

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES.

The meeting was called to order by Chairperson Garry Boston at 1:30 p.m. on January 30, 2001 in Room 210 Memorial Hall

All members were present except:

Committee staff present: Dr. Bill Wolff, Kansas Legislative Research Department
Norman Furse, Revisor of Statute's Office
June Evans, Secretary

Conferees appearing before the committee: Dr. Arnold Z. Balanoff, Kansas Immunization Action Coalition
Dr. Michael Moser, Director, Division of Health, KDHE
Sally Finney, Kansas Public Health Association, Inc.
Jose Torrez, Developmental Disabilities Council
Terri Roberts, Kansas Nurses Association
Stan Newby
Marlin Rein, Kansas University Medical Center
Randy Williams, CEO, National Kidney Foundation for Kansas and Western Missouri
Trish Pooley, former dialysis patient and kidney recipient

Others attending: See Attached Sheet

The Chairperson brought the meeting to order and requested introduction of a bill concerning the Behavioral Sciences Regulatory Board (1rs0410).

The bill was introduced without objection.

The Chairperson continued the hearing on **HB 2041 - Concerning proof of inoculations; requiring hepatitis B.**

Arnold Z. Balanoff, M.D., FAAP, responded to a question asked the previous day which was how many cases of Hepatitis B had been reported in Kansas. Dr. Balanoff stated Kansas is low in comparison to other states, but being a mobile society all children need to be immunized (Attachment 1).

Dr. Michael Moser, Director, Division of Health, testified in opposition to **HB 2041**. The Department supports the goal of full immunization of our young people against hepatitis B infection. However, we do not believe that a statutory mandate to require hepatitis B immunization for school entry is a good public health policy for Kansas at this time and on that basis, we do not support this bill (Attachment 2).

Sally Finney, M.Ed, Executive Director, Kansas Public Health Association, Inc., testified stating KPHA strongly supports adding hepatitis B vaccination to the list of school entry requirements, but are concerned about using legislation to accomplish this. Current statute grants the secretary of health and environment the authority to enact regulations regarding immunization for school entry. KPHA supports the continuation of this policy and, therefore, asks that rather than acting on **HB 2041** a statement be issued directing the secretary to comply with national recommendations and use his regulatory authority to require immunization against hepatitis B for school entry (Attachment 3).

Josie Torrez, Kansas Council on Development Disabilities, Partners in Policymaking, Coordinator, testified stating they would like to see language added to this bill that parents are informed of the option to give the MMR immunization in three separate vaccinations. The MMR vaccination is given between the age of 15-18 months. Many children are diagnosed with autism at around this same age period. If the MMR can be offered split up, parents perceptions that the MMR immunization "caused" their child's

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autism would be eliminated (Attachment 4).

Terri Roberts, Executive Director, Kansas State Nurses Association, testified as a proponent of **HB 2041**, stating they supported a Hepatitis B school entry requirements to add the Hepatitis B immunization (Attachment 5).

Shari Sauer, Sterling, testified that her 2 sons have autism. No one knows what causes autism, however there is concern with the dramatic rise in the incidence rate that closely parallels the increase in vaccinations, particularly the MMR. Although a cause and effect relationship has not yet been established by scientific evidence, the current trend suggests research is imperative. Would ask your consideration to include in this bill or write a separate bill that would require health care providers to disclose the potential risks associated with the MMR, and give parents the needed information about immunizations to make an informed decision. Some evidence suggests that a schedule of breaking up the MMR into three separate immunizations may benefit some children who's immune systems cannot handle all of the shots at once (Attachment 6).

Written testimony only on **HB 2041** by Cindy Burback, RN (Attachment 7) and Chris Collins, Kansas Medical Society (Attachment 8).

The Chairperson closed the hearing on **HB 2041** and stated would open at a later time for questions

The Chairperson opened the hearing on **HB 2059 - Renal Assistance Program**.

Dr. Bill Wolff, Legislative Research Department, stated the Health Care Reform Legislative Oversight Committee concluded and recommended the enactment of a bill directing the Executive Vice Chancellor of the University of Kansas School of Medicine, with necessary support staff, to establish a program for the care and treatment of persons suffering from chronic renal disease who require lifesaving medications and transportation to treatment for renal disease. The Executive Vice Chancellor is to develop standards for determining eligibility of persons under the program, and may adopt rules and regulations necessary to properly administer and enforce the provisions of this act.

Further, the Committee found that a program to assist patients with the costs of medications and transportation to treatment for renal disease is worthy of state financial support and recommended the Legislature provide funding for such a program (Attachment 9).

Stan Newby, a proponent for **HB 2059** testified he received a kidney and pancreas transplant in 1995 after being a diabetic and on dialysis for renal failure. Medications for transplants are very expensive and believe this aid is of vital importance (Attachment 10).

Randy Williams, Chief Executive Officer, National Kidney Foundation of Kansas and Western Missouri, testified in support of **HB 2059**, stating that kidney disease ranked 8th as a cause of death in Kansas (Attachment 11).

Trish Pooley, testified in support of **HB 2059**, testified that transportation and medications are very expensive for renal disease patients and funding is necessary for these patients as they should not have to drastically lower their standard of living to pay for treatment (Attachment 12).

Marlin Rein, University of Kansas, testified stating the bill would direct the University of Kansas Medical Center to establish a program for the care and treatment of persons suffering from chronic renal disease who require lifesaving medications and transportation to treatment. The Executive Vice Chancellor of the institution would be authorised to appoint needed support staff to assist in the administration of the act and to develop standards for determining eligibility for care and treatment under the program. Finally, the legislation establishes within the State Treasury a renal disease fund. The University would be authorized to accept monies from any source to be credited to this fund to defray the costs of the program. While the act does not specify the source of those monies, one might presume that the state would be a source for at

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least a portion of the funding.

The University is going to be supportive of any initiative that extends quality healthcare to Kansans. Whether the University is the appropriate agency to be charged with administering the program envisioned by this bill is another issue (Attachment 13).

Written Testimony only: Stan Langhofer, Administrator, Kansas Dialysis Service (Attachment 14), Beth Witten, MSW, Life Options Rehabilitation Programs, Missouri Kidney Program (Attachment 15), Ronald R. Hein, National Kidney Foundation of Kansas and Western Kansas (Attachment 16), Scott Solcher, MD, FACP (Attachment 17), Wendy Funk Schrag, LMSW (Attachment 18), Robert Whitlock, Executive Director, Missouri Kidney Program (Attachment 19).

The meeting adjourned at 3:00 p.m. The next meeting will be January 31.

Report of cases of Hepatitis B in the state of Kansas 1990-1998

	Total cases	cases age 0-18
1990	39	10
1991	60	4
1992	66	8
1993	65	9
1994	31	3
1995	53	2
1996	32	1
1997	32	2
1998	28	1

Information provided by Stephanie Bialek of CDC

Submitted by Arnold Z. Balanoff, MD, FAAP
January 30, 2001

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KANSAS
DEPARTMENT OF HEALTH & ENVIRONMENT
BILL GRAVES, GOVERNOR
Clyde D. Graeber, Secretary

Testimony Presented to
House Health and Human Services Committee
by
Dr. Michael Moser, Director, Division of Health

January 29, 2001

Chairman Boston and members of the Health and Human Services Committee. I am Dr. Michael Moser, Director of the Division of Health at the Kansas Department of Health and Environment. Thank you for the opportunity to speak to you today regarding the legislation designated as HB 2041. The Department supports the goal of full immunization of our young people against hepatitis B infection. However, we do not believe that a statutory mandate to require hepatitis B immunization for school entry is a good public health policy for Kansas at this time and on that basis, we do not support this bill.

Hepatitis B is a large public health problem throughout the world. In other parts of the world, many children are infected as infants, a time in life when infections are far more likely to become lifelong and place the victim at risk of major complications. In the United States, infections among children are much less common and the vast majority of U.S. cases in recent years are occurring in adults. Sex and drugs consistently dominate the risk factors associated with hepatitis B cases in the United States in recent years. Elementary and middle school children register the lowest hepatitis B rates. In 1998 (the most recent year for which national data have been published), the Centers for Disease Control and Prevention's national surveillance system reported a rate of new hepatitis B infections among children ages 1 through 14 that was less than one in 100,000. Among the states, Kansas consistently ranks in the lowest range of documented case occurrence. Annual rates of confirmed new hepatitis B infection among our total population have been under one in 100,000 in recent years, approximately one-sixth of the national rate. The annual rate of confirmed new infections in Kansas among children ages 1 through 14 was less than one in a million for the period 1998-2000, with only one case observed during that period in this age range.

KDHE currently recommends that all children be immunized against hepatitis B, preferably as infants, and if not, upon the earliest opportunity thereafter. This policy is entirely consistent with the published recommendations by the Centers for Disease Control and

Prevention (CDC) and the American Academy of Pediatrics. School entry requirements are an optional method to achieve the goals of these recommendations. KDHE has looked very carefully at the question and concluded that at this time in Kansas that method should not be undertaken. We base our conclusion on the following points: (1) the low documented occurrence of hepatitis B in Kansas, particularly among children of elementary and middle school age; (2) the epidemiology of hepatitis B infection indicating the absence of significant risk of hepatitis B transmission in association with elementary and middle school attendance; (3) the potential harm done to the overall immunization program by institution of such a requirement.

The authority granted to public health officials to require parents have their children immunized as a condition for entry into school confers awesome power upon us. It is a power that we believe is necessary to protect public health but we recognize just how great is the trust implicit in that grant of authority. Immunization is an invasive medical procedure. Public policy in this country and our state has historically granted parents/guardians the final say about whether or not their children undergo a medical procedure. The power to override parental authority has typically been granted in only two situations: (1) the need to protect others who might be significantly endangered if the procedure is not performed; (2) the child is in proximate danger of substantial harm if the procedure is not performed. The authority to order immunization has generally been based upon the first of these criteria. Our study of the epidemiology of hepatitis B in Kansas and elsewhere leads us to believe that neither of these criteria are met relative to mandating hepatitis B as a condition for school entry.

The authority to order immunizations as a condition for school entry is an authority which carries an associated responsibility to use it only when there is a clear-cut public health need that cannot be met in a less intrusive or coercive way. Our ability to retain this very important power to protect public health is dependent upon such proper use. There was a time in this country when medical authority was accepted by most citizens with little demure. That is no longer the case. Many citizens, in Kansas and elsewhere, are skeptical of conventional medical practices. Immunization is one of the practices about which there is widespread suspicion. Hepatitis B immunization has been the subject of considerable controversy. There have been Congressional hearings investigating the question of side effects from this immunization and anyone who looks on the Internet can find multiple organizations of citizens with substantial concerns about hepatitis B immunization. I have looked into the concerns raised about hepatitis B immunization and as both a parent and a professional determined that they were not sufficient to oppose hepatitis B immunization for my son or for the children of Kansas. My son is immunized against hepatitis B and I encourage every Kansas parent to obtain that protection for their children. But KDHE does not dismiss the concerns of parents who do not yet agree with us on this point. We believe public health needs to do a better job of communicating why we think this is a desirable protection for all children. We believe that riding roughshod over the concerns of parents who hold a contrary opinion and ordering them to immunize their children against hepatitis B in the absence of a very strong justification for this override of parental authority can only foster greater mistrust of the public health system and greater resistance to future

immunization activities. In discussions with my colleagues in other states where hepatitis B requirements have been instituted, concern has been raised about rising calls for exemptions from immunization school entry requirements, not just for hepatitis B but for all required vaccines. We are fortunate in Kansas that the grounds for exemption from immunization school entry requirements are narrow and the use of these exemptions is limited. KDHE believes that the best way to maintain this advantage for public health is to limit our use of the coercive power of school entry mandates to situations where the case is clear-cut and definitive. We do not believe that this is the case with hepatitis B immunization and we therefore ask that you not support HB 2041 which would establish such a mandate.

