

Approved \_\_\_\_\_ Date 2-5-91  
54

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE

The meeting was called to order by Carol H. Sader at \_\_\_\_\_  
Chairperson

1:30 a/m./p.m. on January 30, 1991 in room 423-S of the Capitol.

All members were present except:

- Representative Theo Cribbs, excused absence
- Eloise Lynch, excused absence

Committee staff present:

- Bill Wolff, Research
- Norman Furse, Revisor
- Sue Hill, Committee Secretary

Conferees appearing before the committee:

- William A. Dean, Board member of National Kidney Foundation
- Carole Herron, National Foundation Kidney Patient Services
- Beth Witten, Licensed Specialist Masters Social Worker
- Dr. Sue Anderson, Nephrologist, St. Francis Hospital
- Dr. Robert Porter, Nephrologist, Ks. Dialysis Specialist, Topeka, Ks.
- Dr. Kirk Duncan, Community Dialysis Services (Written testimony only)
- Dr. Richard Huseman, Nephrologist, Community Dialysis Services of K.City. (Printed testimony only)
- Jim Haffner, Clinical Social Worker, Community Dialysis Services of Kansas City
- Scott Buckley, Kansas Kidney Program, (transplant patient)
- Cathy Baer, Social Worker, Kansas Dialysis Services, Topeka, Ks.
- Fred Howell, transplant patient, (printed testimony only)
- Jean Marie Tressler, transplant patient, (printed testimony only)
- Patty Molinar, transplant patient, (printed testimony only)
- Patricia Pooley, transplant patient, (printed testimony only)

Chairperson Sader requested members read over committee minutes prepared.

Rep. Scott moved to approve minutes of January 28, 1991 as presented, seconded by Rep. Carmody, motion carried.

Chair announced committee meeting will be held tomorrow 1:30 p.m. at the Board of Healing Arts offices, 235 S. Topeka Blvd. Directions were given.

Chair inquired if anyone present had requests for legislation. None came forward this date.

Chair drew attention to hearings scheduled.

HEARINGS CONTINUED ON HB 2016.

William A. Dean, Board member of National Kidney Foundation called attention to attachments, i.e., (Attachment No. 1) Map of Dialysis patient census, (Attachment No. 2), kidney donor advertisement, (Attachment No. 3), client flow chart, then introduced conferees that would appear this date on HB 2016.

Unless specifically noted, the individual remarks recorded herein have not been transcribed verbatim. Individual remarks as reported herein have not been submitted to the individuals appearing before the committee for editing or corrections.

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE,

room 423-S Statehouse, at 1:30 /a.m./p.m. on January 30, 1991

HEARINGS ON HB 2016:--

Carol Herron, Executive Director of National Kidney Foundation of Kansas and Western Missouri offered hand-out, (Attachment No. 4). Ms. Herron outlined the goals of his organization and budget which allows them to support the following services, i.e., patient services; public and professional education; research; fund raising; administration. She described end stage renal disease (ESRD) and the effect it has on patients and families of those afflicted. She noted this population is continuing to grow. She explained limited treatment choices, i.e., center hemodialysis, peritoneal dialysis, transplantation. Each patient must choose one, and all too often they are forced to sustain themselves on a treatment option that is not necessarily their choice. A patient profile was defined from data they have received. She noted funds that would be provided if HB 2016 is enacted are a small investment when considering the number of lives that can be saved. She answered questions.

Beth Witten, Licensed Specialist Masters Social Worker, offered hand-out, (Attachment No. 5). She explained care problems of an ESRD patient, explained different treatment options. Noted there are but a few dialysis machines in the state. She gave an in-depth explanation of the Medicare for in-patient and out-patient reimbursement. She noted that a dialysis patients are eligible for Medicare as long as they need dialysis. She detailed both Medicare and Medicaid coverage and eligibility requirements. She drew attention to pages 5,6,7 of her attachment that indicate financial projections and the average costs per dialysis treatment. Ms. Witten asked for support of HB 2016, then answered numerous questions.

Dr. Sue Anderson, a nephrologist, St. Lukes Hospital, gave hand-out, (Attachment No. 6). Dr. Anderson spoke to the technology of the dialysis, but noted since it is man-made, there are limitations. She detailed complications that occur if proper medication and diet modifications are not properly followed. There are no quick fixes with kidney disease. A Kansas Kidney Program would benefit Kansans who have renal failure, and all Kansans would benefit knowing that should the need arise in their lives, this program would be in place to help. She answered numerous questions, many technical in nature about medications prescribed.

Dr. C. Robert Porter, nephrologist practicing in Topeka, gave hand-out, (Attachment No. 7). Dr. Porter noted the areas where Medicare-Medicaid and private resources do not cover costs for dialysis patients. He has often seen kidney patients who do not have funds for medications that are vital to their well being because they need the money for food for their families. These patients quickly have to be hospitalized due to severe hypertension or diabetic problems. He answered questions.

Mr. Dean asked that printed testimony be recorded as part of committee minutes for Dr. Kirk Duncan, (Attachment No. 8) and Dr. Richard Huseman's testimony recorded as (Attachment No. 9).

Mr. Jim Hafner, Social worker Dialysis Center in Kansas City, gave hand-out, (Attachment No.10). Mr. Hafner is a specialist in the program offered by the Missouri program, where many Kansans are treated also. He asked members to envision what life might be like when dealing with a chronic illness. He stressed the help and services persons with ESRD need, the change in life style, adaptation to medications and dietary adjustments, as only a few things that must be dealt with. Patients living near the state line and the difference in treatment services available for Missouri and Kansas dialysis patients. It is difficult for some to understand. He urged members to help lend a hand to these patients needing help, and asked members to follow their consciences when voting for HB 2016. He answered questions.

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE,  
room 423-S, Statehouse, at 1:30 /a.m./p.m. on January 30, 1991

HEARINGS ON HB 2016:---

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Scott Buckley, a kidney transplant patient offered hand-out (Attachment No. 11), gave his background as a kidney patient, his gratitude for caring medical staff and support services. He spoke of concerns for others with this disease who are unable to have insurance coverage, or enough insurance coverage. He detailed medication costs that continue to help maintain his good health at this point. He does have fears and concerns that one day he will no longer be able to pay for cyclosporine or other health care costs. He is also concerned for the many others with this disease. He emphasized many factors that contribute to a kidney patients well-being. He commended the outstanding members of the renal team at KUMC. He asked for members to favor support of HB 2016.

Cathy Baer, Licensed Master Social Worker, (Attachment No. 12) spoke of aspects of financial hardships for ESRD patients, i.e., they must manage cost of transportation to and from dialysis treatments; rarely does insurance cover costs of medications that often run between \$100-\$200 a month; must adhere to severe dietary restrictions requiring purchase of foods that often are more costly in addition to the purchase of foods needed for family members. She noted the psychological impact of renal failure is devastating. Renal dialysis patients, she said, represent the resiliency of the human spirit, and it is within the power of this group to help alleviate to some extent the burden of their suffering by supporting HB 2016.

Other printed testimony recorded as attachments on HB 2016:--

Testimony from Fred Howell, (Attachment No.13).

Testimony recorded from Jean Marie Tressler, (Attachment No. 14).

Testimony recorded from Patty Molinar, (Attachment No. 15). Mrs. Molinar stated briefly that often there must be a choice made in purchasing food for her husband and 2 children, rather than the purchase of needed medications for herself. Their income is only \$536.00 per month, a social security disability check.

Testimony recorded from Patricia Pooley (Attachment No. 16).

Chair concluded hearings on HB 2016.

Rep. Samuelson announced there will be meeting of the sub-committee on HB 2017 Friday a.m. in her office 181-W.

Chair adjourned the meeting at 3:05 p.m.

