muscle contractions in the remaining limb and converting that impulse into an electric signal. When introduced early enough, it is actually easier for a child to learn to operate than a conventional "hook" prosthesis, and it looks very much like a real hand. The realistic appearance can be a great boost to the child's body image and self esteem, and the functionality provides for a more seamless transition into the "two-handed" world we all live in. The one drawback? Cost.

According to our research, a typical myoelectric prosthesis for a child with a below elbow limb deficiency can cost between \$8,000 to \$25,000, depending on the provider. As the child grows, the prosthesis will need to be adjusted and modified for growth periodically and then replaced entirely — approximately every 2-3 years. These adjustments and modifications alone can amount to several thousand dollars, which is in addition to the original cost of the prosthesis.

Unfortunately, most insurance policies, like our own, will only provide for only one prosthesis per lifetime. This condition is completely unrealistic for even an adult, much less a growing child. This would be like asking a person to go their entire life

Senati I I a I attachment 8 2/10/98 wearing the same pair of glasses. Only a new pair of glasses are only a fraction of the cost of a myoelectric. Compounding the problem is the fact that there are no agencies or foundations in the State of Kansas that specifically help families of children with limb deficiencies. We were referred to the Shriner's hospital in St. Louis, but after meeting with them, were told that they would not be able to meet our needs. And very few families have the financial resources to pay for these ongoing expenses on their own.

Fortunately, through our own resources as well as several generous one-time gifts, we were able to purchase Karlee's first myoelectric a little over a year ago. We are happy to report that she is now able to preform most of the same two-handed activities as her peers, and her frequency of use and proficiency are improving each day. Without her myoelectric (or Powerhand, as we like to call it), Karlee either can't preform some tasks, or takes much longer to accomplish them — sometimes giving up out of sheer frustration. She is even beginning to recognize what a help it is to her, asking us to put it on her in the morning.

But we have no assurance that the necessary resources will be available when Karlee's myoelectric needs to be replaced a little over a year from now. We have already used the one prosthesis allowed by our insurance company when we obtained a preparatory "passive" hand about a year before the purchase of her myoelectric. And since they are under no contractual obligation to do so, there is little hope our insurance company will provide for any of Karlee's future prosthetic needs.

Only by the passage of Senate Bill 509 will we have the peace of mind of knowing that Karlee will have the prosthetics necessary to help her become a confident, productive member of society. We support Bill 509 and strongly urge those involved to vote in its favor. Thank you.

Eur & Knother Cagner

Sincerely,

Steve and Kristin Cooper 1424 N. Westfield Ct.

Wichita, KS 67212

(316) 722-5882



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## Kansas Council on Developmental Disabilities

BILL GRAVES, Governor TOM ROSE, Chairperson JANE RHYS, Ph. D., Becutive Director Docking State Cff. Btlg., Room 141, 915 Harrison Topeka, KS 66612-1570 Phone (785) 296-2608, FAX (785) 296-2861

"To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities"

### FINANCIAL INSTITUTIONS AND INSURANCE

February 11, 1998

Testimony in Regard to SB 509 MANDATING COVERAGE FOR DURABLE MEDICAL EQUIPMENT.

Mr. Chairman, Members of the Committee, I writing today on behalf of the Kansas Council on Developmental Disabilities in support of SB 509 Mandating Coverage For Durable Medical Equipment.

The Kansas Council is a federally mandated, federally funded council composed of individuals who are appointed by the Governor. At least half of the membership is composed of individuals who are persons with developmental disabilities or their immediate relatives. We also have representatives of the major agencies who provide services for individuals with developmental disabilities. Our mission is to advocate for individuals with developmental disabilities, to see that they have choices in life.

The Council is aware of many individuals who have an insurance cap of \$1,000 or less for durable medical equipment. We funded a grant to the Cerebral Palsy Research Foundation (CPRF) in Wichita to assist individuals in purchasing such equipment when they had inadequate or no insurance and no access to other funding sources. During the course of our three year grant CPRF received over 947 inquiries for items whose estimated costs exceeded \$3.0 million. Such items ranged in cost from walkers at under \$150 to eye gaze computers at \$25,000. Items requested included wheelchairs (ranging from under \$400 for manual to over \$18,000 for electric models); communication devices (ranging from under \$400 to over \$9,000); hand controls and lift devices for vehicles, (ranging from under \$600 to over \$32,000); seating systems, ramps, custom seating devices, elevated chairs, bath chairs, light boxes, accessible showers, special computer software, TTYs, home modifications, lift devices for home use, scooters, and many other items. The vast majority of these items cost in excess of \$1,000.

Sencite FS. I attachment 9 2/10/98 e is a great need for items, such as those previously mentioned, to assist persons with disabilities in accessing their communities. Without communication devices, wheelchairs, van lifts and other items these individuals cannot communicate, are not mobile, and cannot live in the community of their choice with family and friends.

SB 509 would help such individuals and their families to purchase the equipment they very desperately need. It would also help them to purchase new equipment when they have outgrown what they have or when their devices wear out, just as do cars, TV sets, VCRs and other items which we use on a daily basis.

We urge you to give careful consideration to passage of this bill for Kansans with disabilities.

Thank you for the opportunity of presenting written testimony.

Jane Rhys, Ph. D.
Executive Director
Kansas Council on Developmental Disabilities
Docking State Office Building, Room 141
Topeka, KS 66612-1570
913 296-2608
E-Mail jrhys@idir.net



## WRITTEN TESTIMONY AS PRESENTED TO THE FINANICAL INSTITUTIONS AND INSURANCE COMMITTEE February 10, 1998

**RE: SENATE BILL 509** 

Good Morning! I am Donna Stevenson, the Community Services Director at Community Action, Inc., Topeka, KS. We are particularly interested in this bill because it has a direct impact on the low-income clients (of all ages) we serve in Shawnee and Wabaunsee Counties through our Medical Equipment and Supply Loan Program. We began this program to specifically address the lack of adequate coverage for prescribed Durable Medical Equipment.

We are supportive of this bill because it addresses maintaining personal independence and lowering health care costs related to unnecessary hospital and nursing home stays. These are issues that are very important to voters as found through the Survey of Kansas Seniors. These issues are also very important to the state from an economic standpoint as presented by the Public Assistance Coalition of Kansas

During 1997, Kansas Department On Aging surveyed 3,220 seniors across the state. They were asked to identify any of the 25 concerns listed which they believed would be a concern to them within the next five years. Their responses reflected that "Maintaining personal independence" and "Expense of medication and medical supplies" were ranked, by importance, one and two respectively. When those same seniors were asked to identify three of the concerns selected in the above question that needed addressed first by providers, the answers and their ranking of importance were the same - "Maintaining personal independence" and "Expense of medication and medical supplies".