**KANSAS
PUBLIC
HEALTH
ASSOCIATION, INC.**

KANSAS PUBLIC HEALTH ASSOCIATION, INC.

AFFILIATED WITH THE AMERICAN PUBLIC HEALTH ASSOCIATION

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Testimony presented to the House Committee on Health and Human Services
by Sally Finney, M.Ed, Executive Director
on January 29, 2001

Thank you for this opportunity to appear before you today to on behalf of the Kansas Public Health Association regarding HB 2041. I would like, for or the benefit of those of you who are new to this committee, to give you a brief background of our association before presenting KPHA's views on the bill.

KPHA, the state affiliate of the American Public Health Association, is a non-profit membership organization established in 1920 to promote sound public health policies and programs in the Kansas. Today, KPHA represents more than 500 individuals interested in improving the health of our citizens.

In 1999, the Centers for Disease Control and Prevention (CDC) released a report titled, "Ten Great Public Health Achievements—United States, 1900-1999." **Vaccination was listed as the top achievement of the century.** Why? Because immunization against infectious disease works. It is safe and effective. Vaccines have saved countless persons from death and disability, realities that in earlier times devastated families and communities.

The attached lists show the 10 leading causes of death in Kansas for the years 1900 and 1998. Six of the causes shown in 1900 (influenza/pneumonia, cancer, diphtheria, typhoid fever, measles, and whooping cough) are now vaccine-preventable. Concerted efforts by the public health system, with support from policy makers, have resulted in significant changes in this picture. By 1998, four causes included on the 1900 list no longer appear. It is important to note here that one form of cancer, liver cancer, is now preventable to some extent by immunization against hepatitis B.

The United States enjoys the highest immunization rate of any nation on Earth. We achieved this success by applying one simple public policy strategy - requiring children to be immunized before they enter school. Alan Hinman, M.D, M.P.H, former Director of the Immunization Division of the CDC explained the importance of this policy in protecting the public's health in an article he wrote for the medical journal *Pediatrics* in 1991. According to Dr. Hinman,

"Immunization coverage among children enrolled in institutions is among the highest in the world. **An important factor has been the enactment and enforcement of school**

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immunization laws... Enforcement of these laws has led to attainment and maintenance of very high immunization levels in children in school or in licensed day care centers. These immunization levels have been associated with dramatic reductions in the incidence of diseases preventable by vaccine. Both the data on immunization coverage and on morbidity indicate remarkable success of immunizations in the United States.”

In other words, enforcement of school entry requirements ensures a highly-immunized population protected against a number of preventable diseases that can cause disability and death, including measles, rubella, mumps, polio, and hepatitis B. Without such requirements, immunization coverage levels would be significantly reduced.

Continuation of current immunization policy in Kansas is essential to assuring our progress in safeguarding the lives of our citizens. While acknowledging successes in this area is important, it is equally vital that we press forward in our efforts to eradicate vaccine-preventable disease. Such efforts must include staying current with national recommendations, which now include immunization against hepatitis B and varicella (chicken pox). **We must also recognize that Kansas is part of a global community with global disease exposure risks.** At a time when the farthest parts of the globe are only hours away by airplane, the threat for a resurgence of these infections still exists. The state line does not provide immunity.

While KPHA strongly supports adding hepatitis B vaccination to the list of school entry requirements, we are concerned about using legislation to accomplish this. Current statute grants the secretary of health and environment the authority to enact regulations regarding immunization for school entry. KPHA supports the continuation of this policy and, therefore, asks that rather than acting on HB 2041 you issue a statement directing the secretary to comply with national recommendations and use his regulatory authority to require immunization against hepatitis B for school entry.

Leading Causes of Death in Kansas

1900

1. Heart and kidney diseases
2. Influenza and pneumonia
3. Tuberculosis
4. Gastritis, duodenitis, enteritis, and colitis
5. All other causes
6. Cancer
7. Diphtheria
8. Typhoid fever
9. Measles
10. Whooping cough

Source: Kansas Department of Health and Environment, Office of Health Care Information

Leading Causes of Death in Kansas

1998

1. Heart disease
2. Cancer
3. Stroke
4. Chronic obstructive pulmonary disease
5. Influenza and pneumonia
6. Diabetes mellitus
7. Motor vehicle accidents
8. All other accidents
9. Suicide
10. Kidney disease

Source: Kansas Department of Health and Environment, Office of Health Care Information

NEEDLE TIPS

Volume 1 - Number 1

September - December 1994

Hospitals & Doctors Sued for Failing to Immunize

Three lawsuits against physicians and hospitals who failed to immunize came to the attention of the Coalition in the December 27, 1993, issue of CDC's *Immunization Action News*. Since the publication of that article, the Coalition has sought further information about these cases. To date, four additional lawsuits were discovered and descriptions of all seven cases follow.

• **Case #1: Hepatitis B** - In 1989 on the West Coast, a woman was identified as a hepatitis B carrier during her prenatal care. However, this information was not transmitted to the newborn nursery at the time of delivery. Her baby received neither HBIG nor hepatitis B vaccine and the infant subsequently became a chronic carrier. The mother sued the hospital, the obstetrician, and the pediatrician. A substantial settlement was awarded.

• **Case #2: Hepatitis B** - In a large Midwestern city in approximately 1988, a woman was screened in pregnancy and was found to be HBsAg positive. Her baby was born and appropriately immunized at birth with HBIG and hepatitis B vaccine. The baby returned for well child care with a nurse practitioner who was at the hospital-based clinic. The parents asked if the baby needed a second dose of hepatitis B vaccine. The provider reviewed the birth record and told the parents that the vaccine was not necessary and did not give the follow-up dose. The nurse practitioner did not understand the indications for hepatitis B vaccine. At 12 months of age, the child was found to have chronic persistent hepatitis B by the hospital's follow-up clinic that tracks the infants born to HBsAg positive mothers. The hospital was sued and the case was settled out of court.

• **Case #3: Measles** - A 26-year-old woman who worked in a private clinic as a nurse's aide in California contracted measles and died in February of 1990. The clinic in which she worked had seen patients with measles and this was her only known exposure. This woman had received one dose of MMR as a child. In late 1989, the ACIP recommended a second dose of measles vaccine for new employees in medical facilities, since they are at higher risk for measles than the general population. The ACIP also recommended "catch-up" programs for employees already working at these sites when resources were available. This nurse's aide never received a second dose of measles vaccine. The

family has sued the physician's practice. The case is pending.

• **Case #4: Hib meningitis** - In 1991, a California infant developed Hib meningitis and the family has sued the private clinic for failure to immunize. The case occurred in early 1991, shortly after the new Hib vaccine became available (November 1990) and shortly after the ACIP approved Hib vaccine for infants at 2 months of age. The clinic had provided some doses of both DTP and polio vaccines to the infant. The mother asked for Hib vaccine for her infant in January 1991 but was told that it was only recommended for children 15 months and older. She returned in March of 1991 with her infant and was again told that the vaccine was not indicated. (The provider was not aware of the new recommendation.) In spring 1991, the infant developed Hib meningitis. The child remains developmentally delayed three years later. The case is pending.

• **Case #5: Invasive Hib disease** - The information on this case is sketchy. At the time of this occurrence, the child was between ages of 2 and 5 and eligible to receive Hib vaccine. The case occurred between 1985 and 1990 at some point after Hib vaccine became recommended for children at 15 months of age. The child required hospitalization and today has some residual effects of the disease. This West Coast family has sued their child's physician for failing to provide the vaccine.

• **Cases #6 and #7: Hepatitis B** - Both of these cases occurred at a large teaching hospital affiliated with a medical school in a state where a law exists mandating prenatal hepatitis B screening. In this hospital, mothers were not routinely screened at delivery, but the neonatologist tested every infant for HBsAg as part of a panel of tests that were routinely done on cord blood. If this test was negative, no hepatitis B vaccination was given. If the test was positive, sometimes vaccine and HBIG were given and sometimes they were not. ("too late - baby already infected.") Both of the infants at the centers of these lawsuits were born in 1991 when this policy was in effect.

In one case, the mother had been tested during her pregnancy but the test results were not communicated to her or to the hospital. The infant's cord blood test was negative. In a subsequent pregnancy she was discovered to be

HBsAg positive and was referred to the state's perinatal program. Her other children were tested as a part of this program and the one child was discovered to be a carrier.

In the other case, the mother had not been tested during the pregnancy. The cord blood of this infant was positive for HBsAg, but the report was received after the discharge of the infant and the report was filed without action.

In both cases, the infants were not treated for perinatal exposure because the hospital was relying on cord blood testing to determine the need for hepatitis B prophylaxis. The hospital policy has since been changed and all mothers are screened on admission to labor and delivery. Lawsuits are pending in both cases.

By contrast, according to Dr. S. Michael Marcy, president of the Los Angeles Pediatric Society, there have been no successful immunization-related lawsuits against physicians giving required vaccines and following standard practices since 1977.

CDC has published the *Standards for Pediatric Immunization Practices* which is endorsed by the National Vaccine Advisory Committee, the American Academy of Family Physicians, and the American Academy of Pediatrics. For a free copy, call CDC's Immunization Hotline at 800/232-2522.

Do you know of additional situations similar to the cases described above? If so, please contact the Immunization Action Coalition editor.

Item #P2060 (9/94)

3-5



Kansas Council on Developmental Disabilities

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

House Health and Human Services Committee

January 29, 2001

Testimony in Regard to HB 2041 – Immunizations

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

Mr. Chairman, Members of the Committee, I am appearing today on behalf of the Kansas Council on Developmental Disabilities regarding immunizations.

The Kansas Council is a federally mandated, federally funded council composed of individuals who are appointed by the Governor, include representatives of the major agencies who provide services for individuals with developmental disabilities, and at least half of the membership is composed of individuals who are persons with developmental disabilities or their immediate relatives. Our mission is to advocate for individuals with developmental disabilities, to see that they have choices in life about where they wish to live, work, and what leisure activities they wish to participate in.

The Council understands the importance of immunizations for all children at the suggested time line.

We would like to see language added to this bill requesting physician's and/or their staff to provide written information to follow sound, informed consent practices in regard to all immunizations.

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We would also like to see language added to this bill that parents are informed of the option to give the MMR immunization in three separate vaccinations. The MMR vaccination is now given between the age of 15-18 months. Many children are diagnosed with autism at around this same age period. If the MMR can be offered split up, parents perceptions that the MMR immunization "caused" their child's autism would be eliminated.

Kansas is doing a great job in providing parent's "choice" when it comes to their children with disabilities. We hope you will consider our requests for additional language to be put in this bill that will enable Kansas parents to make informed decisions on behalf of their children.

We appreciate the opportunity of appearing before you.

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January 29, 2001

HB 2041 Requiring Hepatitis B in Kansas

Chairperson Boston and members of the House Health and Human Services Committee, my name is Carolyn Middendorf and I represent the KANSAS STATE NURSES ASSOCIATION, the professional organization for registered nurses.

Promoting immunizations for children and adults has been a priority of KSNA's for the past ten years. We were instrumental in the formation of what is now the *KANSAS IMMUNIZATION ACTION COALITION*, we provided leadership and staff support to the Immunization Task Force which was in existence for seven years prior to the statewide Coalition being formed. During the seven year campaign of Operation Immunize we worked closely with KDHE to coordinate volunteer nurse training and staffing of immunization outreach and non-traditional sites.