GUEST REGISTER

HOUSE PUBLIC HEALTH AND WELFARE COMMITTEE

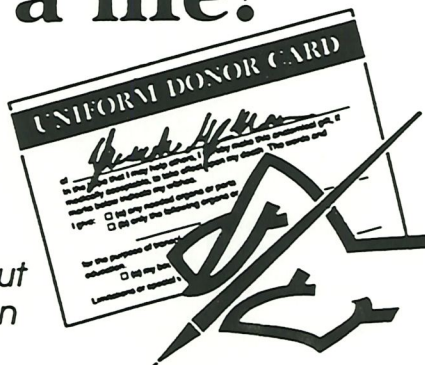
Date Jan 30, 1991

Name	Organization	Address
Robert Pater M.D.	Kidney Foundation	
Scott Buckley	Kidney Foundation	
Carole Herion	Kidney Foundation	1900 W 47th St. Westwood
Bill Dean	NKF	O.P. KS
Elijah Witt	To Co Dialysis, Inc.	Lenexa, KS
Wendy Bibbes	To Co Dialysis, Inc.	PKS
Barbara Tressler	DCI	KC Mo.
Ared Howell	CDC	KANSAS CITY, KANS.
Jim Hojner	CDC - Overland Park & Midland	O.P. KS.
Mary Kaye Testi	National Kidney Foundation	
Kelly Kuitala	N.O.W. Nat'l Org. for Women	KCKS
Patty Malinen		
Patricia Foley	Dialysis Patient	2318 SW Greenwood Plaza #303A Topeka
Cathy Pacy	Kansas Dialysis Services	634 Mulvane, Topeka, KS
Sue Anderson	NEPHROLOGY ST. LUKE'S	2502 W 71st St N 105 66208
Cassie Lanner	KDHE	1005 N LEOB
Amanda Heibel	mother of dialysis patient Patricia Foley	2206 Francis St Topeka, KS 64501
KATHA R. LORDES	KANSAS MISCELLANEOUS COMMITTEE ON PUBLIC HEALTH FOR KANSAS	TOPEKA
George Goebel	AARP-SLC - Capital City Task Force Chair	Topeka
LISA Getz	WICHITA Hospitals	WICHITA



YOUR MOST IMPORTANT  
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*Discuss your feelings about  
organ and tissue donation  
with your family.*

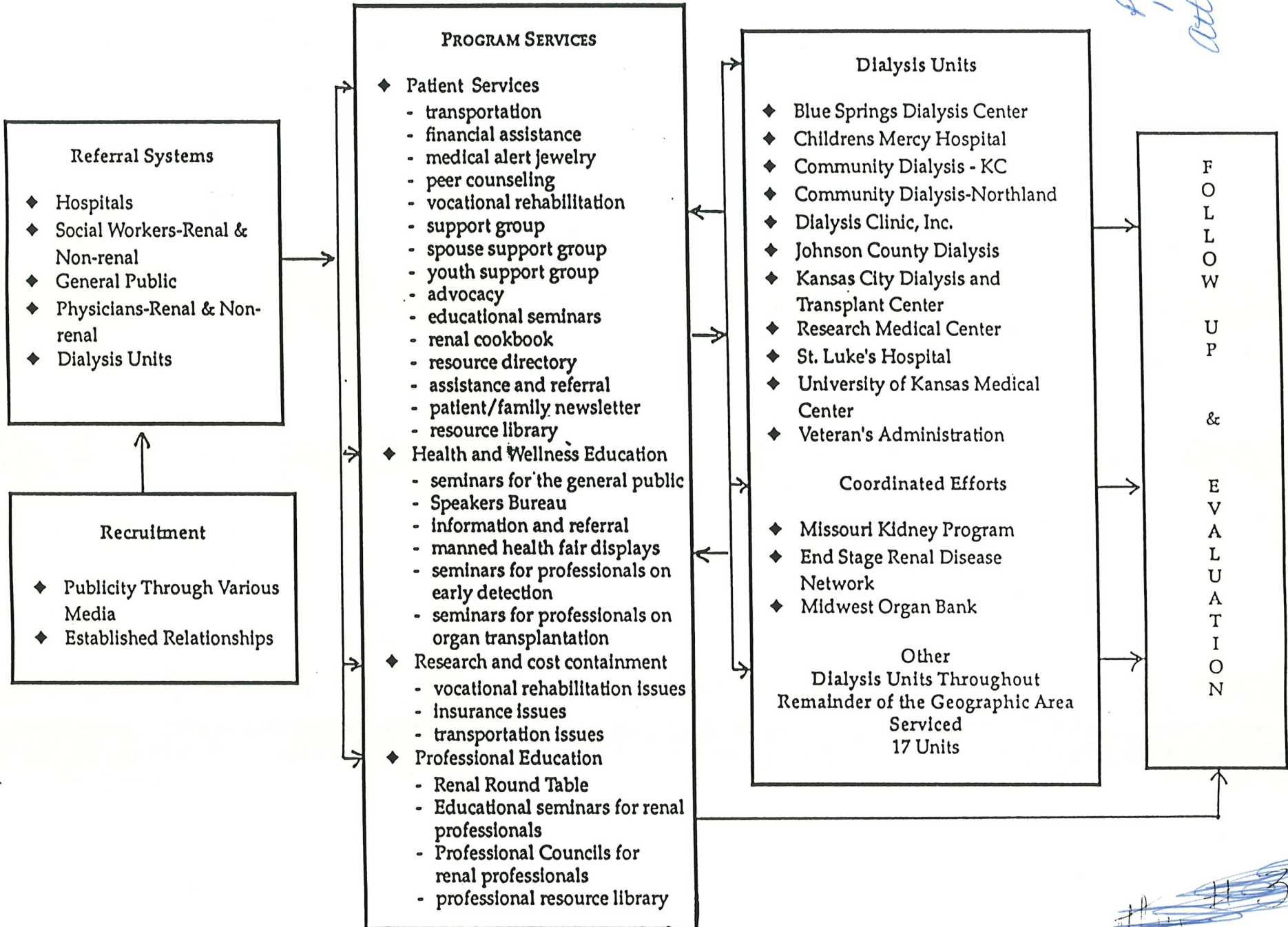
**K THE NATIONAL  
KIDNEY FOUNDATION**  
FOR MORE INFORMATION CONTACT

**National Kidney Foundation of Kansas and Western Missouri**  
1900 W. 47th Place, Suite 107  
Westwood, Kan., 66205  
262-1551 or 1-800-444-8113

PHKW  
1-30-91  
Attraction  
#2

NATIONAL KIDNEY FOUNDATION OF KANSAS & WESTERN MISSOURI CLIENT FLOW CHART

*PAKCC  
1-30-91  
Attn #3*



*PAKCC  
1-30-91  
Attn #3*

KANSAS HOUSE PUBLIC HEALTH & WELFARE COMMITTEE TESTIMONY  
Carole L. Herron, Executive Director National Kidney Foundation of Kansas

January 28, 1991

Honorable Members of the Committee:

My name is Carole Herron. I am the Executive Director of the National Kidney Foundation of Kansas & Western Missouri. Our Affiliate is one of 49 Affiliates reaching across the United States. I appreciate the opportunity to speak to you today about end stage renal disease and the impact it has on individuals and families residing in Kansas.

The ultimate mission of the National Kidney Foundation is the eradication of diseases of the kidneys and urinary tract. In striving toward this mission it is both essential and prudent to address several shorter term goals, which move us toward this end and gives us a greater sense of focus and priority in our efforts including:

- I Adequate support of research and research training
- I Fostering continuing education of health care professionals
- I Expansion and development of patient services and community resources to improve the quality of life of those suffering with end stage renal disease
- I Public health education
- I Involvement in health policy development

Our organization has a paid staff of four full time employees and one part-time employee. We are governed by a volunteer Board of Directors representing the community-at-large, dialysis and transplant patients and family members, business leaders, and renal professionals. Our organization currently has an operating budget



of approximately \$350,000.00 which supports the following services:

I Patient Services	35%
I Public Education	33%
I Professional Education	15%
I Research	2%
I Fund Raising	11%
I Administration	4%

End stage renal disease is a term that haunts those persons who suffer from its effects, their family members, and renal professionals. It is a disease that can attack anyone regardless of age, race, or economic status. Kidney failure is a phrase that elicits feelings of fear, anxiety, and often depression. Modern technology now offers a sense of hope, but the pressing reality is a radical lifestyle change. The trauma of kidney failure can have a major impact on families. Suddenly, a family is faced with life and death decisions, medical jargon, and a responsibility to become informed and make the best personal decisions regarding treatment alternatives. Coping with emotions, changes in lifestyle, and living with chronic disease are all important aspects of coping with chronic disease.