2/16/98 (0126 225/0561 The Public Assistance Coalition of Kansas has reported that the cost to SRS in 1994 for nursing home care averaged slightly over \$16,000 per year per person - a total of \$225 million for 14,000 nursing home residents. From an economic standpoint alone, it makes sense to enable our citizens- young and old - to remain in their own homes for as long as possible. Additionally, maintaining personal independence also positively impacts upon such issues as self-esteem and quality of life.

It has been our working experience at Community Action, that in many situations, the only barrier between maintaining personal independence IS the expense of needed medical equipment. The clients we have served through our Medical Equipment & Supply Loan program have lacked the necessary resources to obtain prescribed durable medical equipment. Government programs and private insurers limit coverage for items that make the difference between independent living and unnecessary hospital and nursing home stays.

Senate Bill 509 would directly allow citizens (of all ages) the ability to maintain personal independence and limit unnecessary hospital and nursing home stays by providing adequate coverage for prescribed durable medical equipment. It appears that insurance companies, the State of Kansas, taxpayers, and voters will benefit economically with its passage.

# Financial Institutions and Insurance Committee Testimony on Senate Bill 509 Jennifer Schwartz Parent

Thank you for the opportunity to come before you today in support of Senate Bill #509. This bill has three main sections. They are as follows: 1) A definition of durable medical equipment (DME) which will include the concept of increasing independence and overcoming functional limitations. 2) Annual policy limits for DME of a minimum of \$10,000 per individual. 3) Coverage of power equipment when prescribed by a physician. Each of these sections would personally affect my daughter, Jessica, and I.

An expanded definition of DME would be helpful when trying to advocate for equipment to be covered by our insurance policy. Because there is not a unified definition, insurance companies and consumers often disagree on the types of equipment to be covered.

Raising annual policy limits of DME would greatly impact our lives. Jessica is a six year old diagnosed with cerebral palsy. She requires a wheelchair or other ambulatory aides for mobility along with a wide array of different equipment. This year alone, Jesi has required a walker (\$500.00), foot braces (\$400.00), and a bath chair/support (\$600.00). These three items exceed our policy DME limit of \$1,200.00 per year in less than six months. Since I am a single parent, our family has only one income. There is seldom extra money to purchase items that are essential in Jessica's life. Only a few years ago Jesi was medically involved, and required equipment so that she could live at home instead of in the hospital. She used a feeding machine (\$150.00 per month) and a heart monitor (\$60.00 per month). This equipment met our DME limit in less than a year.

Having a power wheelchair has now become a goal for Jessica. With a price tag of \$5,000.00 or more, it will be a challenge for us to find funding. At this point our insurance would be unable to cover even a portion of this because it does not cover power equipment. Our doctor has written a prescription for a power chair and it (the power chair) is an essential step toward independence for Jessica. She will always be forced to depend on others to push her wheelchair if she doesn't have power.

I hope this information proves helpful to you in understanding what effect this bill will have on an individual's life. I ask for your support in the passing this necessary bill. This will make a significant difference in our life and the lives of many families and individuals with disabilities.

Thank you

Jennifer Schwartz 3004 W 30th Court Lawrence, KS 66047

> Senate ISI) attachment 11 2/10/98

STATE OF KANSAS

## DEPARTMENT OF HUMAN RESOURCES

Bill Graves, Governor



Wayne L. Franklin, Secretary

#### COMMISSION ON DISABILITY CONCERNS

1430 S.W. Topeka Boulevard, Topeka, Kansas 66612-1877 Voice: (785) 296-1722 • TTY: (785) 296-5044 • Fax: (785) 296-0466 Toll Free: (Outside Topeka) 1-800-295-5232

February 10, 1998

TO:

Senate Committee on Financial Institutions and Insurance

FROM:

Sharon Huffman

Legislative Liaison

SUBJECT:

SB 509

Mr. Chair, members of the Committee, thank you for providing this opportunity for us to present our views regarding a very important issue in the State of Kansas.

The Kansas Commission on Disability Concerns (KCDC) was established by law nearly 50 years ago to carry on a continuing program to promote a higher quality of life for people with disabilities. One of our responsibilities is to submit recommendations to the legislature believed necessary to promote the independence of people with disabilities.

Throughout the past five years KCDC has cooperatively conducted Town Hall Meetings with Kansas Rehabilitation Services (KRS). We have held meetings each year in all regions of the state including Liberal, Hays, Chanute, Parsons, Independence, Wichita, Emporia, Topeka, Kansas City, Olathe, Leavenworth and Lawrence. During these meetings the public is invited to present their opinions regarding services offered by KCDC and KRS, voice their concern about issues concerning them, or just speak about something happening on the state or federal level that they think should be handled by KCDC or KRS. Most of the people who attend the Town Hall Meetings are either individuals with disabilities or friends and family of individuals with disabilities.

The issues addressed have varied slightly from year to year, but one of the major issues that surfaces each year is the need for increased funding for services in the community for people with disabilities. Although SB 509 is not asking for actual funding of community services for people with disabilities it would be, in a sense, privatizing some of the services currently being provided by state and federal dollars. Rather than the State Rehabilitation Services (SRS) purchasing durable medical equipment (DME) for those who are in receipt of private insurance benefits, it should be the insurance company paying for the equipment. What follows is my personal story, but it is one that is repeated day after day for others throughout the state.

Senate I De I attachment 12

Our Mission: To provide quality employment services in an efficient manner which exceeds customer expectations.

2/10/98

Two years ago, after what seemed like an entire lifetime of tests that poked, prodded and totally invaded my body to determine the cause of my severe chronic pain and fatigue, I was diagnosed as having Fibromyalgia. At that point in time I had held my current position as Legislative Liaison for KCDC for a period of four years and had begun to reach the point of total exhaustion by the end of an eight hour day. When it became almost impossible for me to make it through the day, much less an entire week of work, and when this impairment began to concern my boss, I discussed the possibility of obtaining a motorized scooter with my Rheumatologist. He said that he would support anything that would enable me to remain employed and wrote a prescription for a scooter.

I went through the procedure to obtain prior authorization from my insurance company and ultimately was told that even though my benefits provided coverage for up to \$2500 per year to purchase DME, they would only pay for \$800 of the cost of the almost \$3000 scooter and none of the cost of the \$1000 scooter lift required to transport the scooter in my car. The \$800 maximum was based on the reimbursement for a manual wheelchair even though my doctor certified that I was physically incapable of propelling a manual wheelchair.