As a professional organization we assume responsibility for communicating and educating RN's about the changes in the immunization schedule and nationally are a partner with the NATIONAL NETWORK FOR IMMUNIZATION INFORMATION (NNII). *The mission of NNII is to provide the public, health professionals, policy makers, and the media with up-to-date, scientifically valid information related to immunization to help them understand the issues and to facilitate informed decision making.* We are all aware that varicella and pneumococcal vaccines, and other emerging vaccines will continue to challenge health professional in educating and promoting age appropriate immunizations. Every addition to the immunization schedule requires an accompanying educational component for doctors, nurses and the public. There is always a risk that if education is not adequate, the recommended schedule compliance will decrease. We want to believe that Kansas in the past has been a leader, model if you will in our support by the healthcare provider community reflected in our immunization rates of infants and children.

In the past two years KSNA has participated in the discussions and advocacy work to add Hepatitis B to the list of immunizations required at school entry. We have partnered with the Kansas Public Health Association, Kansas Association of Local Health Departments and others interested in promoting Hep. B immunization for adolescents, and supported the Greater Kansas City campaign to administer Hep. B in the middle-schools. We strongly support the addition of Hepatitis B to the school entry schedule in Kansas. School nurses and public health nurses have repeatedly requested KSNA's support for gaining passage of a school entry requirement for Hepatitis B immunization. Until the summer of 1999 (late May 1999) Kansas was on its way to a school entry requirement for the fall of 1999. The decision by KDHE to back away from their previously supportive position on this matter was very alarming and certainly very disappointing.

We support a Hepatitis B school entry requirement, and we hope that following today's hearings that this committee will recommend and support this change to the school entry requirements to add the Hepatitis B immunization.

Thank you.

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

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Testimony to Kansas House of Representatives Committee
Monday, January 29, 2001

My name is Shari Sauer. My husband, Shannon and I and our three children Grant, Reed, and Annie live in Sterling. I want to thank Representative Bethell for inviting me to speak today.

I've come today to tell you about my sweet little boys. Grant is 5 1/2 and Reed is 4. Both have autism. It is a developmental disability that typically appears during the first three years of life. It's the result of a neurological disorder that affects the brain. According to the Autism Society of America, "over 500,000 people in the U.S. today have some form of autism, making it the third most common development disability--more common than Down's syndrome. Every year another 50,000 parents hear the word "autism" for the first time as their child is diagnosed!" The Centers for Disease Control and Prevention in 1997 estimated that autism occurred in 1 in 500 individuals. According to the National Vaccine Information Center the incidence has skyrocketed to 1 in 150. Something is causing this tremendous increase. I am not claiming to have the answer. I am here today to plead with you to help us search for one.

I would like to paint a picture for you of just a glimpse of our lives affected by autism:

It begins with Grant around 18 months old talking--he had a vocabulary of over 100 words--laughing, smiling, interacting, sleeping well . . . to Grant around 2 years old retreating into his own little world, running sand through his fingers . . . disengaged from the rest of us . . . turning his words around . . . then immediately following the trauma of a tonsilectomy, losing all language, unable to give eye contact, squealing, spinning, flapping hands, tantruming for no apparent reason . . . at age 3 1/2 diagnosed with autism. Just as we were going through the shock of trying to swallow this news with Grant, we are watching the same symptoms being displayed in our little Reed, who had just turned 2. Reed was diagnosed one month later with autism as well.

We are grateful for the boys' educational program. They attend a developmental preschool Monday through Thursday. On Fridays when Preschool is not in session as well as through the summer, their teachers come to our home for instruction.

When the boys are home it's a constant extremely demanding job of keeping them occupied and out of dangers such as Reed crawling in the dryer and the washer, or making a mad dash for the street--highway 96 . . . or Grant crawling in the sandbox & pulling the cover over him in 100 degree weather. Because of the boys' inability to communicate & lack of a sense of danger, we either have double key deadbolts or magnetic doors & must constantly be on our guard.

Potty training and meals are a daily struggle, as well as the tantrums that occur resulting from the communication barrier. Sleep, especially lately, has been nearly non existant with Reed. We are trying a new medication with which we must daily monitor his blood pressure.

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Testimony to Kansas House of Representatives Committee
Monday, January 29, 2001

No one knows what causes autism, however I am greatly concerned with the dramatic rise in the incidence rate that closely parallels the increase in vaccinations, particularly the MMR. Although a cause and effect relationship has not yet been established by scientific evidence, the current trend suggests research is imperative.

Last Fall, I had the privilege of attending the International Vaccination Conference in Washington, D.C. While there I visited the Jefferson Memorial, and would like to share one of Thomas Jefferson's quotes which is engraved on a wall there. I quote: "I am not an advocate for frequent changes in laws & constitutions. But laws and institutions must go hand in hand with the progress of the human mind. As that becomes more developed, more enlightened, as new discoveries are made, new truths discovered and manners and opinions change with the change of circumstances, Institutions must advance also to keep pace with the times." (End of quote.)

Immunizations have served us well thus far. They have prevented many childhood diseases. However, in light of current research, perhaps it is time for us to closely examine the benefits versus the risks for some individuals, and allow for changes that would accomodate safer vaccination regulations for all children.

I would ask your consideration to include in this bill or write a separate bill that would require health care providers to disclose the potential risks associated with the MMR, and give parents the needed information about immunizations to make an informed decision. Some evidence suggests that a schedule of breaking up the MMR into three separate immunizations may benefit some children who's immune systems cannot handle all of the shots at once.

As mentioned earlier, autism is no longer a disorder seen in isolated cases. Chances are that each of you in this room today has the potential to be touched by this disability. Until research can prove no causal relationship between immunizations and autism, I plead with you to consider changing the law to allow the MMR to be given in three separate inoculations. I wish we had been given this information as new parents who thought we were doing the right thing by innoculating our boys. Grant received the MMR at 16 months; Reed at 15 months. In light of what we've experienced following the MMR immunization, we have chosen not to give it to our 2 1/2 year old daughter, Annie who is typically developing, if not above average. By being bold and stepping out to make a change from the norm, perhaps you will prevent for you own family, as well as those families you represent, the heartache that my family has endured with the diagnosis of autism for our sons, Grant and Reed.

Thank you for your attention.

Shari Sauer, Mother of Grant, Reed, and Annie Sauer
423 South Broadway
Sterling, KS 67579
(316)278-3744

Testimony to Kansas House of Representatives Committee
Monday, January 29, 2001

Each legislator that served in the last session should have received a copy of "The Vaccine Reaction: Autism and Vaccines: A New Look At An Old Story" published by the National Vaccine Information Center. If you are a new legislator, and did not receive this publication, please call me and I'd be glad to have one sent to you. Or you can visit the National Vaccine Information Center's website at: <http://www.909shot.com>

Attached is a copy of a report by Dr. Andrew J. Wakefield FRCS, and Scott M. Montgomer PhD. This report discusses the lack of safety studies conducted on the triple MMR vaccine.

Also attached is a copy of a graph taken from a report to the California Legislature by the Department of Developmental Services: "Changes in the Population of Persons with Autism and Pervasive Developmental Disorders in California's Developmental Services System: 1987 through 1998". **Please note the drastic climb in the number of enrolled persons with autism after 1979, which is the year the MMR was mandated in the U.S.** If you would like to read this report in its entirety, go to: <http://www.dds.ca.gov/Autism/main/AutismReport.cfm>.

I regret the fact that the weather prevented me from delivering this in person. I trust that you will read, with an open mind, my testimony as well as the attachments, and seriously consider making some changes for the safety of all children. Please feel free to call me if you have questions, or better yet, come visit our family in Sterling!

Thank you for your time.



Shari Sauer
(316)278-3744
423 South Broadway
Sterling, KS 67579

July 22, 2001

Search www.feat.org/search/news.asp

Also: UK MMR Vax Media Reports

Measles, Mumps, Rubella Vaccine: Through a Glass, Darkly.

[This is at the cause behind the MMR Vaccine controversy sunami hitting the UK, the latest research from Andrew Wakefield.]

(Adverse Drug Reactions 2000,19(4) 1-19. Authors: Andrew J Wakefield FRCS, Scott M Montgomery PhD.)

Confidence in vaccine safety is essential for the success of vaccination programmes.

There is growing parental and professional concern about the safety of the trivalent MMR vaccine.

Suspected long-term adverse events from MMR include some forms of regressive autism and inflammatory bowel disease (Crohn's disease and ulcerative colitis).

Some doctors and scientists suspect that the combination of the three live viruses in one vaccine increases the risk of these adverse events. In 1999 we reported data - endorsed by the Medical Research Council, peer reviewed and published - showing that concurrent exposure to natural (or vaccine) measles and natural mumps infections is a significant risk factor for inflammatory bowel disease.

Vaccine manufacturers and departments of public health unanimously assert the safety of the trivalent measles, mumps and rubella vaccine, citing extensive safety testing. Moreover, the public is assured that there is nothing in the safety studies to provide a basis for any anxiety over possible delayed adverse effects.

This important new article examines the safety trials of MMR and finds no grounds for complacency. Instead the adverse autistic and gastrointestinal side-effects now asserted by tens of thousands of parents in the US, UK and elsewhere are foreshadowed in the results of medical research and of the safety trials even before the vaccine was introduced.

▪ Pre-licensing trials of MMR revealed gastrointestinal events that persisted to the end of the trial period in significant numbers of children from developed countries. Despite this, the follow up period for subsequent trials was reduced from 28 days to 21 days.

Furthermore, in subsequent trials the data from contrasting populations (developed and developing countries) was aggregated, masking the potential significance of gastrointestinal side effects in children from developed countries.

▪ The decision to combine the three vaccines in one (undoubtedly atypical) exposure was taken without specific consideration of the known associations between concurrent exposures to common childhood infections and later consequences. By 1979, atypical patterns of exposure to measles, mumps, rubella and chickenpox were identified as possible risks for autism.

▪ In addition to the above, the very first pilot studies of MMR revealed that the component viruses of MMR could interfere with one another.

Despite evidence of potential dose and strain-dependent interactions affecting immune responses to the vaccine viruses and therefore possible adverse events, the question was never investigated further.

▪ The import of the article is enhanced by the publication of the comments of four reviewers. Taken as a body, the reviews are highly supportive of this new paper. Two reviewers, in particular, concur that, on the evidence presented by Wakefield and Montgomery, the safety trials of MMR were at best weak and at worst inadequate.

Clearly in the context of MMR one plus one plus one never did equal three.

In summary, the authors suggest that until such time as the question of MMR safety is resolved, the public must, at the very least, be offered a choice.

As the last Minister for Health, the Hon Frank Dobson said, in another medical context, "If there is even a hypothetical risk (of harm) and a safer alternative exists, we should use it".

In the current circumstances, given the significant index of suspicion which exists in relation to the safety of MMR, regressive autism and inflammatory bowel disease (Crohn's disease and ulcerative colitis), then it is surely right to allow parents to use the monovalent vaccines where they are, rightly or wrongly, concerned.

Perhaps the strongest endorsement of the value of this paper comes from one of the reviewers, Dr A Peter Fletcher, MB BS PhD, a former Principal Medical Officer in the Medicines Division, now MCA, of the Department of Health who served as Medical Assessor to the Committee on Safety of Medicines.

"With all the benefits of hindsight, what may now be said about the decision to grant a Product Licence (as they were then called) to MMR 10 or so years ago? Evidence on quality and efficacy was probably adequate so a decision had to be made on grounds of safety.

Being extremely generous, evidence on safety was very thin. Being realistic there were too few patients followed up for insufficient time. Three weeks is not enough, even for RCT's, neither is 4 weeks. By 1988-89 we knew from experience with pertussis vaccination that longer duration was essential- how much longer it is difficult to say but as long as humanly possible.