The dialysis population is changing and the needs are increasing. Since 1987, our organization's direct patient service budget allocation has increased 124% based on the level of need that can be met within our current overall budget restrictions. The number of dialysis units, within our geographic area, has increased by ten. Direct assistance grants, requested for eligible patients by unit social workers, of \$100.00 per year have doubled from 1,200 requests to 2,400 requests. Analysis of this increase charts the following reasons as being responsible for this influx:

*PKW*  
*1-30-91*

*Attn # 4-2*

- 1) the changing economy
- 2) the length of illness which causes household funds to be re-directed to life sustenance areas
- 3) more persons between the ages of 27 and 40 years of age are beginning dialysis with families to raise and incomes limited to Supplemental Security Income (SSI) benefits and disability

Recently, our organization distributed a questionnaire for completion by patients throughout Kansas. Over 30% of the approximately 1,500 patients responded. Undoubtedly, those who invested the time to respond did so because they have a vested interest - themselves and their families. Not everyone on dialysis needs assistance. Not everyone on dialysis is forced to quit their work because of their illness. Not everyone on dialysis is the same. ESRD patients do have one major area in common - their lives depend on dialysis or transplantation.

Patients do have some limited treatment choices. Some can choose center hemodialysis. Some can choose peritoneal dialysis. Some can choose transplantation. But, each patient must choose one of these treatment options and all too often they are forced to sustain themselves on a treatment option that is not their choice. Not all choices are available to every patient because we are all biologically different. Not all choices are available to every patient because of the financial limitations. Our concern is that not every patient has equal access to the level of care they need to sustain themselves.

On the basis of the collected data we can share with you a profile of a typical Kansas dialysis patient. You are looking at a person who has been on dialysis from one to five years. Over 70% of our respondents are over age 56 and are high school graduates who desire full time work. (Note: The dialysis population has increased over the past year by about 10% and we are now seeing patients in their late 20's and 30's with children at one end of the spectrum and persons over age 68 at the other end.) This profile family, on the average consists of two adults with a family income of less than \$1,000.00 per month. Our profile patient receives Medicare, but not Medicaid or Medi-Kan, which probably means that they are reluctant to give up their last vestiges of their independent lifestyles. Our profile family receives no assistance with rent/mortgage or housing costs and no assistance with

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*Attn # 4-3*

transportation. They spend a monthly average of \$50-99 each on medicine and transportation. Those with health insurance pay an additional \$50-99 per month on insurance premiums and all pay less than \$50 on Medicare premiums. Basic calculations made by inserting modest amounts for housing costs, food, etc. leave absolutely nothing for expendables. How do they manage? They are caught in the health care trap. Technology has given us the means to live longer, without the benefit of the means to develop the financial resources to afford this life-sustaining technology. A Kansas City Star article discusses this dilemma and concludes, "As long as health care costs continue to outrun our ability to pay many more patients will have to beg for their lives."

Visualize with me the challenge the end stage renal disease patient faces daily. The physicians, the testing, the machines on which their lives depend. What next? Studies show that patients who benefit from State Kidney Programs are less stressed. These programs offer necessary support to those patients who can ill afford not to take prescribed medications because of cost. They offer support to patients who have no means of transportation and get them to the doctor when they need to go instead of days or weeks later. ESRD patients are no different than you or I and I, for one, know that if I want to stress out my family I only have to mention financial concerns with no alternatives.

Some people raise the issue against setting a precedence for other "special interest health" concerns. To these persons I would respond that chronic illness is devastating regardless of the name of that illness. But, research has made a difference in the impact of some diseases. Polio is no longer a killer threat because of the Salk vaccine. Kidney failure is no longer a killer threat because of the life-sustaining treatments of dialysis and transplantation. Other catastrophic illnesses have developed preventive treatments with the "potential" for saving lives, but none of these treatments can specifically earmark a person whose life has been saved. We can identify over 1,500 Kansans today, whose life has been sustained because of dialysis or transplantation.

There are those who would make the claim that this recessive economy can not afford \$3.3 million for these patients. I contend that the economy can not afford to turn their backs on this amount which will easily double when paid out through

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*Attm # 4-4*

excessive hospital stays from the Medicare and Medicaid budgets. These funds are a small investment in the lives of 1,500 Kansans - an investment that will grow as organizations work together to implement cost-containment strategies. These funds will not replace any funds currently being used to support ESRD programming efforts, but will simply bring these patients into the 90's and provide a safety net to lessen the burden they are now carrying.

Thank you again for the opportunity to offer my concerns. Our organization stands ready to work cooperatively with the state of Kansas to develop an exemplary program to meet the needs of Kansans.

PNW  
1-30-91

attmt # 4-5

**Johnson County Dialysis, Inc.**

10405 West 84th Terrace  
Lenexa, Kansas 66214  
(913) 492-2044

Kansas House Public Health & Welfare Committee Testimony

January 29, 1991

Madam Chairperson and Members of the Committee:

My name is Elizabeth Witten. I am a licensed specialist clinical social worker and have practiced nephrology social work with dialysis and transplant patients for over 13 years. For the past seven years, I have been employed at Johnson County Dialysis, Inc., a free-standing dialysis facility in Lenexa, Kansas.

In addition to my work responsibilities. I have been active as the volunteer chair of the Patient Services Committee of the National Kidney Foundation of Kansas and Western Missouri. In that capacity, I have been involved in issues related to patients' needs including establishment of a state kidney program for eligible Kansans similar to one available in our neighboring state of Missouri. I am here before you requesting your support of H.B. 2016 which would establish an advisory commission and a program to assist eligible ESRD patients.

As you may be aware, there is a three month waiting period for Medicare unless a dialysis patient receives a transplant or begins home training in that three months. For 93% of ESRD patients, there is no premium for Medicare Part A (inpatient), but Part B (outpatient, doctors, and dialysis) has a \$29.90 premium in 1991. Dialysis patients are eligible for Medicare as long as they need dialysis. If as rarely occurs, kidney function returns, Medicare coverage continues for one

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Att. #5

year. After a transplant, Medicare coverage lasts only three years and then the patient is on his or her own.

Medicare does not pay all of the cost of dialysis and transplant. There is an inpatient Medicare deductible of over \$600 per admission and an outpatient deductible of \$100 annually. Although Medicare pays 80% of allowable outpatient charges after the waiting period for eligible patients, the balance can be beyond many people's means. National estimates of Medicare payments per ESRD patient in 1988 were \$29,400 meaning that the balance owed by insurance, Medicaid, and/or the patient at 17.7% was \$6,190 counting only those inpatient and outpatient services covered by Medicare. This figure does not include such Medicare noncovered indirect costs of treatment as transportation, most take-home medications, and insurance.

We all know that health care costs and the number of medically indigent continue to skyrocket. Even in Johnson County estimates are that 1 in 8 working poor have no health insurance at all.

Medicaid does not cover all dialysis and transplantation expenses for those who earn less than \$427 monthly and who are eligible for total state medical assistance. Federal law extends Medicaid coverage to certain low income Medicare beneficiaries earning a mere 27% more monthly under Qualified Medicare Beneficiary (QMB) legislation. Under QMB, Medicaid is supposed to pay deductibles and coinsurance (the 20% balance) on any Medicare covered service. Although other states routinely pay the 20% balance, Kansas Medicaid only "considers" payment of deductibles and coinsurance up to the Medicaid allowable for QMB eligible persons. Kansas Medicaid's low allowables effectively limit patients' access to services since many providers do not accept Kansas

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Att# 5-2

Medicaid. QMB is supposed to also provide state buy-in for Medicare Part B premiums as well; however, SRS has not aggressively pursued eligible Medicare beneficiaries who are currently covered by Medicaid. Those patients who pursue state buy-in for Medicare Part B premiums must often reapply several times and wait months for state purchase of premiums. In the interim, patients who cannot afford Medicare Part B premiums risk loss of Medicare coverage and delays in reinstatement. This program would assist these eligible patients with purchase of Part B premiums and could be reimbursed by Medicaid later for those QMB eligible patients.

Obviously, ESRD patients requiring dialysis or transplantation frequently sacrifice to pay the high costs of care. Kansas nephrology social workers in 1990 surveyed patients' needs. They found that although Medicare pays 80% of the direct cost of outpatient treatment, 6% were not Medicaid eligible and did not have and could not afford the cost of obtaining Medicare supplement insurance to pay the remaining 20%. Purchase of supplemental insurance for Medicaid eligible persons, could save state funds on inpatient and outpatient charges and deductibles even at Medicaid's 50% federal match. In addition, this benefit could help many other low middle income patients pay the 20% balance effectively expanding options.

Most dialysis facilities in the state are located in highly populated areas. Patients living in rural areas must travel great distances to the closest dialysis facility. Transportation is a factor in the decision to do home dialysis, however, some are not candidates for this modality due to physical or emotional problems or lack of support. Social workers estimated that 6% of their patients had

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1-30-91  
Attn # 5-3*

transportation needs that could not be met by existing resources.