At the suggestion of a fellow disability advocate I applied for services through Kansas Rehabilitation Services, a division of SRS. Because their policy is to provide pre and post-employment assistance for people with disabilities, I qualified for services and requested their help purchasing a scooter, lift and portable word processor (necessary for note-taking at the meetings I am required to attend as part of my job). My income level placed me in a category that is required to pay a significant portion of the cost of equipment, so it was almost a year and a half before I could scrape up the money to finally get my scooter. During that time period I came very close to losing my job and had already investigated the possibility of beginning proceedings to apply for KPERS Disability Retirement and Social Security Disability Income. I knew, as did my boss, that I could no longer continue in my position without the use of a motorized scooter.

When I finally obtained a loan from my parents (only after my mother received an early retirement bonus from her job), my case worker finally began the paperwork to purchase the equipment I needed. There is a very interesting twist to this whole story. At the beginning of my case file with KRS I was told by the case worker that we would have to exhaust all other sources of payment, including private insurance, before they would pay for any equipment. I had been told by Tenth Street Medical Inc. that if I purchased the scooter and lift through KRS, the State contract rate provided a discount. My case worker and I were figuring this into our estimates of how much I would owe. When he was preparing the purchase request he was informed by Tenth Street Medical Inc. that if they submitted the bill to my insurance company it would be for the full amount, rather than the discounted amount. Because the discount was almost \$800, the amount my insurer had agreed to pay, my total owing after insurance would be the same amount as the discounted amount. Needless to say, we did not submit the bill to Blue Cross/Blue Shield.

Something is very wrong with this picture when a fully employed individual is forced to use government funding in lieu of private insurance in order to remain fully employed and stay off government benefits! I have been employed by the State of Kansas for over ten years and have never once turned in a claim for durable medical equipment. When I finally ask them to pay for

something that is necessary for me to continue living my life as a productive tax-paying citizen, they renege on what I believe to be their responsibility. Passage of SB 509 would make mandatory something that private insurance companies have made very clear will not be made available on a voluntary basis. Even though as a State of Kansas employee I would no longer benefit from this proposed legislation because we are now self-insured, I urge this Committee's support for passage of SB 509 so that citizens of our great State who are in receipt of private health insurance benefits can receive up to \$10,000 per year benefits for durable medical equipment.

Thank you very much for your consideration of this very important issue. I would be happy to answer any questions you might have at this time.

## February 5, 1998

### Jeff Drake Testimony

I am 43 years old and have Multiple Sclerosis that was diagnosed in 1981. Now I would be classified as a secondary progressive patient. That means my condition will continue to worsen. I've had problems with Prudential Insurance Company. I started with them in January 1993. My body has changed through the years as the progression of my disease worsens. I have different needs now and require a larger wheelchair due to an increase of approximately 75 pounds caused by the medication I must take and by not being ambulatory. Unfortunately, Prudential Insurance has adopted the Medicare standard regarding wheelchairs. Medicare has a five years rule that says they will only pay for an electric wheelchair once every five years. Any kind of change in my medical condition is not considered when assessing whether I need a new wheelchair. Five years must pass from the date the last one was purchased. I'm at the five year mark and they would purchase a manual chair two to three inches wider than the one I have now but since they purchased an electric wheelchair just over three years ago, they will not consider buying an electric one for another two years.

The new wider manual wheelchair will not fit on my chair lift in my van. That means if I buy it I will be homebound and not able to see a doctor or dentist unless I use an ambulance. I will not be able to go anywhere. The Lift buses need a week's notice for a ride, which is not feasible when you have a immediate medical problem. I am also concerned that the new wider manual wheelchair Medicare wants me to buy will not fit on the disabled accessible buses. Also, right now I'm able to transfer but as the disease progresses I will need a lift system to get in and out of bed.

When the balanced budget was passed in July, drastic funding cuts occurred to Medicare home health care. As of April 1, 1998, Medicare is cutting home health dollars so instead of having an attendent 7 days a week, I will only have an attendent for three days a week. Many people have been hit with these medicare changes and most do not have the secondary insurance. In the vast effort for Congress to balance the budget, I think it has backfired on those who need benefits the most. Since passing the balanced budget last July, many cuts in Medicare have occurred to home health and a lot of people don't know about these changes yet.

I need an electric wheelchiar with wheels that don't protrude as much as a manual so it will fit in my van lift. I couldn't use the electric wheelchair I got three years ago any longer because it was too big to use in the house and I could not transfer anymore in it. The new electric wheelchair I need has a new set-up and is called the Jazzy Drive-Wheel. The wheel is right in the middle where you sit on top of it and pivots on itself. The turning radius is next to nothing and you can go around in circles in it. This chair accommodates my changing medical condition with a wider seat and a wheelbase small enough to fit on the lift in my van.

Senate Fl. I attachment 13 2/10/98 In going through my Doctor to try to obtain these medical devices, my Doctor feels like she is banging her head against a wall with no results. I've basically dropped out of the loop with private insurance. I feel if I'm going to get any funding for this wheelchair at all I'm going to have to look at private sources, not my insurance carrier.

With the attendent coming only three days a week, I will lie in bed the other four days increasing the chances of bedsores and respiratory problems. Even mental health problems become an issue. I am 43 years old with a family and a 16 year old son. When I'm in bed and can't even go out to the living room or attend my son's school functions, I can't interact with my family. If I had this wheelchair, I could attend school functions. The attendent comes for 1 to 2 hours and gives a bath, dresses me and helps me get in the wheelchair. My wife is employed as a first grade teacher. Combined with my health problems and raising a 16 year old son, she is overloaded with work. Congress has very little knowledge of what's really going on out here concerning people with severe disabilities. Mobility Magazine, for instance has some great products but the costs are prohibitive for most of us. Insurance companies lack any imagination to try something new to help the disabled. I'm in a Catch-22 situation where we make too much money to qualify for certain things but not enough money to be able to afford the high price of durable medical equipment.

The sad thing is that part of the game the insurance companies play is to wear you down. It becomes tiresome and requires stamina to get medical needs paid by private insurance. You must keep up with the paperwork concerning requests for more information, denials and appeals. I feel that the more successful you are at playing this insurance game matters more than what the patient really needs. Before I became disabled I worked for an insurance company from 1980 to 1988.

Jeff Drake 7901 W. 91st Terr. Overland Park, Kansas 66212-3101

### Testimony in support of S. B. No. 509

Members of the Senate Financial Institutions and Insurance Committees, my name is Glen W. White, Ph.D. and I live at 416 Nancy Court, Lawrence, KS 66049. I am an assistant professor at the University of Kansas and am also have been a researcher in the field of disability for the past 15 years. I have been a wheelchair user since 1964, or for the past 34 years.