We also knew that numbers, big numbers were equally necessary. Additionally we knew that observational cohort studies could be conducted on 10,000 or more patients for up to 18 months. Primary care computerised databases (GPRD for example) were already up and running which would permit prospective record surveillance on several million patients. There was insufficient information on the immunological effects of a trivalent vaccine compared to monovalent vaccines.

Was there detectable immunosuppression with trivalent vaccine versus monovalent? From known clinical experience with measles mumps and rubella infections we could make an estimate of the incidence of serious disease outcomes which would be prevented by effective vaccination. From these figures we could make an informed guess of ADR levels that could be tolerated.

Did the available evidence on the trivalent vaccine support the belief that benefit would outweigh risk? On the basis that effective monovalent vaccines were available the CSM could be confident that delay in granting a licence would not result in a catastrophic epidemic of measles, mumps and rubella.

Caution should have ruled the day, answers to some important questions should have been demanded and strong encouragement should have been given to conduct a 12-month observational study on 10-15,000 patients and a prospective monitoring programme set up with a computerised primary care database. The granting of a Product Licence was premature."

One of the authors of the paper, Andy Wakefield FRCS, makes the following additional comments.

"This paper is a summary of a detailed analysis of safety trials for measles containing vaccines that I began in 1994."

"The Department of Health (in the United Kingdom) were in receipt of an earlier draft version of this paper, which was sent to them some months ago in order to permit adequate time to prepare sufficient stocks of monovalent vaccine pending publication of the paper."

"I am a firm believer in the protection of children against serious infectious diseases and their consequences. This paper advocates vaccination against measles, but the issues of vaccine safety are vitally important and must be of paramount concern."

Table 3 shows the percent change in occurrence of the other PDDs in comparison to autism. There was a 273 percent increase in the number of persons with autism between 1987 and 1998 and nearly a 2000 percent increase in the PDD categories. Table 3 also shows that as of December 31, 1998, there were 1,635 individuals coded on the CDER as "autism suspected, not diagnosed."

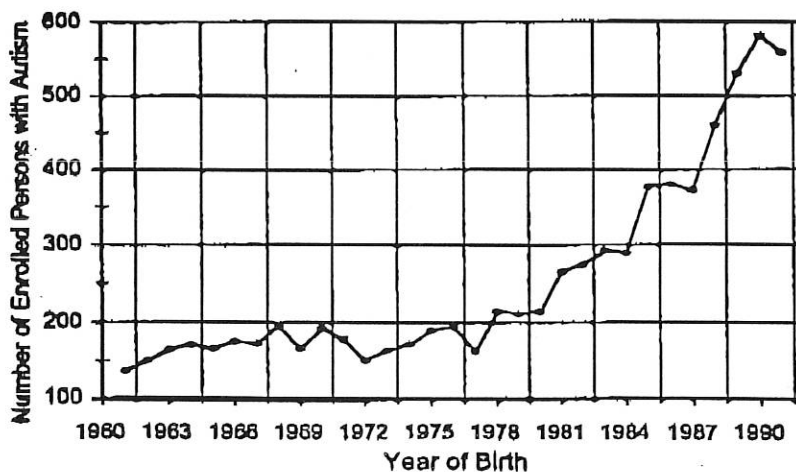
Table 3 - Autism and the Other PDDs Compared

	1987	1998	Percent Change
Autism (CDER Levels 1 & 2)	2,778	10,360	272.93%
Other PDD Types (CDER Level 4)	38	785	1,965.79 %
Autism Suspected, Not Diagnosed (CDER Level 9)	1,086	1,635	50.55 %

B. Changes in Population Rates of Intake

One method of recognizing if there is a change in the number of persons entering the system is to plot changes in the number of persons in the system across a number of years in order to identify trends and significant changes in the numbers. Figure 1 plots the 1991 population of persons (7,915) with autism by year of birth. Data points in Figure 1 do not show how many persons entered the system in a given year, but how many already in the system were born in a given year.

Figure 1 - Distribution of Birth Dates of Regional Center Eligible Persons with Autism



6-6

Hepatitis B Requirements for School Children

1-29-01

It isn't encouraging to live, practice public health, and try to protect the safety of our children and youth in one of only six states in the U.S. that does not by law require Hepatitis B vaccinations for its school children. We've actively defied recommendations of the "highest court in the land" (Centers for Disease Control) which include a statements as early as November, 1991, that this should happen. When will we learn? How many children will have to be placed at risk because of this disregard?

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Health & Human
Services
1-30-01
Atch #7



KANSAS MEDICAL SOCIETY

TO: House Committee on Health and Human Services
FROM: Chris Collins *Chris Collins*
Director of Government Affairs
DATE: January 29, 2001
RE: HB 2041: Hepatitis B Immunizations

Chairman Boston and Ladies and Gentlemen of the Committee:

Thank you for the opportunity to present written testimony today in support of HB 2041. The Kansas Medical Society respectfully urges this committee to pass the bill as written.

Hepatitis B is a serious and completely preventable disease. Each year, Hepatitis B kills an estimated 4,000 to 5,000 Americans and 75% of hepatitis B cases are contracted within the 15-39 year-old population cohort. Certain studies have estimated that Hepatitis B is one hundred times more communicable than HIV. (CDC 1991)

Required kindergarten and middle-school entry immunizations are the most practical and effective method of ensuring that this vital public health issue is adequately addressed. Hepatitis B vaccines have been proven to be safe when administered to infants, children, and adults (CDC 1991) and the benefits associated with an organized immunization program far outweigh the negligible risks involved.

You have received testimony today which advocates that physicians should be mandated to provide informed consent materials to parents. The Kansas Medical Society opposes such language because it unnecessarily codifies what is now common practice within the medical community.

For the foregoing reasons, the Kansas Medical Society urges passage of HB 2041 as written.

*Health & Human
Services
1-30-01
Atch #8*

TO: Health Care Reform Legislative Oversight Committee
FROM: William G. Wolff, Associate Director
Kansas Legislative Research Department
RE: State Kidney Program in Kansas

Conclusions and Recommendations The Committee recommends the enactment of a bill directing the Executive Vice Chancellor of the University of Kansas School of Medicine, with necessary support staff, to establish a program for the care and treatment of persons suffering from chronic renal disease who require lifesaving medications and transportation to treatment for renal disease. The Executive Vice Chancellor is to develop standards for determining eligibility of persons under the program, and may adopt rules and regulations necessary to properly administer and enforce the provisions of this act.

Further, the Committee finds that a program to assist patients with the costs of medications and transportation to treatment for renal disease is worthy of state financial support and recommends the Legislature provide funding for such a program.

Background

From the early 1970s to 1988, the State of Kansas operated a program for the care and treatment of persons suffering from acute or chronic renal failure requiring dialysis. The program was designed by statute to assist persons suffering from end stage renal disease "who require lifesaving care and treatment for such disease, but who are unable to pay for such services on a continuing basis" (KSA 65-199, repealed 1988).

The program was under the jurisdiction of the Secretary of Health and Environment. The Secretary developed standards for eligibility and programs for care and treatment of eligible persons, extended financial assistance to persons suffering from the disease, and instituted educational programs among health care providers, public health departments, and the public concerning kidney disease.

The state program was funded for about ten years, but after 1984, the program remained on the statute books but unfunded. In 1988, the Legislature repealed the statutes which had established the program. In part, the existence of other funds, specifically, Medicare coverage, contributed to the demise of the state program. The Social Security Act Amendments of 1972 had extended Medicare coverage to most people, regardless of age, suffering from end stage renal disease.

While Medicare Part A (hospital) and Part B (medical) help with costs associated with kidney disease, Medicare does not cover all costs. Deductibles and copayments associated with Medicare coverage, certain drugs and medicines, including immunosuppressives after three years following a transplant, and transportation costs for dialysis are not covered benefits. Technology has advanced treatments and extended life expectancy, but there are costs associated with sustaining a quality life that are both financial and psychological and represent a burden to those afflicted with renal disease and their families.

Committee Activity

Health Human
Services
1-30-01
Atch #9

The Health Care Reform Legislative Oversight Committee received testimony primarily from the National Kidney Foundation of Kansas and Western Missouri. Conferees included a medical director of a dialysis service, a nephrology social worker, a transplant recipient, and the Executive Director of the Missouri Kidney Program. Additional materials submitted to the Committee included patient letters and copies and of letters and forms used in a survey of Kansas kidney patients. The findings of the survey also were presented.

A spokesperson for the Foundation, told the Committee of patient needs as disclosed in a survey of patients. He indicated funds distributed through a state program would not help facilities or physicians, but would assist needy patients with transportation, insurance premiums, prescription medications, education about kidney disease, and treatment prior to dialysis.

The medical director of a dialysis service described kidney failure and its treatment, lifestyle restrictions on patients, and issues that prevent patients from maximizing treatment. He emphasized that, not only does poorer compliance with treatment lead to poorer outcomes, but improved compliance leads to improved outcomes.

The nephrology social worker noted great advances have been made to help patients cope with the physical aspects of kidney disease. But, the basic problems associated with the disease - financial burdens, loss of personal identity replaced by patient identity, and family stress - remain the same.

A transplant patient shared her story which included financial hardships caused by treatment after a transplant and the impact kidney disease has on others. The hidden costs associated with dialysis and transplantation were described as so profound that nearly one-third of all successful transplants are allowed to fail because the medication costs after Medicare coverage ends are prohibitive. The patient recalled for the Committee the wording of the prior statute establishing the Kansas State Kidney Program: “. . . no person, afflicted with acute or chronic renal failure requiring dialysis, shall be required to devote such a portion of his income and assets for treatments as will tend to cause unjust and unusual hardships to himself and to his immediate family, including, but not limited to, a drastic lowering of the standard of living” (KSA 65-198 repealed).

The Executive Director of the Missouri Kidney Program described the program as one not only important from a patient and a quality of life perspective, but as an investment in cost avoidance by keeping the transplant patient as healthy as possible and, whenever employed, eligible for insurance. He reported about \$4 million is allocated by the Missouri Legislature to fund the program which is assigned to the University of Missouri for administration.

All conferees supported public funding for a reconstituted Kansas kidney program as represented in two budget proposals, a basic plan and a comprehensive plan, submitted by the National Kidney Foundation of Kansas and Western Missouri. Cost of the basic plan would be about \$1.5 million and would provide financial assistance to eligible persons to help with Medicare and insurance premiums, transportation costs, and patient education. The cost of the comprehensive plan was estimated at \$2.98 million and would add financial support for medications and nutrition supplements

to the items in the basic plan. Federal poverty guidelines would be used to determine eligibility.

Conclusions and Recommendations

The Committee concluded costs for the care and treatment of persons with kidney disease exceed the financial support available either through private insurance or Medicare. The Committee recommends the enactment of a bill directing the Executive Vice Chancellor of the University of Kansas School of Medicine, with necessary support staff, to establish a program for the care and treatment of persons suffering from chronic renal disease who require lifesaving medications and transportation to treatment for renal disease. The Executive Vice Chancellor is to develop standards for determining eligibility of persons under the program, and may adopt rules and regulations necessary to properly administer and enforce the provisions of this act

The Committee further finds that a state assistance program is worthy of financial support and recommends the Legislature provide funding for a program to assist patients with the costs of transportation and medications.

Testimony ON HB 2059

Stan Newby

Thank you for your time to listen to an ordinary Kansas citizen. I would not waste your time or mine if I did not feel that this bill is important.