Fully 21% of Kansas patients have either inadequate coverage or no coverage for medications which cost from \$100 to over \$300 per month. Medicare does not cover most take-home drugs. Insurance companies and Medicaid do not cover many drugs prescribed for dialysis and transplant patients and even those living below the poverty level must purchase these drugs or go without. Facilities and physicians provide free samples when available, but there are not enough to go around.

→ Most persons with kidney failure are severely anemic, a condition which lowers their quality of life and rehabilitation potential. Medicare pays 80% of the cost for the anti-anemia drug EPO, a synthetic hormone which stimulates red blood cell formation (red blood cells carry oxygen throughout the body). Kansas Medicaid does not. At this point 14% of our patients have inadequate coverage for EPO.

→ Following a transplant, the anti-rejection medicine, Cyclosporine, must be taken forever. It is covered by Medicare at 80% for only one year post transplant. Medicaid covers it with prior authorization. However, 7% of Kansas transplant patients have limited or no coverage for this drug which costs an average of \$6,000 annually.

ESRD is a fatal illness, but dialysis and transplant are proven means to extend useful life. Others presenting testimony after me will discuss quality of life issues and the reduced level of stress felt by Missouri Kidney Program eligible patients compared to Kansas patients. In your deliberations, I ask you to consider all of the facts presented as well as the potential return on Kansas' investment through greater rehabilitation. Your support and passage of H.B. 2016 will be greatly appreciated by ESRD patients, families and professionals.

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Attmt 5-4



KANSAS KIDNEY PROGRAM  
FINANCIAL PROJECTIONS  
(Based on Current ESRD Population)

DIRECT TREATMENT-RELATED EXPENSES

- A. Hospital Benefits \$ 401,200.00  
25 new patients have no coverage for surgery or inpatient expenses during 3 month Medicare waiting period @ \$10,000/patient
- 76 patients have no secondary coverage for inpatient hospital expenses @ \$1,200/patient:
- 10 patients have no secondary coverage for transplant work-up, hospital surgery, etc. @ \$6,000
- B. Outpatient Dialysis Benefits \$ 809,000.00  
25 new patients have no coverage for dialysis during Medicare waiting period @ \$5,000/patient
- 76 patients require dialysis and have no secondary insurance @ \$4,000/patient annually

INDIRECT TREATMENT-RELATED EXPENSES

- A. Transportation \$ 205,200.00  
171 patients need transportation assistance @ 1,200/patient/year
- B. EPO \$ 454,584.00  
25 patients have no coverage for EPO during Medicare 3 month waiting period @ 1,560/patient
- 19 patients have Medicaid only - no coverage for EPO @ \$ 6,240/patient
- 238 patients have no secondary coverage for EPO @ \$1,248/patient
- C. Cyclosporine (anti-rejection) \$ 244,800.00  
34 patients have no secondary coverage @ \$1,200/patient/year
- 34 patients have no coverage after first year post-transplant @ 6,000/patient

*P.H.W.*  
*1-30-91*  
*Attn # 5-5*

C.	Other Medications	\$ 718,800.00
	599 patients need financial assistance for meds @ \$1,200/patient/year (dialysis)	
D.	Premiums	\$ 198,684.00
	105 patients need Plan D (under 65) @ \$1,200/patient/year	
	114 patients need Plan 65 or AARP @ \$486/patient/year	
	48 patients need assistance paying Medicare Part B @ \$360/patient/year	
E.	Transplant Assistance	\$ 16,500.00
	Donor assistance	
	4 patients need help for family member to donate (living expenses) @ \$2,000/patient	
	Recipient Assistance	
	20 patients need assistance with living expenses during followup after transplant @ \$425/patient	
F.	Education	\$ 72,832.00
	In-community pre=dialysis education for patients, donor awareness education for community, professional education	
G.	Research	\$ 75,000.00
	Prevention, innovations and cost-containment	
	ADMINISTRATIVE COSTS (5% Of Total)	\$ 159,830.00
	*Includes staff salaries, costs of per diem for Advisory Commission, equipment & supplies	
	TOTAL BUDGET REQUESTED	\$3,356,430.00
	Estimated cost/Kansas ESRD patient \$ 2,205/year	

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Attn # 5-6

Average Cost per Dialysis Treatment

Supplies for treatment:

Needles Fistula (2)	\$11.00
Dialyzers (depending on size)	\$50.00-70.00
Concentrate	\$11.00-12.00
Blood Lines	\$ 4.00- 6.00
Transducers	\$ .50- .75
Normal Saline (2-3 bags)	\$ 2.00- 3.00
Needles for Heparin/Lidocaine	\$ .30- .50
Gloves (2 pair)	\$ 2.00- 3.00
PVP Wipes	\$ .05- .10
Lidocaine	\$ .07
Heparin (average)	\$ .30
Dressings	\$ .32
Tape	\$ .05
IV Line	\$ 1.00

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Total \$170.00

Patient transportation to and from unit-1 to 2 hours.

Patient treatment time (put on, take off, waiting time)-4 to 5 hours.

Machine cost- \$13,000 to \$15,000.

Staff time for patient care (not ancillary) for average patient time-- \$65.00 to \$85.00.

The water and electricity needed to run the machine have not been calculated into the cost.

The price of the machine and maintenance costs were not included into the cost per treatment.

*P.H.W.*  
*1-30-91*  
*attm # 5-7*

Thank you for providing me with an opportunity to speak to you in favor of House Bill 2016 (The Kansas Kidney Program). I am a Kansas resident and a nephrologist. I have practiced nephrology at Saint Luke's Hospital in Kansas City, Missouri since completing my fellowship in this specialty in 1982.

Because of my hospital's location near the state line of Missouri and Kansas, my patient population consists not only of Missouri residents but also fellow Kansans who are faced with end stage renal disease and who require dialysis and/or kidney transplantation to remain alive.

The technology of the artificial kidney (or Dialysis) is marvelous but because it is man-made, it has limitations when compared with the normal anatomy and physiology of the native kidney. Medication and diet modifications must be initiated along with dialysis in order to insure the best medical outcome. If these treatments cannot be conducted at home, the additional problem of getting to and from dialysis must be addressed and the emotional toll for the individual and his loved ones continues to mount. There is so much to learn, so much to monitor and so much to worry about.

The courage of the individuals on dialysis and their families never ceases to amaze me. They must face living each day with a chronic illness that affects not only their physical health but can also have significant impact on their emotional well being and self esteem as they face living in a world where productivity and being independent are highly valued and not easily maintained or achieved in the face of this kind of adversity.

The medical field has continued to increase its' understanding of the immune system, and renal transplantation survival rates have continued to improve, but it must be noted that although renal transplantation is the ultimate goal for the majority of people on dialysis, there are limitations at this time. These includes limited number of kidneys available for transplantation and limited knowledge of the immune system and medications to insure a 100% success rate. There are a group of patients whose immune systems are capable of rejecting the vast majority of available kidneys, and research will have to address their problem on the levels of the immune system and medication, but in the interim dialysis is a necessity for them.

Individuals who suffer from renal disease are from diverse backgrounds and although they share the common bond of loss of renal function, their response and needs are variable both on an emotional as well as a physical basis. There are no quick fixes or easy answers.

The Kansas Kidney Program would benefit some Kansans who have renal failure by relieving stress and some fiscal problems (i.e. they wouldn't have to choose between a prescription for blood pressure medication and food for the family.) Some Kansans with renal failure could benefit from the educational program designed for

*PKW*  
*1-30-91*  
*Attn # 6*

pre-dialysis patients and their families. Others would be relieved to know they could get to dialysis and back home three times per week.

All Kansans, however, would benefit from the knowledge that should the need arise in their lives or the lives of loved ones, the Kansas Kidney Program would be there for them.

Sue Anderson, M.D.  
Nephrologist  
St. Luke's Hospital  
Kansas City, Missouri

PH+ll  
1-30-91

Allen # 6-2

I speak in support of House Bill No. 2016. I am a nephrology physician who provides medical care for patients with failed kidneys who require dialysis in order to survive. There are several areas where Medicare-Medicaid-and Private resources do not cover costs for patients, yet, were the costs covered, other larger expenses could be obviated.

For instance, in the early months of chronic hemodialysis (before Medicare or Medicaid coverage), patients may not buy medications because they have no remaining funds for food or children. Other patients fail to buy prescribed expensive medications or medical supplies such as chem strips for self blood glucose testing. Such patients have been hospitalized due to severe hypertension or diabetic problems.