I am a very active person both professionally and in my community. My participation in these and other domains such as work, leisure, education, transportation and so forth are facilitated by the use of assistive technology. I use my wheelchair for locomotion from one place to another. The wheelchair in a sense is my legs. Thus, it is important to have a wheelchair that is most appropriate for daily use. Wheelchairs, like other durable medical equipment need to be lightweight, durable, portable, and easy to repair. They wear out and need to be replaced on a regular basis. If a wheelchair breaks down and there are no backup wheelchairs available, the person is relegated to bed rest until one is available.

During one research study I conducted in Topeka with individuals with disabilities, I met a man who had a broken power wheelchair and had been in bed for over 8 months because he could not afford to have the wheelchair repaired. This situation is hard to fathom in our state, yet each day hundreds of Kansans with disabilities are limited by the availability and affordability of durable medical equipment. Availability of such technology would allow them to participate in the work force and contribute to the development of our communities.

Unfortunately, the insurance industry and other third-party payers are often loathe to pay for any type of needed durable medical equipment, or will only provide the cheapest equipment available. For example, I use an active duty lightweight wheelchair and needed one replaced from all the use my previous wheelchair had over the past 6 years. Manual wheelchairs are not inexpensive and my wheelchair cost approximately \$2,000, yet my insurance provider only wanted to pay for a fraction of that cost. Additionally, I have poor balance and need wheelchair arms to help me maintain my balance, yet the insurance company did not pay for the wheelchair arms as they saw them as "options" on my wheelchair.

I spent over 15 hours writing several letters to my insurance carrier to fight to get the wheelchair I received. I was pretty lucky overall. But if it takes this type of effort from a Ph.D. to get the equipment I need, what chance does the average Kansan with a disability have in advocating for the durable medical equipment he or she needs?

I ask that you support the durable medical equipment bill proposed by Assistive Technology for Kansans, which will help to insure that equipment will be available to those who need it. By defining durable medical equipment more broadly, by establishing minimum annual policy limits for equipment, and by mandating coverage of power equipment when

Senate II. I Attachment 14 2/10/98 prescribed by a physician, this legislation will pave the way for Kansans with disabilities to lead more healthy, active and productive lives.

Thank you for the opportunity to present my testimony on behalf of this extremely important and needed legislation.

Respectfully submitted,

Hen W. White, Ph.D.



# FamiliesTogether, Inc.

Parent Training & Information Centers for Kansas

Home Page: http://www.kansas.net/~family

Wichita Parent & Administrative Center 3340 W Douglas, Suite 102 Wichita, KS 67203 (316) 945-7747 1-888-815-6364 Fax (316) 945-7795 e-mail: fmin@fiest.com

Topeka Parent Center 501 Jackson, Suite 400 Topeka, KS 66603 (785) 233-4777 1-800-264-6343 Fax (785) 233-4787 e-mail: family@inlandnet.net

Garden City Parent Center 417 N. 8th St. Garden City, KS 67846 (316) 276-6364 (316) 276-2380 (Espanol) 1-888-820-6364 1-800-499-9443 (Espanol) Fax (316) 276-3488 e-mail: famtogether@gcnet.com

Kansas City Parent Center (913) 962-9657

Senate Flux attachment 15 2/10/98 Date: February 10, 1998

To: Senate Financial Institutions & Insurance Comm.

From: Josie Torrez, Families Together, Inc.

Re: SB 509 - Durable Medical Equipment

My name is Josie Torrez. My husband and I are the parents of two sons. Chris is 15 and Joey is 12. Joey has autism and low muscle tone. At age 8, he was getting too heavy to carry but could not walk far distances (more than a block) so my family visited with his doctor who prescribed equipment that would benefit him. We and the doctor did not feel a wheelchair would meet his needs, but a Pogan Stroller would. This stroller is similar to an umbrella stroller, but much larger and folds up for easy storage and transport.

When pricing this equipment, we found it to cost \$800. Our insurance company denied the request to pay for this stroller. We found funding from several civic organizations across the state and finally obtained the stroller.

I represent Families Together, Inc. We are a statewide organization that assists families in Kansas that include a son or daughter with a disability. The majority of our staff are parents or family members of young people with disabilities. We have four centers in Kansas; our administrative center in Wichita, Garden City, Topeka and

Assisting Parents and Their Sons & Daughters with Disabilities ATTACH MENT 15

our newly opened center in Kansas City. The Kansas City center assists families in Johnson and Wyandotte Counties with the opportunity for personal and individual assistance in that heavily populated area of the state.

We ask for passage of SB 509, which will require health insurance companies to cover Durable Medical Equipment. DME is essential to people with disabilities, allowing them the opportunity to be as independent as possible. Many families we assist across the state advise our staff that coverage is either inadequate or unavailable under their private health insurance policy to obtain needed equipment for their child with a disability. Often times a power wheelchair costs about \$10,000. I know that may not seem like a vast amount of money to some of you, but to a family that already has high medical, and other expenses due to their young person with a disability, this amount is an extreme financial hardship. We at Families Together, Inc. refer families that call our office in regard to DME to Optimist and Kiwanis Clubs along with other civic organizations asking these groups to assist the family by funding a part of the needed equipment.

Families have pride and wish to continue to have their pride, but do go to these organizations and present the need they have. These organizations do not have the financial resources to fund the numerous requests they receive.

We ask this committee's consideration on the passage of this bill for the sake of the children in Kansas who are in desperate need of durable medical equipment in order to begin their independence.

### Statewide Independent Living Council of Kansas



700 S.W. JACKSON, SUITE 1003, TOPEKA, KS 66603

(913) 234-6990 VOICE / TDD

(913) 234-6651 FAX

# Testimony Presented to Senate Financial Institutions & Insurance Regarding SB 509 By Shannon M. Jones February 10, 1998

I am Shannon Jones with the Statewide Independent Living Council of Kansas (SILCK). The SILCK is mandated by federal law, the Rehabilitation Act to study existing services for people with disabilities and make recommendations to improve and expand services that will enable Kansans with disabilities to achieve their optimum level of independence and improve their quality of life.

The SILCK supports SB 509. This bill will definitely address the concerns the Council hears from the constituency we represent, Kansans with disabilities. Every year the Council conducts public hearings across the state to find out what barriers remain in Kansas for people with disabilities to live independent lives. Time after time the Council receives comments regarding the lack of adequate insurance coverage for Durable Medical Equipment (DME). Often times people with severe limitations due to their disability need certain types of equipment that will allow them to maintain their jobs and their independence. However, private insurance companies frequently avoid paying for DME by establishing annual policy limits on DME per beneficiary, narrowing the definition of DME, and refusing to cover power equipment. Inadequate DME coverage can lead to increased physical deterioration and dependence on other caregivers. This can sometimes ultimately lead to nursing home placement, in which case the cost is much higher than the one time cost of the equipment necessary for the individual to remain in their own home and improve their independence.