Before I divulge why this bill is vital to some individuals, I would like to share my background and how it relates to this testimony. I was diagnosed in 1962, at the age of six, with Type I, or juvenile diabetes. With diabetes, I have had numerous complications, including renal failure, and was on dialysis. I was very fortunate on July 18, 1995 to receive a kidney and pancreas transplant. This ended a short time on dialysis, and I am no longer diabetic. I grew up on our family farm in Reno County, learning hard work, disappointments, hope, and faith, I graduated from K-State in 1978 and taught students agriculture many years. I am currently teaching students biology at Rose Hill. My wife is a second grade teacher, and have two sons age 16, and 18. The oldest has been diabetic for over five years.

This bill is important to me, but more important to people less fortunate than myself for several reasons:

1. Medications for transplants are expensive. Medicare paid for mine for 18 months. I have no prescription rider so one expensive drug is being paid for by an endowment from St. Francis Hospital in Wichita. Since I was a double transplant, the drug company did pay for the other expensive drug, but now I am paying half, and the other half comes from the transplant office at St. Francis. There are other medications we take also. Right now we spend \$300.00 a month on prescriptions. We can budget for it, but if the help from St. Francis ended it would be impossible for me.
2. People needing a transplant are going on dialysis because their insurance will cover dialysis, but not anti rejection drugs. Royce Hargue of Arkansas City has a family donor, and wants a kidney transplant. He will not go through with it until he has more money to help with drug expense. He is a maintenance person in the school district, and children in his building had bake sales, and friends are sponsoring money making activities. He checked at the pharmacies and his monthly expense would be \$1,800.00.
3. Transportation costs are expensive. I was on at home dialysis, but some people in Kansas have to travel to dialysis centers. I did have to make about 30 trips to Wichita after the transplant for blood tests and check ups. This is a 100 mile trip from Winfield where I live.

I have been very fortunate for the help I have received over the years. But not everyone is as fortunate. I never thought would be asking for help or aid from the government, but for my future, and for people who are not as fortunate as myself, this would be a bill vital in importance.

Health & Human
Services
1-30-01
Atch # 10

Randy Williams

Chief Executive Officer
National Kidney Foundation
of Kansas & Western Missouri

Today we're here to ask you to support a program that will help people with kidney disease. My name is Randy Williams. I am the chief executive officer of the National Kidney Foundation of Kansas and Western Missouri (NKF). I will present information on the National Kidney Foundation and the results of the survey that we conducted on Kansas residents who have kidney failure.

Other people who will testify before you today include:

- Stan Langhofer
- Beth Witten
- Trish Pooley

Health & Human
Services
1-30-01
Atch # 11

Kansas Kidney Program

**Testimony to
House Health and Human Services
Committee**

January 30, 2000

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Did you know...

Rank of kidney disease as cause of death in Kansas	8 th
Kansas patients seen by nephrologist <1 month before treatment	17%
Diabetes as cause of kidney failure in Kansas	1 st
Kansans diagnosed with diabetes of total population	3%
Hypertension as cause of kidney failure in Kansas	2 nd
Kansans diagnosed with hypertension of total population	21%
Incidence of kidney failure per 1 million population, 1998	249.52
New Kansas residents starting ESRD treatment, 1998	656
Kansas residents on dialysis, 1999	1,905
Kansas counties with residents on dialysis, 1999	97
Kansas residents waiting for a transplant in Kansas, 2000	128
Kansas residents with a functioning kidney transplant, 1999	790
Kansas dialysis patients who do not live with a spouse	55%
Kansas dialysis patients who do not drive themselves	47%
Kansas dialysis patients who have missed dialysis due to transportation problems	8%
Kansas dialysis patients who have chosen not to be evaluated for transplant for financial reasons	10%
Kansas dialysis patients with Medicare	89%
Kansas dialysis patients with Medicaid	26%
Kansas dialysis patients with insurance from an employer	22%
Kansas dialysis patients with Medicare supplement	27%
Average Kansas dialysis patients pay for insurance monthly (range: 0-\$1,000 monthly)	\$73.40
Kansas dialysis patients with no prescription coverage	47%
Average Kansas dialysis patients pay for prescriptions monthly (range: 0-\$1,400)	113.87
Average Kansas dialysis patients pay for transportation monthly (range: 0-\$1,000)	\$38.68
Average Kansas dialysis patients pay for nutrition supplements monthly (range: 0-\$500)	\$15.59
Average Kansas dialysis patients pay out of pocket for all medical care monthly (range: 0-\$6,500)	\$203.85
Kansas dialysis patients who are retired	33%
Kansas dialysis patients on Social Security Disability	46%
Kansas dialysis patients receiving SSI	19%
Kansas dialysis patients who would work if they could continue to get Medicaid	70%

National Kidney Foundation Goals

- Supporting Research and Research Training
- Continuing Education of Health Care Professionals
- Expanding Patient Services and Community Resources
- Educating the Public
- Shaping Health Policy
- Fund Raising



The goals of the NKF include:

- Research
- Professional education
- Patient services
- Public education
- Legislative advocacy
- Fund raising to support programs and services

Reasons for NKF Involvement Kansas Patients

**1,905 dialysis patients
live in
97 of 105 Kansas counties**

Source: ESRD Network 12, 1999

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People with kidney disease are your neighbors and constituents. Kidney disease strikes people of both sexes, all ages, races, and income levels. Kidney disease doesn't care whether you live in an urban area within a mile of a dialysis facility or on a farm.

Any of you could be at risk, especially if you have diabetes or hypertension, or if you are African American, Hispanic, or Native American. And worst of all, you may not know it.

We are willing to confidentially test committee members or other legislators at a later time at the group's convenience. Testing takes about 10 minutes.

Kansas Dialysis Patients' County of Residence



This map shows where Kansas dialysis patients live. When there are 1-4 patients living in any county, this is designated by the value "<5" to protect the identity of individual patients.

Reasons for NKF Involvement Kansas Patients

**Kansans are at risk of kidney disease,
especially those with**

- **Diabetes - 67,684 (3%)^{1, 2}**
- **Hypertension - 557,351 (21%)²**

Sources: ¹American Diabetes Association, 2000

²Health Risk Behaviors of Kansans 1997

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The NKF understands the importance of early intervention. We're currently involved in an effort to identify people who are at risk to encourage them to ask their doctors to verify the results of our assessment and treat them.

Diabetes is the most common cause of kidney failure in the U.S.

- 3% of Kansas residents (67,684) have diabetes.

Hypertension is the second leading cause of kidney failure in the U.S.

- 21% of Kansas residents (about 557,000) have hypertension.

In early intervention screenings that we've conducted on over 2,200 people, 62% of those with diabetes or hypertension and first degree relatives (parents, siblings, children) of those with kidney disease, diabetes and hypertension have signs of possible kidney disease like hypertension, high blood sugar, or proteinuria (protein in the urine). Most did not know they were at risk. Research has shown that proteinuria may be an early indicator of heart attack and stroke.

Why Does NKF Care?

**Kidney disease leads to
unnecessary
loss of productivity.**

Source: USRDS 1999 Annual Report

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Kidney disease leads to unnecessary loss of productivity because:

- Most dialysis treatments take 3-4 hours 3 times each week.
- Most dialysis clinics are not open after 5 p.m. limiting patients' work hours
- Kidney failure complications can lead to physical disability.
- Dialysis patients fear losing Medicaid and transplant patients fear losing Medicare coverage if they return to work
- Most dialysis patients are not eligible for Vocational Rehabilitation because funding has been cut drastically so only those who can't perform most basic activities of daily living are eligible for services

The NKF wants to help more Kansans remain productive.

Why Does NKF Care?

**In Kansas, kidney disease is the
8th leading cause of death and
the fastest growing cause of death.**

Source: KS Dept of Health & Environment 1998
Annual Summary of Vital Statistics
Kansas Age Standardization of Kansas Death Rates:
Implications of the Year 2000 Standard

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- Although dialysis and transplantation saves lives, too many people in Kansas die of kidney failure.
- People may be dying of kidney failure because:
 - They don't know they have kidney disease;
 - Their primary care doctors don't offer kidney treatment or refer them to nephrologists;
 - Patients don't know about kidney disease and treatment options that can help them live quality lives;
 - They believe treatment will be too burdensome to their families or themselves.

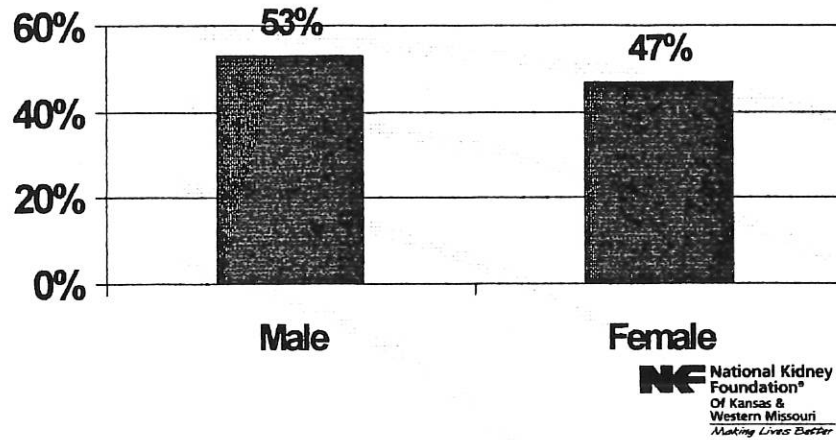
The NKF wants to ensure that more people with kidney disease understand their options for treatment, learn how to participate actively in their care, and know when and where to seek help when needed.

Kansas Patients Needs Assessment Survey

- **2,000 surveys mailed to facilities**
- **687 patients (34%) responded**
- **Needs identified**
 - **Early intervention and education**
 - **Transportation costs**
 - **Insurance premiums costs**
 - **Prescription medication costs**

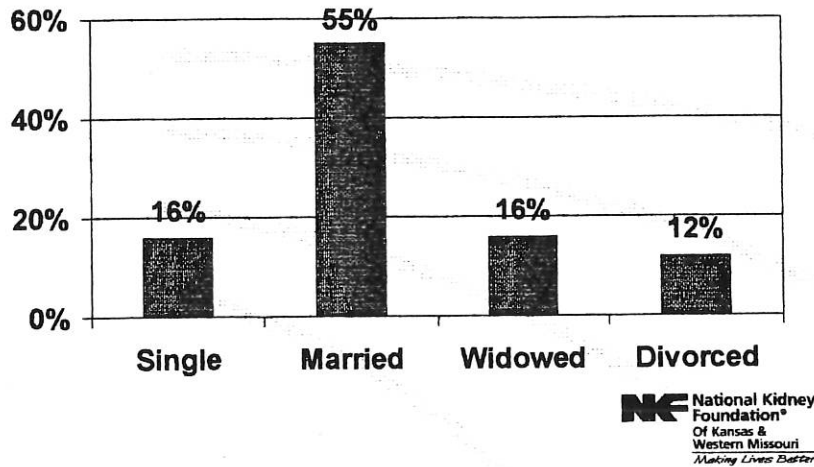
- To determine need, we surveyed patients who were receiving treatment for kidney failure. Dialysis social workers distributed surveys so most respondents were center hemodialysis patients.
- The NKF is seeking state support for a state kidney program in Kansas. We are not asking for funds to help facilities or physicians. Monies requested would help needy patients with transportation, insurance premiums, prescription medications, and education about kidney disease and treatment prior to starting dialysis.
- Missouri, Iowa, Nebraska, Arkansas, and Oklahoma all have state kidney programs. Robert Whitlock, director of the Missouri Kidney Program (MoKP) and vice-president of the National Organization of State Kidney Programs (NOSKP) will testify today on state kidney programs and MoKP specifically as well as how MoKP collaborates with other agencies.