*R D Porter MD*  
Robert D. Porter, MD  
Nephrologist

*P.H.W.  
1-30-91  
Attachment #7*

# COMMUNITY DIALYSIS SERVICES OF KANSAS CITY

*D. Duncan*

9367 West 75th  
Overland Park, KS 66204  
Tel. (913) 381-7800

Honorable legislators, Staff Members, and Fellow Kansans:

As a nephrologist in Johnson and Wyandotte Counties since 1983, and as the Medical Director of the largest dialysis unit in either county - I write on behalf of my patients.

Born and raised in Kansas, I am deeply concerned about health problems patients on dialysis suffer, not only from the illness that lead to the need for dialysis, but also for the many complications which may afflict them related to kidney failure. These medical problems lead to great personal stress, but then the added burden of family strain, worry, anxiety, and depression, and financial worries usually compounds these problems several-fold. I ask for your help in easing some of the burden these patients share. A Kansas Kidney Program may help ease the severe financial strain these patients suffer, as I will explain further.

Diabetics are the fastest growing segment of the dialysis population, and the elderly represent the fastest growing age group. Both groups represent a very high utilization of medical resources related to multiple complications of their illnesses. One hundred percent of my patients have financial concerns, and many of them are severe. Three primary areas focus their financial concerns: medication, hospitalization, and transportation.

*PHW  
1-30-91  
attm # 8*

There are many excellent medicines available, but many of these are new and very costly. With appropriate medications properly administered, a significant reduction could be made in patient morbidity, leading to improved health, lower hospitalization rates, lower utilization of other medical resources, and overall lower total cost. Many of my patients refuse new medicines or refuse to take the ones I have ordered due to cost. Another group dutifully tells me how well they take their medications and deny missing doses, when, in reality, tests indicate they do not take these medicines. I believe they bend the truth so they won't have to tell me they can't afford them, and to avoid disappointing me as their physician. By helping these patients purchase the medications they need, the overall health care cost should be reduced.

A second primary financial concern for my patients is hospitalization, including outpatient surgery, diagnostic studies, and tests. Approximately one-third to one-half of my patients delay or never obtain needed procedures or diagnostic studies because of cost. One patient with severe bone disease in her spine constantly refuses hospitalization, out patient therapy, referral to specialists, and even some analgesic medications because of the bills she will incur, even though her pain is with her continuously, completely limiting her lifestyle. Several other patients take whatever samples I can provide for them for their bone disease, heart disease, high blood pressure, infections, or other needs, and they simply do without when these samples run out and I am unable to locate any more. Obviously, untreated illness leads to more disease and increased utilization of the health care dollar overall.

PHecc  
1-30-91  
8-2



My third primary concern for my patients is transportation, Most of my patients cannot drive due to medical problems or to inadequate financial resources to own a car. All of these people depend on others to provide transportation to dialysis, to the doctor's office, and to the pharmacist. One of my Medicaid patients, with serious health problems who lives alone, must walk several blocks to her Medicaid provider's office to obtain a written referral to see a specialist when she needs to do so. But then, she often delays her visit to the specialist until she can find someone to take her there since the distance is greater. When the choice comes down to paying for a cab to dialysis or for food, medicine, or tests, most patients choose to pay the cab and do with less of the rest. The Catch-22 for Medicaid patients on dialysis is that their financial worth must be minimized in order to qualify for Medicaid. This often involves selling their car and their home, leading to a lack of transportation to the dialysis treatment they require. Also, new regulations by the Department of Social & Rehabilitation Services requiring that transportation for nursing home patients be paid by the nursing home will discriminate against dialysis patients.

I am also concerned that after attempting to pay for hospitalization, medication, and transportation, many patients have few funds left over. Thus, the very specialized diet they need suffers because they can't afford to buy the proper food items, leading to other health problems. A few dialysis patients don't want to consider the change a transplant would require in life because they have finally figured out how to make ends meet - barely. Many other patients - after dealing with medical and financial problems - have little, if any, money left over for simple pleasure and fun which

*PKW*  
*1-30-91*  
*8-3*

is so vital for these patients in whom depression is a frequent and serious problem. The cost of all of this is enormous for individuals, and this has contributed to the decision to discontinue dialysis for several of my patients, leading to their deaths.

Honored legislators, I could discuss a multitude of other concerns of this variety that I share with my patients, but time is unfortunately limited. I implore you to help your fellow Kansans in the hour of their greatest need, and to help provide for a Kansas Kidney Program so that these patients can lead a life that has a somewhat greater semblance of normal than it does now. The burden they bear is so great, can not we help our fellow man by sharing this burden? Please create a Kansas Kidney Program urgently.

Yours in concern,

Kirk A. Duncan, M.D., F.A.C.P.

PHred  
1-30-91  
J-4

7

**Johnson County Dialysis, Inc.**

10405 West 84th Terrace  
Lenexa, Kansas 66214  
(913) 492-2044

Kansas House Public Health & Welfare Committee Testimony

January 30, 1991

Honorable Members of the Committee:

My name is Richard A. Huseman, M.D. I have been a nephrologist in the Kansas City area for over 13 years and have owned and operated a free-standing dialysis clinic in Lenexa, Kansas, since 1983. I have always accepted Medicare assignment for my fees and dialysis charges. I wish I could present my testimony in person, but because of a heavy schedule of patient appointments, I am unable to attend.,, Therefore, I ask that my testimony be read into the record.

Since 1977, I have seen considerable growth in the ESRD population and those at risk for ESRD. Diabetics and elderly patients make up the fastest growing segment of the ESRD population. Hypertension and glomerulonephritis are other common causes of kidney failure.

My facility serves 59 Kansas and 12 Missouri patients. Of these 24% are home dialysis patients. Although our facility is located in an affluent county, many of our patients face great financial hardship associated with their diagnosis and essential treatment. Fully 25% of the patients treated at our facility are Medicaid eligible and many others could be considered medically indigent although over Medicaid guidelines. We have an open unit policy and accept patients from K.U. Medical Center when their facility cannot accommodate the need or the patient requires higher technology they cannot provide.

residents and requires nursing homes to pay associated costs from their current per diem, the nursing home requires that the patient come to our facility by ambulance reimbursable by Medicare and Medicaid. The patient has diagnoses to justify this transportation, but this is in direct opposition to our unit philosophy which promotes patient rehabilitation and independence and, in our opinion, is medically and fiscally unnecessary. The patient is being transported at a charge of \$300 each way three days per week when she could be transported by a private wheelchair van for approximately \$20 each way or by Special Services wheelchair van at a current cost of \$2 each way. If transportation assistance were available to reimburse a patient like this one, such abuses of the system could be eliminated saving federal and state funds.

I am appealing to you for your support of H.B. 2016. The comparably small level of funds requested could not only save patients lives and health, but could be very cost effective to the State of Kansas. Remember our people are our state's best resource. Thank you for your consideration of H.B. 2016.

*PH+CC*  
*1-30-91*

*Attn 9-2*

# COMMUNITY DIALYSIS SERVICES OF KANSAS CITY

## KANSAS KIDNEY PROGRAM LEGISLATURE COMMITTEE MEETING

9367 West 75th  
Overland Park, KS 66204  
Tel. (913) 381-7800

Honorable Committee Members:

My name is Jim Hafner. I am a Social Worker for Community Dialysis Services of Overland Park and also work at our other facility, Community Dialysis Services of Northland, in Missouri. Several Kansas residents dialyze there because of proximity and availability of dialysis machines. Together, I provide care for some 170 patients, 88 of whom are Kansans. I have worked in the field of dialysis for some 3-1/2 years and am presently the chairperson of the Council of Nephrology Social Workers, Kansas and Western Missouri Chapter.

I have seen changes in the health care field over these years which have affected the quality of care and quality of life that our patients must endure. It is for this reason that I wish to encourage you to envision what life may be like dealing with a chronic illness, the many adaptations people who go on dialysis must face, and the concerns and stresses that plague their daily existence.

For the most part we all take for granted that we will be spared from any health afflictions or tragedies, but that is not always the case. For many patients kidney failure comes about suddenly. People feel sick, go into the hospital, and then are confronted with the crisis of having kidney failure. They have to decide what type of treatment to choose, whether in-center hemodialysis or some form of home dialysis. The concern for cost for treatments, the additional demands for medication, transportation expense and dietary changes also abruptly impacts them. Even those with some forewarning of kidney failure are not as prepared for this when dialysis begins.