The SILCK urges this committee to favorably pass Senate Bill 509 which will expand the definition of DME; increase the annual maximum coverage provided by private health insurance companies; and require that power and certain other types of DME be provided when prescribed by a physician.

Senate Flis attachment 16 2/10/98



## Envision.

PLEASE REPLY TO: Michael Byington, Director

Envision Governmental Affairs Office

P. O. Box 1063

Topeka, Kansas 66601

(785) 575-7477 (local office and voice mail)

(785) 233-2539 (FAX)

mbyington@delphi.com or mbyingto@ink.org

February 10, 1998

TO SENATE COMMITTEE ON FINANCIAL INSTITUTIONS AND INSURANCE

IN SUPPORT OF SENATE BILL 509:

This bill needs to become law. All too often, it is not medical rehabilitation, physical therapy alone, occupational therapy, or any other treatment modality which makes the difference as to whether a person who is disabled will function successfully, and at maximum potential and productivity. It is the acquisition of a piece of equipment, durable medical equipment, which means the difference between functioning and not functioning.

As well as the concept of this bill being correct, one of its most positive aspects is the definition it contains of the term, "durable medical equipment." Currently, many insurers define such equipment with regard to such parameters as where it hooks on to a disabled persons' body.

For people who are blind, this outmoded type of definition is particularly impractical and illogical. It has lead to an insurance system where a prosthetic eye, which does nothing to restore vision or the functions lost due

Senate FDI attachment 17

2/10/98 801 East Lincoln • Wichita, KS 67211

Tel 316.267.2244 • Fax 316.267.4312

Web http://www.envisionus.com

to the decline of vision, is often covered, while a CCTV magnification device, an electronic reading machine which will read printed material for the individual, or a refreshable Braille display and scanner which can convert printed material to readable Braille are not covered because the individual does not hook them into the required places on his or her body. Such items can restore the functions of reading, looking at pictures, interpreting diagrams, etc., but even though they are much more practical than the prosthetic eye, they are not covered.

My vision, with the best correction possible, is only about 10% of normal. I am thus writing this testimony on a computer which shows me what I am writing in very large print. Because even the largest of print sometimes does not allow me to proof read accurately, after I am finished writing this testimony, I can have my computer read it back to me in clear, Decktalk speech. In this manner, I can often catch errors which I would completely miss visually.

My wife is totally blind. She uses the same system I have described above to scan printed text into the computer. She can then have the Decktalk read it to her, and if she wants, she can run a Braille translator and have the material printed out in Braille. Because we own equipment of this magnitude, my wife and I are among the 26% of all working age blind and legally blind people who have jobs. We work for a living; we pay taxes. We also are in hawk up to our not-so-functional eyeballs because we had to buy equipment such as that which I have described, about \$23,000.00 worth. No third party payer helped us with any of it, and even at that, our computer system is probably not as up to date as most of yours.

Now I am not really complaining. I feel honored, as does my wife, to have the ability to work. Many people who are blind or legally blind, and who are of working age, however, simply can not make the initial investment to be able to get the first job. That is probably why 74% of such people in the United States remain unemployed.

Many insurance companies may tell you that rates will have to go up if this bill passes, or tell you that they can not afford to buy such equipment. I submit that they can not afford to decline the purchase of such equipment. When I look at what my durable medical equipment, as defined by this proposed legislation, does for me, and how much more competitive and

productive it makes me, I can assure you that neither my wife or myself would be paying the five figures of tax we pay each year without our doodads and gadgets.

My employer, Envision, has every desire to be on the cutting edge of developing new employment opportunities for persons who are blind, in both our production settings and in totally integrated community settings. Given the potential of assistive technology and durable medical equipment for the blind, the possibilities are virtually limitless. It will not happen, however, if durable medical equipment for the blind can not be made more readily available to those who need it.

February 6, 1998

Steve Richardson Testimony

On February 4, 1977 I received a spinal cord injury when I was run over by a car while employed by Yellow Cab. I walked with a bad limp using a cane from injuries to my left knee, leg and back. I had two surgeries on my knee and leg and severe pain in my back. The later part of 1977 I began suffering problems with my bladder and muscle spasms throughout my body.

The doctors did not know what was causing the problems with my bladder and the muscle spasms so I entered the hospital for tests. They found I was showing symptoms of Multiple Sclerosis. That was when my world turned upside down. They also found vertebras in my back were pressing against a nerve. This injury was caused by the pressure from walking on one side with a cane due to my accident. I went from a cane to a walker and then a walker to a wheelchair as my legs became weaker and I lost mobility. My disease (Multiple Sclerosis) has progressed steadily since then.

I paid for my first manual wheelchair myself because I did not have any insurance. That chair only lasted three years. The second wheelchair was partly paid for by Medicare and I paid for the remainder. Medicare would not pay for repairs to the wheelchair. The repairs cost so much that I had to weld the chair back together myself. The wheelchair literally fell apart and I had to put it back together. A wheelchair goes through a lot of abuse. For example, when A & A Services, a company that specializes in transporting people with disabilities, came to pick me up, damages would occur such as bent wheels and broken leg rests.

Medicare will only pay for certain wheelchairs. I am a big man and wheelchairs paid by Medicare would not fit me. Medicare wheelchairs are cheaply made and do not last long. Medicare will only pay for a wheelchair once every five years. This is not enough, as wheelchairs last only about two or three years and changes in medical condition are not taken into consideration when replacement needs occur.

I used a manual wheelchair from 1978 to 1996. I could not pay for an electric wheelchair when my income consisted of \$477 per month, out of which I had to pay for rent, utilities, medical supplies, food and everything else I needed. I went without medical supplies, food and many times had my utilities cut off because I simply could not pay for them. I began experiencing numbness and pain in my neck and right arm from pushing myself in my manual wheelchair. After entering the workplace in 1995, I received an electric wheelchair, paid for by Kansas Vocational Rehabilitation in 1996.

I only have private insurance Blue Cross (Blue Select) now. I had a waiting period of 247 days when I took out Blue Select because of my pre-existing condition. During that time they would not pay for my medicine or anything. Blue Select will not pay for

Senate IDD D Attachment 18 2/10/98 any repairs to the wheelchair that Kansas Vocational Rehabilitation bought. I have to pay for repairs to my electric wheelchair. Some doctors will not even take Blue Select. Medicare pays nothing now.