Gender of Kansas ESRD Patients (N=687)



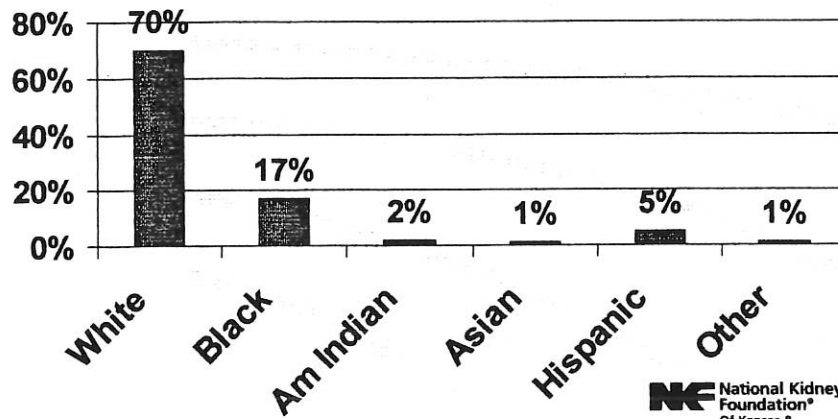
Patients in Kansas were very similar to the national profile. There are 53% male and 47% female.

Marital Status of Kansas ESRD Patients (N=676)



55% of Kansas dialysis patients are married. The others may have less support.

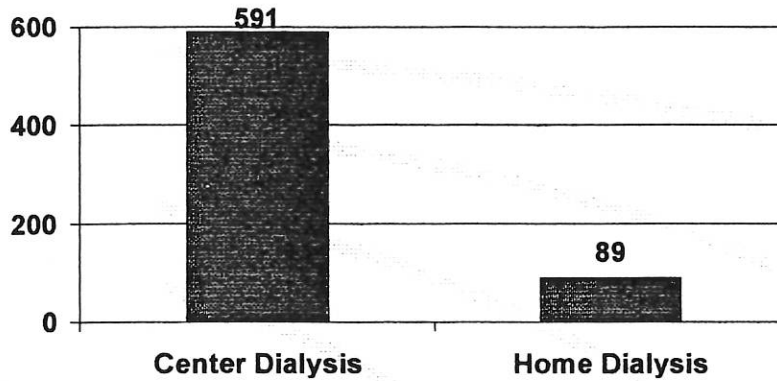
Ethnicity of Kansas ESRD Patients (N=666)



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Respondents were overwhelmingly Caucasian, but 26% represented minorities at high risk due to the incidence of diabetes and hypertension.

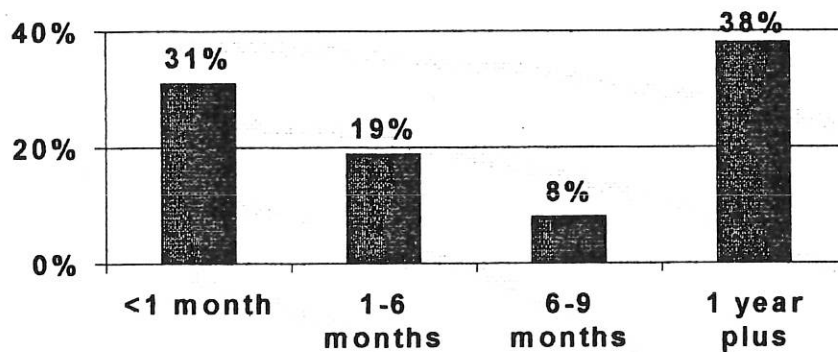
Dialysis for Kidney Failure in Kansas (N=680)



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Although most of our respondents were on center hemodialysis, in our 4-state area (Kansas, Missouri, Iowa, and Nebraska) about 20% of dialysis patients do some form of home dialysis.

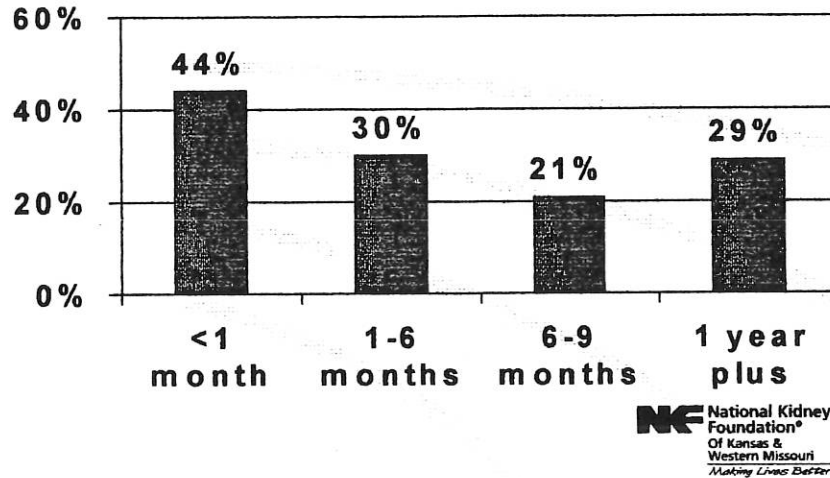
Referral to Nephrologist Before Initiating Treatment (N=660)



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- 50% saw a specialist too late for the best type of dialysis access -- a fistula -- to be placed and have time for it to develop or to be educated about treatment options well enough to make informed decisions
- Since only 38% of those with kidney disease saw a nephrologist one year or more before starting treatment, most Kansans who have kidney disease have almost no chance of prolonging or preventing kidney failure.

Patients Not Reporting Good Pre-treatment Education (N=210)

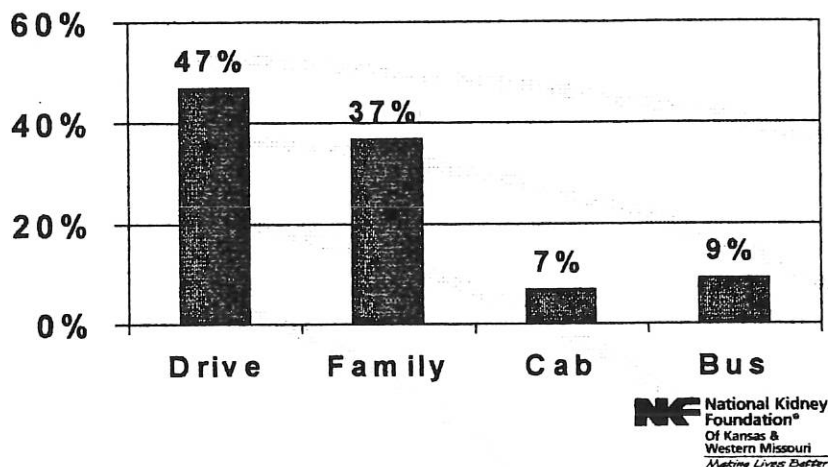


210 patients (32%) said they had not received enough education.

Those who saw a nephrologist more than a month before starting treatment were more likely to advocate for a treatment that fit better with their lifestyle or use their healthcare team to help them make this decision. Those who saw a nephrologist one month or less before starting treatment were less likely to participate in the treatment decision process.

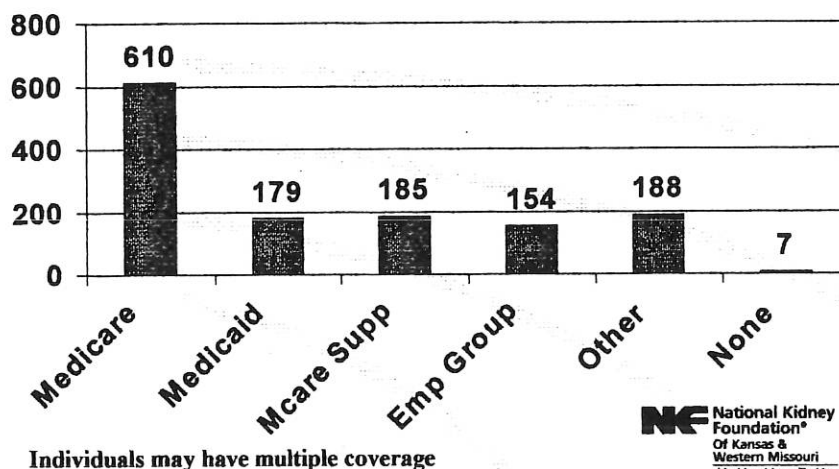
The NKF wants all those with kidney disease to have access to a specialist who can help them know how to manage their illness and live full lives.

Transportation for ESRD Treatment (N=610)



- 55 patients reported they missed or shortened dialysis treatments because of transportation problems. Missing or shortening treatments increases hospitalizations and death risk.
- Medicare does not pay for routine transportation. Medicaid can pay for transportation.
- 322 patients (53%) said they rode with someone else to dialysis. They traveled an average of 28 miles (range 300-500 miles).
- Patients paid an average of \$39 per month, but could pay up to \$1,000 a month.
- 173 patients had incomes at or below 100% of the federal poverty level.

Kansas ESRD Patients' Insurance

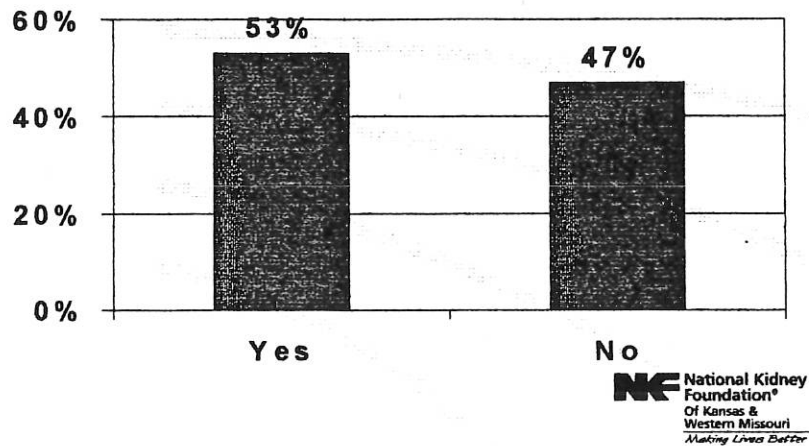


Individuals may have multiple coverage

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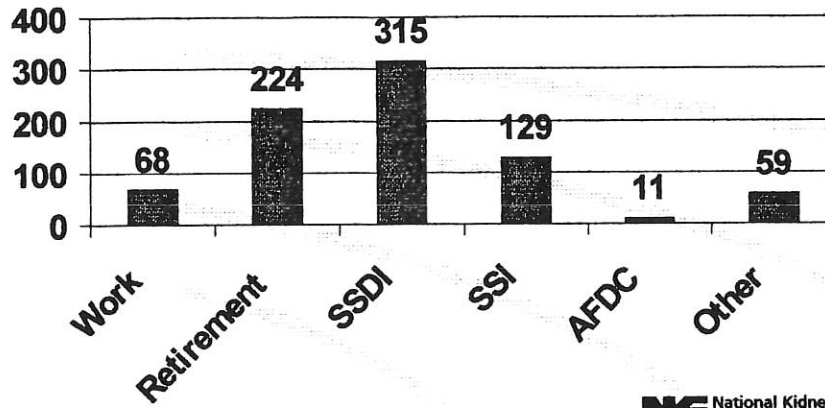
- 10% of respondents reported that cost was keeping them from seeking transplant evaluation.
- 7 told us they have no health insurance. Lack of health insurance leads to delays diagnosing and treating, poor adherence.
- 89% have Medicare. Medicare pays 80% of the cost of outpatient care but NOT prescriptions or transportation.
- 26% have Medicaid that pays for transportation and prescription medications.
- 27% have a Medicare supplement. These pay the 20% that Medicare doesn't pay. Few pay for prescriptions or transportation.
- 22% have coverage under an employer group plan. These usually cover prescriptions, but not transportation.
- 27% have some other type of health insurance.
- 360 respondents who made less than \$10,000 reported they paid an average of \$89 per month (range \$0-\$1,400 per month)

ESRD Patients' Prescription Coverage (N=687)



- 47% have no prescription coverage. Depending on their coverage, they paid from 0 to \$1,400 per month.
- Those earning less than \$10,000 paid an average of \$89 per month (range \$0-\$1,400). Those earning between 10,000 and \$25,000 paid an average of \$140 (range \$0-\$1,000 monthly).
- The average cost for low income people was about \$20 per month. Most probably had Medicaid or received samples from doctors or assistance from pharmaceutical companies
- 189 patients made less than \$10,000 and paid \$8 per month for non-covered nutrition supplements (range \$0-\$180 per month).