PH & WS,  
1-30-91  
att #10

People hope to return back to work, maintain a reasonable standard of living and feel that adjustment with their kidney failure will be minimal. For those of us who have adequate financial resources to fall back upon, some sense of security can prevail as we encounter these demands. For others who do not, becoming involved in the bureaucratic processes for Social Security Disability, Medicare coverage, and possible state Medicaid or spenddown coverage can take time and leave people with minimal support to fall back upon.

For those kidney patients who are residents of Missouri, the Missouri Kidney Program provides not only a safety net but on-going support to help meet the need for medication, transportation and insurance premium expenses and allows the patient some comfort to emotionally cope with their illness. So many times the aspect of denial towards their illness and the changes that must take place is the only way people can cope to minimize the adjustment to dialysis. The beginning of dialysis is a crucial time for adjustment. The more support a patient can have to relieve their pressing concerns, especially financial, the more positive will be their compliance with their regimen, the quicker they will regain a sense of control over their life, maintain a sense of responsibility and self-esteem and hopefully return to more higher functioning either at home or work.

Because of the Missouri Kidney Program assistance, a patients transition to dialysis is enhanced and potential liability of additional medical expenses from the aftermath of poor compliance are reduced. For some Kansas patients living close to the state line, their dialysis treatment can be in facilities in the State of Missouri. Kansas residents are not restricted to receive their treatments in a facility within the State of Kansas. Whether having been followed by physicians who practice in Missouri or who have hospital privileges in a facility in Missouri, a person may chose to then receive their care in a facility outside the State of Kansas. As a resident of the State of Kansas, they come in contact with Missouri residents who have access to the <sup>if</sup> missouri Kidney Program and who have been eligible to benefit from their services.

PHW  
1-30-91  
10-2

Honored committee members, do the State of Kansas proud by taking leadership in not only considering the costs involved in helping kidney patients, but foremost in showing how this state can lend a helping hand for those needing help from overwhelming burdens, thereby raising the dignity and self-worth that we all value in ourselves. I implore your help so that we as professionals, can indeed bring about the highest potential in an individual for adapting and adjusting to this life threatening ordeal. Please follow your conscience in supporting our endeavors.

Thank you.

PHW  
1-30-91

Attm # 10-3

**KANSAS KIDNEY PROGRAM**  
**PUBLIC HEALTH AND WELFARE**  
**COMMITTEE MEETING**

**January 30, 1991**

Honorable Members of The Committee:

My name is Scott Buckley, and I appreciate this opportunity to appear before you and offer my thoughts on the need for the Kansas Legislature to reestablish and finance a Kansas Kidney Program. I would like to note, at the outset, that in addition to being a kidney patient, I have been involved in health care planning and policy development for more than 10 years, including 4 years working for the Kansas Department of Health and Environment's Health Planning Program.

I am currently employed as a private health care consultant, and count among my firm's clients about 25 Kansas hospitals. In this capacity, I understand the many financial pressures hospitals and their patients face. I also readily acknowledge that your responsibilities as legislators are quite difficult, and I appreciate the complexity of deciding how to allocate limited state resources to so many urgent and worthy requests.

With that said, I would like to offer my feelings about why I would like this Committee to give priority to the financial needs of both dialysis and transplant patients. I speak as one who has spent more than half his life dealing with kidney disease, having been diagnosed with chronic glomerulonephritis in 1972, when I was 18. I was fortunate to have a caring brother donate one of his healthy kidneys to me when I was 20; my first transplant lasted 11 years and in 1985, when its function was insufficient, I initiated continuous ambulatory peritoneal dialysis (CAPD). After waiting more than two years for a suitable kidney, I underwent a second transplant at the University of Kansas Medical Center in October, 1988; largely because of the advances in preventing rejection, particularly through the use of the immunosuppressive drug cyclosporine, my new kidney functions as well as if it had always been my own, even better than the kidney I received from my brother. I also gratefully acknowledge the critical role played by the highly competent and caring

*PH+W.  
1-30-91  
attm #11*



transplant team at KU; they have become a part of my extended family and represent, in my estimation, one of Kansas' most valuable resources.

I am more fortunate than many other kidney patients because I've had two successful transplants and have been able to finish college and graduate school. I've also been able to continue to work even while on dialysis. Although I've been relatively free from financial worries, I do have a good understanding of those concerns and problems which are common to all kidney patients. The first of these, of course, is to achieve the best possible state of health through an effective dialysis regimen, and thereby obtain a decent and acceptable quality of life. The second is to have enough money to buy basic necessities. These two concerns are not distinct, however; in order to maintain effective dialysis and enjoy a good quality of life, one must be able to buy and eat the right foods, purchase medications, and be relatively free from financial concerns that detract from self-esteem and motivation.

When I initiated dialysis again in 1985, and as my disease progressed, my wife and I faced a period of uncertainty and fear as we considered the potential loss of my job and insurance. Having been married for a short while, we were apprehensive about our future and continued happiness. Had my disease been more complicated and debilitating, and I been forced to quit work, then the financial demands of dialysis would certainly have diminished the quality and satisfaction of our lives, and made financial survival a harsh reality to address, taking precedence over our desire to maintain a healthy and supportive relationship and a near normal lifestyle.

Because I've been able to work throughout my illness, I've been eligible for insurance benefits that were in addition to my Medicare coverage. Currently, my out-of-pocket costs run approximately \$2,800 annually, while my total costs, including what my insurance covers, are about \$8,000 annually.

I believe that my out-of-pocket costs are small, given the invaluable and luxurious benefits of a well-functioning kidney transplant. I don't know of a price that would be unreasonable to pay for good health; I do know, however, that I would prefer not to have to make choices between having a blood test when I become worried about potential rejection, or to check the medication level in my blood. Like many other people, I would probably choose, perhaps not consciously, to delay periodic checkups and tests rather than add to my medical bills.

PH+U  
1-30-91  
Attn #  
11-2

I believe, also, that were I faced with the need for another transplant, and were without a job or insurance to assist me in buying my medications, I would seriously consider whether to remain a dialysis patient. Although other, less expensive medications are available to prevent rejection, they are not as effective as cyclosporine, or other drugs currently being developed. The loss of a successful transplant, especially because the proper medications were not affordable, could be worse than continued dialysis, where survival can be maintained, but where quality of life is difficult to achieve.

The difference between how healthy I feel now and how I felt on dialysis is astonishing. The normal results of my blood tests do not begin to describe my new found vitality. Because of this transplant, I feel as I did when I was 18 years old. Each day I feel more alive and capable; being able to devote myself more to my work, or accomplishing a new physical feat, such as being able to go swimming or mow my lawn. In contrast, while on dialysis, I felt as if my life was, at best, in a holding pattern; at worst, each blood test showed further deterioration in my physical health. My goals on dialysis were to conduct my treatment appropriately, to follow a strict diet to ensure my blood chemistries remained in an acceptable range, and to use my limited energy to continue working. Now, my goals reflect my appreciation and wonder for my new kidney function; now, I try to promote and protect my health and to use my vastly increased energy in a more meaningful and productive fashion.

I do have a simple fear and a genuine concern. I fear that one day I will no longer be able to pay for cyclosporine or other health care costs. I am also concerned for those who are unable to have a transplant because of their inability to buy this vital medication, and for those dialysis patients whose treatment and lifestyle must be compromised because of financial limitations. Without cyclosporine, much of my appreciation and enjoyment of life would be lost; without the opportunity to have a transplant, many others would not experience the joy of newfound health; and without basic financial support, many dialysis patients will continue to struggle with paying bills, before they are able to deal with the physiological and psychological demands of dialysis and staying alive.

In closing, I would like to emphasize that many factors have contributed to my well-being, both as a dialysis patient and a transplant patient, not the least of which has

been my wife and family. I've also been helped through a satisfying job and by the outstanding members of the renal team at KU. Although I have been bolstered with all of this support, the availability of financial resources to meet basic needs took away some of the burden, alleviated my worry, and enhanced my quality of life. I ask that you seriously consider the merits of this modest request presented by the Kidney Foundation and extend financial assistance to those patients who are otherwise unable to obtain it.

Thank you.

w3\ekidney

PHW  
1-30-91  
Attn # 11-4

*Cathy Baer*

My name is Cathy Baer. I am a Social Worker currently employed by Kansas Dialysis Services (KDS) in Topeka. Kansas Dialysis provides services in Topeka to 61 incenter patients and 34 home dialysis patients. The KDS satellite unit in Ottawa, Kansas, provides incenter dialysis to 10 patients. Of this total 105 patients, less than 1/4 qualify for Medicaid assistance, and several of those must meet a spend-down before Medicaid becomes effective.