I feel private insurance (Blue Cross) should pay for repairs to my electric wheelchair or give some kind of benefit for durable medical equipment for the disabled. An electric wheelchair is necessary for mobility to some people with disabilities. Blue Cross (Blue Select) will only pay half of my doctor's bills, half of surgery bills, half of hospital bills, which puts those with disabilities in a situation when you have to have your wheelchair repaired or replaced. Private insurance premiums are getting higher while the quality of service is getting less.

Steve Richardson

Topeka Independent Living Resources Center

Tue Ruharlow

501 S.W. Jackson

Topeka, Kansas 66603

### HEIN AND WEIR, CHARTERED

ATTORNEYS AT LAW
5845 S.W. 29th Street, Topeka, KS 66614-2462
Telephone: (785) 273-1441
Telefax: (785) 273-9243

Ronald R. Hein Stephen P. Weir Susan Baker Anderson

SENATE FINANCIAL INSTITUTIONS AND INSURANCE
TESTIMONY RE: SB 386
Presented by Ronald R. Hein
on behalf of
American Diabetes Association and Dietetic Association of Kansas
February 10, 1998

Mr. Chairman, Members of the Committee:

My name is Ron Hein, and I am legislative counsel for the American Diabetes Association and the Dietetic Association of Kansas.

I appear today in support of SB 386, which requires insurance companies providing health insurance in Kansas to include within their coverage reimbursement for diabetes self-management supplies and education. The legislation does not require first dollar coverage, and makes the coverage subject to any deductions or co-payments applicable to other coverages under the policy.

Diabetes is a killer disease affecting 16 million people nationwide, almost half of whom are undiagnosed. Diabetes is the seventh leading cause of death, the leading cause of new blindness, and the leading cause of end-stage renal disease. Diabetes accounts for 50% of lower limb amputations. Diabetics are far more likely to have strokes or heart disease than the general public. Diabetes nationwide accounts for one of every seven healthcare dollars spent costing \$138 billion annually.

I have previously delivered to each member of the committee the Social and Financial Report on SB 386 required by Kansas Statutes. If you have had an opportunity to review that report, you have seen clearly that all studies indicate that tight blood sugar control of diabetics, while not a cure, can at the worst delay the onset of complications, and at the best, avoid these complications all together.

The studies clearly indicate that money spent on self-management education and supplies will reduce hospitalizations and overall healthcare costs for diabetics. In 1987, the State of Kansas came to that same conclusion after a study that was ordered by the legislature. Then Insurance Commissioner Fletcher Bell issued a bulletin to all companies authorized to transact accident and health business in the state of Kansas. [See SB 386 Social and Financial Impact Report, H1-2.] In that bulletin, the Commissioner stated as follows:

"Based on the findings of the Ad Hoc Committee, there is evidence from a number of studies that appears to demonstrate a clear and convincing association between patient education and a reduction in hospitalizations which result in cost savings. From the limited number of companies offering coverage for out-patient diabetes

Senate I Do D Ottachment 19 2/10/98 Senate Financial Institutions and Insurance ADA/DAK Testimony SB 386 February 10, 1998 Page Two

education programs, the Committee believes the health insurance industry in Kansas is not taking full advantage of the potential savings available as a result of diabetes education program benefits. Conversely, the Kansas insuring public is not receiving the economic benefits and health enhancements because of the unenlightened design of most health insurance policies.

"At this time, the Ad Hoc Committee does not recommend requiring or mandating coverage for diabetes self-management education programs. However, in view of the substantial savings potential, the Committee recommended that the Kansas Insurance Department inform insurers issuing medical expense health insurance contracts in Kansas of the Committee's findings and encourage insurers to include benefits for in-patient and out-patient diabetes self-management education.

"The Kansas Insurance Department fully supports the Committee's recommendations. It is the department's belief that by adding benefits for properly administered diabetes education programs which meet nationally recognized standards, the health insurance industry will be providing a meaningful benefit which will, in turn, have a significant impact on the claim costs associated with providing coverage for people who have diabetes.

"It is anticipated that this department will be requested to report the progress of insurers in providing these benefits to a subsequent session of the Kansas Legislature, perhaps as early as 1989. With the cooperation of the health insurance industry the possibility of a legislative enactment requiring coverage for diabetes self-management education programs will be greatly minimized."

The insurance industry in Kansas has responded to some extent, and coverage is far more prevalent today than it was in 1987. However, unfortunately, some companies still do not fully cover these services. It is for those companies that SB 386 is intended.

We would urge the committee to pass this legislation so that the citizens of this state can enjoy the same rights to coverage of this type as is afforded the citizens of 23 other states, and the beneficiaries of those insurance policies that do fully cover those services in this state.

We urge the passage of SB 386.

Thank you very much for permitting me to testify, and I will be happy to yield to questions.



700 SW Jackson, Suite 601 Topeka, Kansas 66603-3731

785/233-8638 \* FAX 785/233-5222 www.nursingworld.org/snas/ks

the Voice of Nursing in Kansas

Debbie Folkerts, A.R.N.P.--C. President

Terri Roberts, J.D., R.N. Executive Director

FOR MORE INFORMATION CONTACT: TERRI ROBERTS J.D., R.N. 700 S.W. JACKSON, Suite 601 TOPEKA, KANSAS 66603-3731 (785) 233-8638 FAX (785) 233-5222

#### S.B. 386: REIMBURSEMENT FOR DIABETES SUPPLIES AND EDUCATION

(DIABETES COVERAGE ACT)

Chairman Steffes and members of the Senate Financial Institutions and Insurance Committee, my name is Robyn Parker. I am a Master's prepared registered professional nurse and family nurse practitioner, clinical nurse specialist, and certified diabetes educator. As a diabetes educator and health care provider, I help persons with diabetes manage their care and teach them self-management skills on a daily basis. I am the chair of the Kansas Delegates for Diabetes Committee of the American Diabetes Association, the State Legislative Coordinator and President-Elect for the Kansas Association of Diabetes Educators, and the Chair of the Advanced Practice Conference Group of the Kansas State Nurses Association. It is on behalf of the Kansas State Nurses Association that I am submitting my testimony in support of S.B. 386.