Kansas ESRD Patients' Source of Income (N=644)



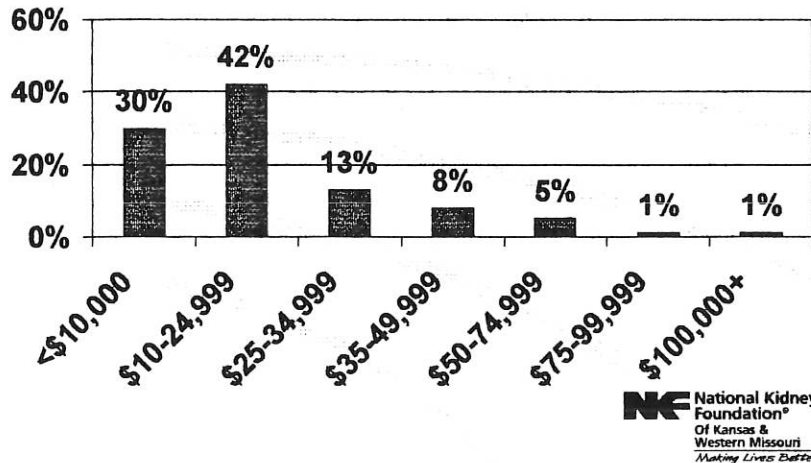
Income may be from multiple sources

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Most Kansas ESRD patients were productive taxpayers whose health has led to a change in their income source.

- 10% receive income from work.
- 33% receive retirement benefits.
- 46% were taxpayers who now receive Social Security Disability Insurance (SSDI).
- 19% receive Supplemental Security Income (SSI) and have very limited savings.
- 8% receive income from other sources such as a spouse's employment or investments.

Household Income of Kansas ESRD Patients (N=638)

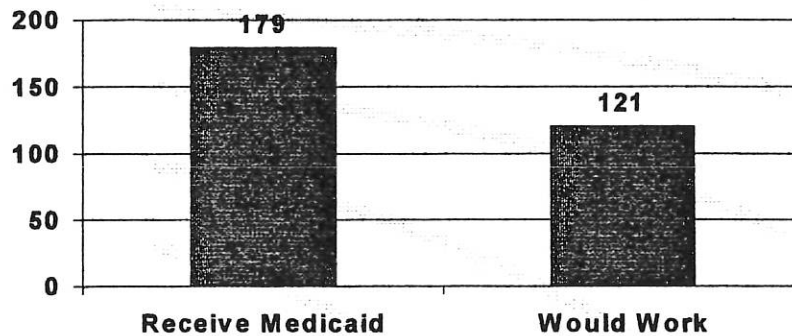


Rather than asking specific annual income, we asked income by bracket.

- The most common income bracket is \$10,000-24,999, with almost half of these households consisting of 2 members. Families larger than 4 were likely to live near or below the federal poverty level.
- SSI recipients have income below the federal poverty level.. SSI recipients often can't afford their living expenses much less medical expenses that are not covered by Medicare and/or Medicaid.
- The average single SSDI recipient is poor or near poor if SSDI is their only source of income.

The Kansas Kidney Program is designed to help those who are living near the poverty level pay necessary medical expenses to reduce unnecessary hospitalizations and costly complications.

Kansas ESRD Patients Who Would Work if Medicaid Covered Working Disabled



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Kidney disease is costly even though Medicare pays 80% of many outpatient services.

- Of those who receive Medicaid, 70% said they would return to work if they could continue to receive Medicaid benefits.

Many Kansas ESRD patients are among the poor or near poor.

- 50% of those who work reported that they make less than \$25,000.

The NKF would like to encourage Kansas legislators to consider passing legislation in Kansas to expand Medicaid benefits to working disabled persons who earn less than 250% of the poverty level as recommended by the Ticket to Work and Work Incentives Improvement Act of 1999.

TESTIMONY
HEALTH & HUMAN SERVICES COMMITTEE
JANUARY 30, 2001
Trish Pooley

The State of Kansas operated a Kansas State Kidney Program from 1970-1988. In creating this program the Legislature declared, as a matter of policy, "that no person, afflicted with acute or chronic renal failure requiring dialysis, shall be required devote such a portion of his income and assets for treatment as will tend to cause unjust and unusual hardships to himself and to his immediate family, including, but not limited to, a drastic lowering of the standard of living (K.S.A. 65-198, Repealed, 1988). This repealed in 1988.

In 1991, I stood before the Standing House Committee on Public Health and Welfare, as a dialysis patient, to ask for support of HB2016 because the hidden costs associated with ESRD can be financially and psychologically devastating. (A copy of my 1991 testimony is attached). At that time, I provided documentation showing that the costs associated with medications, insurance premiums, and transportation totaled 49.5% of my monthly income, which, at that time, was \$742. Surely, this must be considered hardship".

And, I was one of the lucky few who had qualified for Medicare status in 1988, two years prior to starting dialysis on December 12, 1990. Had I instead been covered by my previous insurance policy, I would have been responsible for 20% (or \$17,600) of my first three months medical costs, which totaled \$88,000.

I stand before you today, nearly ten years later to once again implore you to create a Kansas State Kidney Program. Since I last addressed a legislative committee, I have had 28 surgeries, the most recent being a successful kidney transplant on September 8, 1999. Ironically, it was never my intention to pursue a transplant. I felt that it was morally irresponsible to accept a gift of life from any family that was compassionate enough to donate organs after the tragic death of a loved one, only to see such an enormous gift squandered. I knew that the maintenance drug costs were beyond my financial capability. Having done my research, I knew that one third of all transplants that fail do so because maintenance drugs are not available, so I declined the option of transplantation at that time for financial reasons.

Transplantation became a necessity for me due to medical complications that threatened my ability to continue dialyzing. In essence, I was running out of time on dialysis. Again, I was lucky. I was married at that time and had insurance available to me through my husband that would cover the cost of transplant related drugs not covered by Medicare.

I am no longer married and now face the very dilemma I once feared not being able to afford the drugs necessary to sustain my gift of life from a donor family I have come to know and love. To maintain my former husband's insurance under COBRA the premium cost will be \$255 in addition to my \$50 Medicare premium. My drug co-pays total \$270 monthly along with \$34 for needed supplements. Total cost per month for insurance and drugs is \$593.63. This does not include the \$500 deductible I will pay or charges not covered by Medicare and COBRA. My disability income is \$937 a month. I work two days a week with earnings of an additional \$400 per month. My medical costs remain almost 50% of my income, just as they were 10 years ago, and I am incurring mounting debts. Surely, no one "must be required to devote such a large

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portion of income and assets for treatment”over such a long period of time. Yet hundreds of Kansas patients like myself do undertake such hardship to remain alive.

Transportation is another critical problem, especially for rural Kansans who receive transplants or are on dialysis. Some dialysis patients elect not to dialyze at all because transportation to a unit is prohibitive. My aunt was one such person and I am her namesake. She was born and raised in a rural western Kansas community and married a farmer. When her kidneys failed and she required dialysis, the 350-mile round-trip commute three times a week was impossible. She died a painful and protracted death because transportation to a dialysis unit was unavailable. The two of us shared a common illness. I lived. She died. Surely her death “was an unjust and unnecessary hardship for our family.”

In closing, I want to debunk few myths:

First, the failure of one’s kidneys doesn’t imply any particular failure on the part of the patient. It can happen to anyone and does at an increasingly alarming rate. Our society frequently places an economic valuation on human life and I never saw that more clearly than when I found myself judged for needed and using public funds for my survival. I had worked hard, been successful, been followed for years by doctors to maintain my health, but nonetheless, my illness, invisible to most, resulted in a “drastic lowering of my standard of living”. My kidneys failed. I didn’t.

Second, the hidden costs associated with ESRD and transplantation is profound. Most people assume that a combination of Medicare, Medicaid or private insurance covers the major costs associated with kidney disease, and this is largely true. However, I think I have illustrated that the costs of medications and supplements, transportation, insurance premiums and sometimes in-home services during recuperation from an illness can be catastrophic for most renal patient whose income often places them in the “nearly poor” category. Most of us have had to make choices between paying for rent and food or paying for medications that will keep us healthy. Some have had to choose whether they could afford dialysis and/or transplantation, both life-reserving treatments, when no insurance was available to cover the hidden costs I have mentioned.

Third, transplantation is not a panacea. It is another treatment option with its own accompanying costs and health complications. Most transplant patients who worked before their transplant will return to work after their transplant. Some transplant patients, like myself, who were on dialysis for many years and relied on SSDI, do not find a return to work easy. Perhaps my situation can be likened to the “stay-at-home-Mom” who tries to re-enter the workforce many years later, only to find that the skills she possesses are no longer those that are most needed in the workplace. The difference is that I have a medical history that makes me additionally undesirable.

When Medicare coverage ends, those transplant recipients who have not negotiated a return to work, will find themselves without insurance, perhaps for the first time in their lives. And, they are then without the medications needed to maintain their transplant. A gift of life is sacrificed and return to dialysis inevitable, only for the cycle to repeat itself. Economically, it makes no sense. Emotionally, it is a tragedy for all involved.

There is a touchstone that has provided me needed inspiration and a renewed sense of determination many times over the years. Let me share with you this quote from Norman Cousins:

“DON’T DENY THE DIAGNOSIS; DEFY THE VERDICT”.

Please help kidney patients here in Kansas defy the verdict of economic and emotional hardship by re-establishing and funding a Kansas State Kidney Program during this legislative session.

As a matter of policy “no person, afflicted with acute or chronic renal failure requiring dialysis (or transplantation), shall be required to devote such a portion of his income and assets for treatment as will tend to cause unjust and unusual hardships to himself and to his immediate family, including, but no limited to, a drastic lowering of the standard of living”.

Respectfully submitted,

Trish Pooley

Testimony: House Bill 2059
House Health & Human Services Committee
January 30, 2001

Mr. Chairman, Members of the Committee:

My name is Marlin Rein and I am here on behalf of the University of Kansas to offer comments regarding House Bill 2059.

House Bill 2059 would direct the University of Kansas Medical Center to establish a program for the care and treatment of persons suffering from chronic renal disease who require lifesaving medications and transportation to treatment. The Executive Vice Chancellor of the institution would be authorized to appoint needed support staff to assist in the administration of the act and to develop standards for determining eligibility for care and treatment under the program. Finally, the legislation establishes within the State Treasury a renal disease fund. The University would be authorized to accept monies from any source to be credited to this fund to defray the costs of the program. While the act does not specify the source of those monies, one might presume that the State would be a source for at least a portion of the funding for this program.

The University of Kansas Medical Center has a long and successful history in the provision of superb health care services to persons suffering from chronic renal disease. Likewise, we have a very active and cutting-edge research program as well. The sponsors of House Bill 2059 apparently desire to establish a program making available financial assistance for medications or transportation to persons in need of such services. It is my understanding that there are concerns regarding the time limits on Medicare payment for immunosuppressant drugs for transplant recipients and one purpose of the legislation is to provide a funding source to defray the cost of those drugs once Medicare funding ceases. Another concern is apparently for transportation for persons that need assistance to get to and from treatment for chronic renal disease.