Financial hardship appears in three primary areas:

1. Patients must manage the cost of transportation to and from dialysis three times a week. For patients who must drive over 45 miles one way, that amounts to over 1000 miles a month.
2. Patients may have a secondary insurance to Medicare, but rarely does that insurance cover the cost of medications which can often run between \$100-\$200 a month.
3. Patients must adhere to severe dietary restrictions requiring purchase of foods which are more costly in addition to the purchase of foods needed for family members.

Though I have been working with End Stage Renal Disease patients for 3 1/2 years, I have also had the opportunity to work as a social worker in a hospital unit. This provided me the opportunity to work with patients with a variety of newly diagnosed diseases, e.g. chronic pulmonary disease, chronic heart disease chronic gastro-intestinal disease and cancer. No disease process that I have yet encountered requires such constant vigilance as does End Stage Renal Disease.

The psychological impact of renal failure is devastating. The social and emotional ramifications are far reaching (loss of job, higher education interrupted, dependence on family and social support maximized to the point of emotional overload).

All of the above issues are further compounded because of the high financial cost to dialysis patients. The cost of transportation, medications and special dietary needs can simply not be met. Though local resources are utilized by the patients and myself-the limited community resources do not even begin to address the chronic financial needs of the End Stage Renal Disease patient.

I am constantly amazed at the tenacity with which dialysis patients face the financial hardships which daily impact their sense of self worth, their value to family and society. Renal dialysis patients represent the resiliency of the human spirit; it is within your power to alleviate to some extent the burden of their daily suffering by passing House Bill No. 2016.

*Cathy Baer*

Cathy Baer, LMSW  
KDS Social Worker

*PHW  
1-30-91  
Attn # 12*

Kansas House Public Health & Welfare Committee Testimony

January 30, 1991

Members of the Committee:

My name is Fred Howell. I am asking support of HB 2016. In July, 1988, I suddenly suffered from kidney failure. My kidney failure was caused because of a lack of oxygen, in my blood, to my kidneys while I was asleep. The loss of kidney function has affected my life greatly. I have always been a very independent person. This kidney failure made me a very bad person. I was down for the first time in my life. I lost a new truck and all of my credit went down the tube. I was sick, lost my health insurance and if it wasn't for my son, would have lost my home. All of my utilities were turned off. It took five months for me to receive a small general assistance grant to help me maintain myself. My adult children's help is limited because they have families of their own and their own responsibilities. They are paying for my transportation to the dialysis unit when one or the other can not bring me or pick me up from dialysis. They help me with my food and medication needs until they started me on Medicare some 10 months later. Medicaid finally started paying for my Medicare Part B premiums about one-and-a-half years later.

I worked for the railroad for 10 years, but I missed Social Security Disability income by 15 hours. I have not been able to get back to full time work as I would like to. I have a friend who has a car repair service. I help him by calling around for parts and other small jobs. If not for my family, I couldn't have made it. My feelings about myself are very good now. I have come a long way. I feel that with this program I would have the access to health care that I need so that I could go back to work and things would be like before.

FHW  
1-30-91  
att # 13

## TESTIMONY REGARDING HB 2016

My name is Jean Marie Tressler and I live at 10304 W. 62nd Street, Shawnee, KS. I have been on hemodialysis for two and one-half years. I have end stage renal failure from an undetermined cause. My life has been greatly affected by my illness. Before starting dialysis, I was living in my own home in Prairie Village. I was working full time as a child care provider, and my life was relatively full. After I began dialysis, I had to sell my home at a loss, as I was no longer able to maintain it properly. I also lost my job. The life I knew before dialysis was a thing of the past.

The financial costs of being on dialysis have been devastating. I have much difficulty paying for medications, transportation, and other health care costs. Chief among these is the cost of medications. Even with Medicare and Medicaid, I must pay an average of over \$90.00 a month. Many of the medications are not covered by Medicaid and there are times when I must forego certain prescriptions as I do not have the funds to pay for them. This not only adds to my ill health but also adds to the ever increasing amount of stress and depression that I, as a dialysis patient, suffer. The passage of House Bill 2016 would change all of that. It would mean I could take all of my medications, all of the time, thus greatly improving my general state of health, lowering the frequency of costly hospitalizations, and reducing the stress factor in my life. I feel that I could then possibly return to work, at least on a part-time basis. I would then feel like a productive citizen once again. I could continue to have an independent lifestyle and could partake of the quality of life that I enjoyed before suffering renal failure.

I have considered moving to Missouri in order to be eligible for these services, particularly if I were to have a kidney transplant and had to take additional medications, including Cyclosporine and other drugs. Moving would present a hardship for me as I have no funds for security deposits and moving expenses. I am a woman who lives alone, and it is mandatory that I find decent, safe housing. Passage of this bill would enable me to stay in Kansas and allow me to be an asset to the state, financially and every other way. My dream is to have a kidney transplant and to have the kind of assistance with medications and other health care costs that would enable me to return to the life I knew before. However, even if I am never able to realize that dream and must continue on dialysis, I want to be as active, independent and productive as I possibly can. The kind of assistance that would be provided under House Bill 2016 would help make that possible.

DHAW  
1-30-91  
Attm # 14

I, Patty Molinar, am asking you to please support House Bill No. 2016 for the following reasons. I have Type One or Juvenile Diabetes. It has caused major medical problems in my life. One of them is renal failure. I have suffered Renal Failure since November 1989. I have also suffered from Diabetic Retinopathy which has left me legally blind. I chose to go on hemodialysis due to personal and diabetic related reasons. These medical problems have totally devastated my life.

I had to quit my job as a Data Entry Operator for Volume Shoe, which has cut my income to one-third the amount I was used to, I am drawing Social Security Disability in the amount of \$536.00 a month. This amount doesn't even cover my rent and utilities. I do receive food stamps, but it doesn't cover all the food expense I have monthly. I also receive a medical card for my family but I have to meet a \$468.00 spin down before Medicaid will cover any medication, doctor bills, or transportation.

There have been times when I have had to choose between buying food for my family and buying the medicine I have to take daily. I have gone two or three months at a time taking the medicine only when I felt sick. Sometimes I don't even have one dollar to get my medicine with my medical card.

I have two forms of medical insurance at the present time, but as of March 1st, my insurance through Volume Shoe will expire. I will still have Medicare but it will pay only 80% of my medical bills and dialysis treatments. I have called several insurance companies to check on premiums. What I found out is that some of them won't even cover me, and the others will cost me between \$150.00 to \$250.00 dollars. With my income, I cannot afford a second insurance.

My kidney failure has not only affected my life, but also the lives of my family as a whole. My husband is scared to leave the house for fear something might happen to me, and he won't be there to help. My children have fears of mommy dying. In order to go anywhere, I have to depend on a family member to take me.

I have always been a self-dependent person, and now I have to depend on others. This has lowered my self esteem greatly. I feel worthless because I can't work to help support my family. I can't buy the things my children want or need. At times I have felt like life isn't worth living. But, I go on because I dearly love my family and I feel I must be strong for them.

P44W  
1-30-91  
Attn #15

I could go on and on, but I feel I touched on most of the reasons  
I would like to see this bill passed.

Sincerely,

*Agnes P. Molinar*  
Agnes "Patty" Molinar

*PHEW  
1-30-91  
Attn # 15-2*



*Patricia*

I am asking you to support HB 2016 because the hidden costs associated with dialysis can be financially devastating.

As an end stage renal patient with polycystic kidney disease, I began dialysis on December 12, 1990 after a slow but steady deterioration in kidney function which spanned the last five years. Upon learning that this deterioration was imminent and would mean a dramatic alteration in lifestyle, I experienced an episode of major clinical depression which brought me to Topeka for treatment at Menninger's. Although this hospitalization and the ongoing psychotherapy I have received has allowed me to become more realistic in my appraisal of my life options, it was also my ticket of admission into a healthcare system which can financially deplete while at the same time restoring physical or emotional health.

For the past four years I have either been unable to work or able to work only part time due in part to my dual disabilities (depression and renal failure) as well as the regulations imposed upon me by State and Federal sources of financial assistance. As a Social Security Disability recipient, I have just enough income to make qualification for State Medicaid and Food Stamps programs difficult but not enough income to cover all living expenses and medical costs which remain uncovered by my insurance policies. The attached income/expense sheets will demonstrate the high percentage allocation of my meager assets to health care costs not covered by any other source.