Diabetes is a truly devastating disease. The number of people with diabetes in the U.S. has tripled since 1960. There are now 16 million Americans with diabetes. According to the National Institutes of Health, the nation now spends \$138 billion per year on diabetes and related complications. That is an incredible increase of 50% in just the last five years, Diabetes is the leading cause of blindness in adults aged 25-64; it is the leading cause of end-stage kidney disease; and it is a major contributor to heart disease and stroke. Unfortunately, diabetes is also a silent disease: half of the sixteen million people estimated to have diabetes do not yet know it. This is quite serious, as undetected diabetes leads to major health problems. Only preventive treatment can improve the quality of life for diabetes patients at substantially reduced health care costs. According to the December 1995 issue of *Practical Diabetology*, it is estimated that through better treatment and management of diabetes:

- \* the incidence of diabetes-related blindness could be reduced by 90%.
- \* diabetes-related kidney disease requiring dialysis could be reduced by 50%.
- \* diabetes-related complications and amputations could be reduced by 50%.

There is no cure for diabetes. Diabetes can be treated; however, the person who has diabetes is the one who carries out the treatment. This condition is one in which the person with diabetes needs to know how to manage the disease. This management is at least in part based upon blood glucose levels tested by the patient on a daily basis. Obviously, the person with diabetes must have the tools to perform the testing and the knowledge of how to use this information in daily life.

The mission of the Kansas State Nurses Association is to promote professional nursing, to provide a unified voice for nursing in Kansas and to advocate for the health and well-being of all people.

**Constituent of The American Nurses Association** 

2/10/98

women with poor diabetes control during pregnancy, the morbidity and mortality of both the fetus and the mother are significantly increased.

In 1987, the insurance industry in Kansas was advised by the Insurance Commissioner that they should voluntarily provide coverage for diabetes self-management education and supplies because it reduces health care costs. Although some companies have provided this coverage, not all have done so. Many patients are therefore unable to afford the tools to manage their diabetes. This bill would allow these persons to obtain the supplies and self-management skills necessary, which in turn would decrease hospitalizations and the occurrence and severity of long-term diabetes complications.

On behalf of the Kansas State Nurses Association, I ask for your support of S.B. 386, the Diabetes Coverage Act. Not only would this bill dramatically improve the lives of Kansans with diabetes, it would significantly decrease health care costs as well. *Thank you* for the opportunity to speak to the Committee on this important issue.

Robyn Parker M.S.N., ARNP
517 Sagebush
Wichita, Kansas 67230
Home (316) 733-8548
Work (316) 689-5530
Diabetes Nurse Educator, Via Christi St. Francis

# Preferred Medical Associates

Crow-Tretbar

848 N. St. Francis Wichita, KS 67214

Tel: 316-261-3100 Fax: 316-261-3105

Endocrinology James K. Speed, MD James A. Mack, MD

Gastroenterology Alonso Galvan, MD James A. Whitaker, MD

Internal Medicine Ray F. Fisher, MD Joaquin G. Santos, Jr., MD Mitchell A. Morgan, MD Thomas C. Reals, MD Carlene D. Klassen, MD

Neurology Richard W. Murrow, MD Bart A. Grelinger, MD Ty L. Schwertfeger, MD

Pulmonary Richard W. Spann, MD Richard A. Claiborne, MD Guy M. Grabau, MD Brian M. Gross, MD

Rheumatology James D, Anderson, MD Timothy S, Shaver, MD February 9, 1998

#### To Whom It May Concern:

I am an endocrinologist in Wichita, and I have become aware of some proposed legislation regarding the funding of supplies and education for diabetic patients. This is a vitally important issue, and I would like to take a few moments to tell you why.

Diabetes mellitus is a chronic, potentially debilitating disease. Its adequate management is complex and requires, first of all, adequate supplies. Diabetic patients must be able to monitor their own blood glucose levels in the same manner that a motorist driving down the highway must be able to see where he or she is on the road at any given time. This, in turn, requires a home blood glucose meter and testing strips, both of which (and particularly the latter, over time) may be quite expensive.

Adequate monitoring alone, however, is not sufficient for appropriate care if the patient does not know how to respond to the measured blood glucose levels. Therefore, appropriate education is vital in the behavioral and cognitive areas to allow each diabetic patient to maximize blood glucose control.

Why is this important? A landmark study, the Diabetes Control and Complications Trial, clearly showed that in type 1 diabetic patients, control of blood glucose levels as close to normal as possible resulted in a dramatic decrease in the rates of debilitating and expensive complications such as eye, kidney, and nerve damage. These findings are generally believed to apply to type 2 patients as well.

With respect to proposed legislation regarding these issues, I am concerned that an error of short-sightedness may prevail. Certainly, diabetic supplies and education are expensive, but I would view this as a "front-loaded" expense. I firmly believe, and studies have shown, that downstream expenses such as those associated with the complications referred to above will be decreased significantly by adequate initial expenditures. As a society, we are, in effect, shooting ourselves in the foot if we do not supply the necessary funds for diabetic patients to manage their disease effectively.

February 9, 1998 Page 2

In a perhaps overworked but nevertheless appropriate analogy, diabetes management may be thought of as a war, where the enemy consists of not only acute complications (such as hypoglycemia and diabetic ketoacidosis) but also chronic, delayed complications such as coronary artery disease and the other organ problems mentioned above. In this scheme, physicians are the generals who plot strategy and deploy various elements of the armamentarium (medications, behavioral strategies, and cognitive training) at appropriate times in the evolution of the battle. Patients, on the other hand, are the infantry who are "in the trenches", making decisions on a daily basis that affect their ultimate safety and health in a way that is every bit as real as that of a soldier who is faced with difficult decisions in the course of battle. The main difference, of course, is that the effects and consequences of a patient's decisions are delayed, in many cases, 10-20 years after decisions are made. Just as we would think it absurd as a society to send soldiers into battle without, firstly, appropriate battle gear and, secondly, the combat training necessary for their survival, I believe we would be equally foolish to send diabetic patients into the fray without the supplies and skills to do daily battle with their disease.

As this legislation is considered, I urge you to consider the importance of empowering patients to take control of their disease, as this is clearly the most humane and the most effective strategy for management of this disease.

Thank you for your consideration of these thoughts.

Sincerely,

James A. Mack, M.D.

JAM/cs

r 2/9/98 & t 2/9/98

James a. Maca, M.D.

# Testimony-SB 386 Senate Financial Institutions and Insurance Committee February 10, 1998 Marty Glenn, M.S., R.D., L.D.

As one of 750 Kansas dietitian's I'm asking you support SB 386, which is designed to allow insurance coverage for prevention of costly complications from diabetes. I along with many other dietitian's treat diabetics everyday. To provide some context for this discussion there are an estimated 151,000 Kansas residents who suffer from diabetes, and one person from Kansas dies every four hours from diabetes.

This disease not only shortens lifespans;

- -it is also the leading cause of blindness in people ages 25-74.
- -it acounts for 50% of lower limb amputations..
- -diabetics are 2-4 times likely to have heart disease and 5 times as likely to have a stroke.
- -diabetes accounts for 1/3 of all cases of kidney failure.
- -diabetics are 1.5 times more likely to be hospitalized.
- -diabetes is responsible for one in seven Kansas healthcare dollars.

What this data doesn't take into account is the problems diabetes creates that are difficult to quantify but every bit as costly. People unable to perform physically like they used to, unable to keep the job that was providing them and their families with income, which often leads to depression.

Diabetets is unique among chronic health conditions because to a large extent, treatment depends on self-management. Appropriate education enables people with diabetes to understand their disease and perform optimal self-management. People with diabetes must learn how to balance their insulin injection or other medications, diet and exercise regimen to maintain their health. Unfortunately, many don't have the financial resources to fully manage their disease.

The benefits of self-management will not only help the 151,000 diabetics, but will dramatically reduce the amount of money insurance companies have to pay in the form of claims for expensive hospital procedures. As it stands now, insurance will pay for a leg to be cut off, but not for the less expensive preventive measures.

There is no cure for diabetes, however, the measures outlined in SB 386 would greatly improve the lives of those living with diabetes here in Kansas and reduce the one in seven healthcare dollars spent on diabetes. I ask that you support SB 386.

Marty Glenn M.S., R.D. Co Chair, Legislative Affairs-Kansas Dietetic Association

> Senate FIS attachment 21 2/10/98



THE KANSAS PHARMACISTS ASSOCIATION 1308 SW 10TH AVENUE TOPEKA, KANSAS 66604-1299 PHONE (785) 232-0439 FAX (785) 232-3764

ROBERT R. (BOB) WILLIAMS, M.S., C.A.E.

EXECUTIVE DIRECTOR

#### **TESTIMONY**

#### **SB 486**

#### Senate Committee Financial Institutions and Insurance

Tuesday, February 10, 1998

My name is Bob Williams, I am the Executive Director of the Kansas Pharmacists

Association. Thank you for this opportunity to address the Committee regarding SB 486.

SB486 would require group health insurance policies, medical service plan, contract, hospital service corporation contract, hospital and medical service corporation contract, fraternal benefit society or health maintenance organization which provides coverage for accident and health services to provide coverage for equipment, supplies, and outpatient self-management training and education when prescribed by a physician. Diabetes outpatient self-management training and education shall be provided by a certified, registered or licensed health care professional with expertise in diabetes.

Diabetes is a progressive, chronic disease affecting 16 million Americans. There is no cure and its incidence is increasing. According to the new guidelines issued by the American Diabetes Association early diagnosis and treatment can reduce the risk of diabetic complications by as much as 50 to 75 percent. While there is no cure, diabetes can be controlled with the proper treatment. Pharmacists are in a unique position to help patients optimize their drug therapy, including managing the adverse effects of medications. According to a special report by the American Pharmaceutical Association: *Solving Drug Therapy Problems in Patients with Type 2* 

Smate FIS 1 Attachment 22 2/10/98 Diabetes; "The newer antidiabetes agents affect different mechanisms that underlie diabetes and thus offer varying avenues to controlling hyperglycemia. They also present new challenges to physicians and pharmacists alike in determining the optimum dosage for each patient that will control the disease while minimizing adverse effects."

To effectively control and treat diabetes, the entire health care team needs to participate in the patient's treatment plan. Many states have already moved in this direction and have passed similar legislation (AR, IN, MN, TN, WV, MD, TX). Legislation is pending in eleven other states (CA, DE, IL, LA, MA, NC, NH, NY, PA, VT, NM).

We encourage your support of this bill. Thank you.

My name is Patricia Hohman. I am a Registred Nurse with a Masters Degree in Nursing and I am a Certified Diabetes Educator. I feel fortunate to be standing here before you on my own two legs and looking at you through healthy eyes. I have been a diabetic for 21 years and never had diabetic teaching. I graduated from nursing school 10 years ago and during my nursing education I learned the basics of managing diabetes. In 1992 I became employed as a diabetes educator and in 1994 sat for and passed the CDE exam.

Most patients are not as lucky as I have been. Had I not decided to become a nurse I am sure I would not be healthy today. Within the last 2 years, 3 patients I knew died who were Type 1 diabetics, and had been diabetic fewer years than I have.

The first was 34 when I began working with him. His diabetes was diagnosed at the age of 16, but he never had any follow up education or support after the initial diagnosis. He was unable to work, and did not have health insurance. He had a medical card with limited benefits. I supplied him with insulin and test strips as often as I could. Part of his foot was amputated, his kidneys had failed and he was on dialysis. He had had laser surgery to correct the damage caused from retinopathy. He lost the vision in one eye and had limited vision in the opposite eye. He died at home, presumably of a heart attack at the age of 36.

Another Type 1 diabetic died after having diabetes for 15 years. She was in the hospital more times than I can remember with Diabetic Keto Acidosis. Although I did not work with her in the capacity of a CDE, I took care of her many times as a staff nurse. Her repeated hospitalizations may have been prevented but, she never had the education and support that was necessary to manager her diabetes. She was on dialysis and died of congestive heart failure at the age of 36.

The third individual struggled to live a normal life in spite of her diabetes. She wanted to work because it made her feel good about herself and gave some structure to her life. She started selling Tupperware. She was forced to stop because the income threatened her Medical Card which she needed badly to cover her medical expenses. She had never had any formal diabetic education. What she knew she had picked up along the way through some reliable and some unreliable sources. The diabetes had caused the amputation of her left leg, and her kidneys were failing. She died of a systemic infection that the physicians were unable to cure even with very powerful antibiotics. Unfortunately she died at the age of 48 with low self esteem and low self worth.

Everyone knows that there is no cure for diabetes. Education is our best hope for helping diabetics understand how to manage their disease and the consequences of not managing their disease. Unfortunately, most insurance companies do not provide benefits for education. Even if diabetics have the knowledge to manage their disease they still need the tools and support to do so. I feel that if the individuals I discussed had had access to education and supplies at the onset of their diabetes, they would be here today just as I am to tell their stories.

Because I have access to the latest research and information I am able to manage my diabetes and keep myself healthy and free of complications. I recently purchased an insulin pump at a cost of more than \$4,000.00. Fortunately, I was able to afford the insulin pump since it is not a service covered by my health insurance. I am only one of the 81,000 voices of people in the State of Kansas with diabetes. Not everyone may be as lucky as I. Please support Senate Bill 386.

Senate FD. S attachment 23 2/10/98