Two weeks into my dialysis treatments (which occur 3 times weekly for 3 and 1/2 hours per day) my graft or access clotted requiring surgery. As is common with many dialysis patients, I have also developed anemia, with the source of internal bleeding still left to be determined. This has resulted in extreme weakness, nausea and sharp blood pressure drops which are unpredictable and can cause fainting. Under these circumstances I have found myself unable to get to and from dialysis treatments independently, unable to prepare meals necessary to the maintenance of weight and nutrition, and unable to manage the ordinary household tasks such as cleaning or laundry. Transportation, meals, and home health care costs are not covered expenses by any insurance program available to me and yet each of these items is at times imperative to my functioning. In addition, there are numerous vitamin and calorie supplements which I require (see expense ledger) and are not covered by insurance. Frequently a choice must be made between food and heat or drugs and services... all of which are survival items.

I am limited by Social Security Disability regulations to earning a maximum of \$500 a month in addition to my benefits. During the 20 months between the date of my shunt surgery (in preparation for dialysis) and the end of the third month of dialysis when I will be considered a chronic end stage renal patient, my SSDI benefits as well as my Medicare benefits would be at risk of being withdrawn if I were to attempt to engage in "substantial gainful activity" (i.e. earn more than \$500 a month). This would result in my being responsible under my former insurance policy for 20% of all dialysis costs for the first three months as well as all other previously mentioned hidden costs. In essence, due to this illness I can now characterize myself as a part of the infamous "working poor" when at one time I was a stock-broker for a Wall Street firm functioning well with a high stress profession. It is fair to say that at times the stress of managing the financial, psychological, social and health consequences of ESRD exceeds the stress which I experienced as a broker.

*PKW*

*1-30-91*

*Attn #16*

The actual loss of kidney function has affected my life in numerous ways. When unable to work or when forced to work in positions below my level of education or previous responsibility I have at times questioned my very right to exist. I am a born contributor, driven to achieve. This illness has simultaneously curtailed my means of economic contribution and challenged my creativity in finding new ways to define contribution. Consequently, I vacillate between feelings of guilt/shame and feelings of profound inspiration as I redefine who I am and what I'm doing in a society prone to valuing people by virtue of their results.

ESRD is fraught with ambiguities. It is impossible to predict from one treatment to the next how I will feel afterwards, or whether my shunt will clot, requiring surgery. If I receive a transplant, it is impossible to predict whether it will be successful or if I will return to dialysis. As a young woman, I struggled to remain free of all structured, predictable situations. But as the medical ambiguities mount, I find myself clamoring for routine and structure and control in as many other aspects of my life as possible. Lacking control over my body has often left me feeling helpless and fearful as I contemplate my ability to exert control over other aspects of my life.

Chronic illness poses many challenges to all interpersonal relationships. Chronic illness confronts others with the issue of mortality while many of us would prefer to remain in denial. When the illness is a relatively "invisible" one such as renal failure, it is often difficult or tedious to constantly communicate one's needs so they can be met. Requests for legitimate assistance can stress some relationships to the breaking point. As a single woman I find that gender plays a role in this. I find that fewer men are prepared to be occasional caretakers than are women and for me this has meant the dissolution of more than one valued male relationship. Research supports my experience in this regard.

Whereas disabilities resulting from an accident can more easily be understood as happening "to" someone, I have frequently been asked what I did to "cause" my renal failure. In our health-conscious society, illness itself is seen as a kind of "failure".

Within my family this illness has caused disputes to arise amongst my siblings around allocation of parental resources--both financial and emotional. For me, this causes a vacillation between guilt and gratitude for what I receive.

With regard to employment, it is extremely difficult to describe my potential limitations, not to mention the logistical difficulties of finding a way to work a 40 hr. week when more than 10 hrs. of my week is devoted to dialysis. By the time I have finished my treatment, come off the machine, eaten lunch and rested, it is easily 1:00 in the afternoon; few professions will accommodate a full time schedule which begins mid-afternoon three days a week. There are no evening dialysis shifts and I cannot dialyze at home because I do not have a partner. When accommodations are made for my special needs, it is not uncommon to face open resentment from co-workers who perceive these accommodations as special privileges.

At this time, I do not have access to the level of health care I require which is why I implore you to pass this bill. In almost every instance I am someone who falls through the cracks of our healthcare system and unfortunately there are many others like me who need your help. This bill, if passed, would be a start.

Patricia Pooley

*Patricia Pooley* PHCW  
1-30-91

*attm # 16-2*

INCOME:

742 (SSDI)

EXPENSES:

psychotherapy: 8 sessions x \$20=	160
Blue Cross premiums	= 108.75
Medicare premium	= 31.00
calcium supplement	= 8.49
Iron supplement	= 3.29
Multivitamins	= 6.82
Calorie supplement	= 49.00
Transportation (cabs)	= 76.00
(5 round trips in December)	

\*\*\*These expenses (minus cab costs) equals  
49.5% of my income

*PHed*  
*1-30-91*  
*Attn # 16-3*



NAME \_\_\_\_\_

DATE \_\_\_\_\_

LAB TEST	YOUR VALUES	ACCEPTABLE RANGE	MAJOR FOOD SOURCES	CAUSES	COMPLICATIONS
BLOOD UREA NITROGEN (BUN)	This Month _____ Last Month _____		<u>Protein:</u> Meat, eggs, milk, cheese, dried beans, poultry, fish and other seafoods.	<u>Too high:</u> Caused by eating too much protein (meat, fish, eggs, milk, etc.) <u>Too low:</u> Caused by not eating enough protein.	<u>Too high:</u> Nausea and vomiting, hiccups, and lethargy. <u>Too low:</u> Muscles broken down, edema, or increased serum potassium.
POTASSIUM (K+)	This Month _____ Last Month _____	3.8 - 5.5	<u>Fresh fruits and vegetables</u> esp. bananas, oranges, lima beans, greens, dried fruit, potato, etc. <u>Meat and milk</u> (excessive) <u>Salt substitute</u>	<u>Too high:</u> Caused by eating too many fruits and vegetables, esp. those mentioned in the preceding column, or over-eating meat and milk. <u>Too low:</u> Caused by not eating enough fruits and vegetables, bouts of vomiting or diarrhea.	<u>Too high:</u> DEATH!! Cardiac arrest, irregular heartbeats, tiredness. <u>Too low:</u> Muscle weakness, shaking.
PHOSPHORUS (PO <sub>4</sub> )	This Month _____ Last Month _____	4.0 - 5.5	<u>Milk and milk products:</u> such as cheese, yogurt, etc. <u>Dried beans and nuts</u> *Controlled by regularly taking phosphate binder (Dialume, Alucaps, Alternagel) as directed, with meals and snacks, and following diet.	<u>Too high:</u> Caused by not taking phosphate binder at mealtimes, eating too much milk, beans, or nuts, OR maybe phosphate binder needs to be increased. <u>Too low:</u> Caused by taking more phosphate binder than needed.	<u>Too high:</u> Itching, easily broken bones, hardening of blood vessels and blood organs leading to heart attack, difficulty breathing, and painful joints.

*Distric # 16-4*  
*1-30-91*  
*Actual*



LAB TEST	YOUR VALUES	ACCEPTABLE RANGE	MAJOR FOOD SOURCES	CAUSES	COMPLICATIONS
CALCIUM (Ca++)	This Month _____ Last Month _____	8.6 - 10.6	<u>Milk and other dairy products</u>  *Calcium supplement (Oscal, etc.) is often indicated in cases of low serum calcium.	<u>Too high:</u> Caused by taking too much Calcium or Vitamin D supplements  <u>Too low:</u> Caused by not taking calcium supplement, and/or phosphorus binder.	<u>Too high:</u> Calcium deposition in soft tissues such as walls of arteries and heart.  <u>Too low:</u> Low Calcium, together with high phosphorus, will result in bone disease; tingling of fingertips; abdominal cramps.
SODIUM (Na+)	This Month _____ Last Month _____	135 - 150	<u>Table salt, and commercially prepared foods</u>  such as ham, corned beef, luncheon meat, canned meat, salted seasonings, etc.	<u>Too low:</u> Caused by excessive intake of fluids.	<u>Too high:</u> Edema, congestive heart failure, shortness of breath; hypertension, excessive thirst, high fluid weight gains.  <u>Too low:</u> Low blood pressure, dehydration, and weakness.
OTHERS:  _____  _____  _____					

OATMAN # 16-5  
 1-30-91  
 PHRED