Understand that the University is going to be supportive of any initiative that extends quality healthcare to Kansans. Whether the University is the appropriate agency to be charged with administering the program envisioned by this bill is another issue.

With those comments, Mr. Chairman, I would be willing to stand for questions.

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House Health and Human Services Committee Testimony
Stan Langhofer

My name is Stan Langhofer, I appreciate very much the opportunity to testify before you in favor of a Kansas Kidney Program, and your consideration of a bill that would benefit kidney dialysis and transplant patients and the State of Kansas.

I have worked with dialysis patients in Kansas for 20 years as a technician, nurse, educator and new administrator. The dialysis unit I represent has 6 locations in Northeast Kansas and provides care for over 250 patients. I also am a grandson whose grandfather was on dialysis for over 7 years, and learned first hand the impact on a family.

My role today will be to explain the dialysis procedure for those of you who may not be familiar with it. A portion of this testimony was previously given by Dr. Scott Solcher, a nephrologist in northeast Kansas, before the Kansas Healthcare Reform Legislative Oversight Committee. He is unable to be here today due to scheduling, but would be happy to answer any of your questions at a later date. He is very committed to this legislation and will be involved in the process.

In the following order I will address and explain:

- Kidney Failure Causes
- Types of Dialysis (Hemodialysis and Peritoneal)
- Lifestyle Restrictions
- How a Kansas Kidney Program can help.

Kidney Failure:

The most common cause of kidney failure is diabetes. The second leading cause is high blood pressure. Fortunately kidney failure is treatable. Kidney failure can be a slow process or a very rapid one. The symptoms may first be subtle with loss of energy, vigor, or appetite. Symptoms progress to severe fatigue, weakness, vomiting, and profound itching. Often there is water overload with swelling in patient's legs or lungs. These symptoms are caused as toxins (poisons) increase in the bloodstream when the patient does not have adequate renal function. Kidney failure can be treated with either dialysis or transplantation. Virtually all patients who receive a transplant require dialysis while waiting for a kidney due to the complexity and time required for transplant evaluation.

Hemodialysis:

Hemodialysis is blood dialysis performed at a dialysis unit. It typically requires three weekly sessions that last four hours each. Eighty-five percent of patients with end stage renal disease in the United States use this modality. Each session is typically associated with significant fatigue, especially in the elderly. Hemodialysis is, in essence, an attempt

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to fit a week's worth of kidney function into three, four-hour treatments. With hemodialysis, the patient's blood must be transferred to the dialysis machine. In order to do so, an artificial conduit is surgically placed. Ideally the conduit is present in the patient's forearm several months prior to beginning hemodialysis. If there is not enough time prior to the initiation of dialysis, a temporary catheter must be placed in a vein. Typically the large jugular vein in the neck is used. Catheters are associated with increased rates of infection and the quality of dialysis is generally poorer.

Peritoneal Dialysis:

Peritoneal dialysis is the modality that the other fifteen percent of patients use. In this procedure, patients place approximately two liters of dialysate fluid in the abdominal cavity around the stomach. The fluid is infused through a special catheter placed through the abdominal wall. Toxins diffuse into this fluid, with other chemicals diffusing from the fluid into the blood stream. The fluid is then drained. This procedure must be done four to five times daily, every single day. Although peritoneal dialysis allows more flexibility for some patients, it is an enormous amount of work.

Lifestyle Restrictions:

Regardless of how patients dialyze, they have multiple lifestyle restrictions. Included are restrictions of the amount of any fluid they drink, as well as limitations in salt, potassium, and phosphorus intake. These limitations affect every meal and change every aspect of a patient's eating habits. Their lifestyle is additionally burdened by twelve to sixteen hours required weekly for hemodialysis and twenty-eight to thirty-five hours required weekly for peritoneal dialysis. Finally, while many of the most severe symptoms of renal failure improve with dialysis, many persist. The most prominent is fatigue. Weakness, itching and loss of appetite can also continue. While dialysis in general does a good job of clearing poisons: it is not like having adequate kidney function.

Clearly the diet and time schedule is difficult to adhere to. In addition to the dialysis sessions and dietary restrictions, dialysis patients on average take nine different medicines, with many patients taking 15 or 20. The schedules for these medicines are very difficult for anyone to manage correctly.

HOW A KANSAS KIDNEY PROGRAM WILL ASSIST DIALYSIS PATIENTS

Early Intervention and Pre-dialysis Education:

Early intervention is critical. The Kansas Foundation for Medical Care studied patient's initiation of dialysis and published their preliminary results in 1998. They compared patients who were referred early to a nephrologist versus patients who were referred late to a nephrologist. Patients who saw a nephrologist greater than sixty days prior to the initiation of dialysis were considered early referrals. Late referrals were those patients

who saw a nephrologist for the first time less than sixty days before starting dialysis. Their findings included the following.

- Patients who were late referrals were twice as likely to die within two years than early referrals.
- Patients who were late referrals were more likely to start hemodialysis than early referrals.

I have spoken already of the number of medicines taken by the average dialysis patient. Many of these medicines must be taken up to four times daily, and costs generally range from twenty to one hundred twenty dollars per medicine monthly. For the average patient taking nine medicines daily, the costs can be staggering. Often patients simply do not have the adequate income to pay for their medicines after rent and food.

Noncompliance with most medicines taken by dialysis patients leads to adverse outcomes. Common medicines include blood pressure lowering agents, phosphorus lowering medicines, blood thinners, and heart medicines. The literature is extensive and clear that lack of compliance with these medicines will lead to poorer outcomes with more strokes, heart attacks, clotted dialysis accesses, hyperparathyroidism requiring surgery, and a host of other complications. These complications lead to greater expense and early death. It is documented that transplant patients with low incomes are twice as likely to experience a failure of the transplanted kidney and to return to dialysis after one year and after five years versus patients with adequate income.

A Kansas kidney program will make an enormous difference by assisting patients unable to pay for their medicines, whether they have a transplant or are on dialysis. Again, if compliance were improved, patients' outcomes would be better with less hospital costs.

IMPROVED OUTCOMES WITH IMPROVED COMPLIANCE

It is critical to point out that not only does poorer compliance lead to poorer outcomes but also that improved compliance leads to improved outcomes. Data from 1998 show increased medical compliance and increased perception of social support improved mortality. Patients were twenty percent less likely to die. A Kansas Kidney Program could replicate these findings.

- Patients who were late referrals spent twice as many days in the hospital than early referral.
- Other studies have shown that patients who were late referrals were unable to choose peritoneal dialysis over hemodialysis as often as early referrals.
- Late referrals are more likely to need a venous catheter to start dialysis, increasing the risk of infection and decreasing the quality of their dialysis.

- Finally, initiation of dialysis in patients who were referred late has been documented to cost five times as much compared to those patients who were referred early.

Late referral also does not enable for pre-dialysis education and treatment. Kidney disease can often be slowed with appropriate dietary education and blood pressure control. Anemia can be corrected with blood hormone. Bone disease can be prevented with dietary changes and medicines. Blood that has too much acid can be improved with therapy. All of these issues can be addressed with timely referral and education.

A Kansas Kidney Program could increase pre-dialysis education and facilitate early referral. In doing so, patients would feel better, live longer, and initiate dialysis less expensively.

Transportation:

Transportation is a major factor in a patient's noncompliance with their dialysis schedule. Many patients do not or cannot drive themselves to and from dialysis, and transportation can be extremely expensive. Problems with transportation frequently lead to missed or shortened dialysis sessions. Compliance to the dialysis regimen has been well studied and patients live longer if they complete all of their thirteen or fourteen dialysis treatments each month. Here are facts illustrating the importance of compliance to the dialysis schedule:

- Patients who miss one or more hemodialysis sessions monthly are 25% more likely to die than other patients on dialysis.
- Patients who shorten three or more dialysis sessions monthly are 20% more likely to die than other patients on dialysis.

A Kansas Kidney Program could aid in transportation for patients. Reliable transportation would lead to better compliance to the dialysis schedule. Better compliance decreases mortality.

SUMMARY:

Kidney failure requiring dialysis is a life-changing event with complicated, expensive treatment. A program that improves early referral and pre-dialysis education will make a difference. A program that ensures transportation will be available to dialysis will make a difference. A program that ensures patients will be able to purchase their medicines will make a difference. A program that can provide these things makes fiscal sense. There is a wonderful opportunity here to make the lives of Kansans on dialysis better, and I ask you to please help them.

Thank you very much for allowing me to speak

Testimony
Health and Human Services Committee
January 30, 2001

Mr. Chairman and members of the committee, my name is Beth Witten. I received my masters degree in social work from the University of Kansas and worked as a nephrology social worker in the Kansas City area from 1978 until 1996. I currently staff a toll-free phone line for the Life Options Rehabilitation Program which provides free patient and professional education materials and I offer technical assistance on renal rehabilitation. I also coordinate Missouri Kidney Program's Patient Education Program classes for the western half of Missouri. I volunteer with the both the National Kidney Foundation (NKF) of Kansas and Western Missouri and the national office of NKF.

Since I started working as a nephrology social worker in 1978, there have been significant advances. Anti-rejection medications are better and transplant success rates are higher. In 1978 most people on dialysis needed transfusions. Today a manufactured hormone helps reduce anemia of chronic kidney disease without transfusions and allows people to function at a higher level. There are better ways to monitor treatment adequacy and the mortality rate that was once as high as 24% annually is now falling. Persons with kidney failure can have quality lives if they learn how to cope with the multiple physical, emotional, and financial burdens that accompany kidney failure.

As kidneys fail, people become weak and tire easily. They are less physically active and many have difficulty working or even doing routine daily activities. In 1998, nationally about 26% of patients between the ages of 20 and 64 worked six months prior to starting treatment. At treatment initiation, this number declined to about 17%. Research has shown that people with kidney failure are likely to live at or near the poverty level in spite of the fact that most worked prior to their diagnosis. The renal disease fund could help these Kansans.

Those with kidney failure often take eight or more medications and many lack medication coverage. Medication prices have skyrocketed and many people with kidney disease must choose whether to pay their bills or take prescribed medications they need to stay healthy. I have helped Kansans with limited incomes obtain free samples and medications through pharmaceutical assistance programs. However, not all medications are covered and the red tape is overwhelming for patients and providers alike. I've known Kansans who chose forego a transplant because they could not afford the \$10,000-\$15,000 annually for anti-rejection medications alone. The renal disease fund could help these Kansans.

I have known adults with kidney disease who had to live with parents or adult children to afford to pay monthly bills, plus bills for transportation, medications, and insurance premiums. I knew elderly couples who had to move from their homes where they had family and close friends to be closer to dialysis because they couldn't afford to drive long

Beth Witten, MSW, ACSW, LSCSW
Missouri Kidney Program Patient Education Program
Life Options Rehabilitation Program

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distances an average of 13 times monthly and there was no one else to drive them. The renal disease fund could help these Kansans.

I have known people whose employers advised them to take disability when they developed kidney failure only to find out later that they had no health benefits. Often their disability check was too high to qualify for Medicaid yet too low to afford health insurance premiums. I've known people with kidney failure who lost excellent health insurance due to non-payment of premiums. In Kansas, no agency or organization helps these people. I've seen letters from hospitals, doctors, and attorneys threatening patients with legal action for nonpayment of medical bills. I've sat with patients reviewing stacks of bills and insurance explanations of benefits accounting payments to bills, straightening out billing questions, and then helping patients arrange payment schedules to avoid legal action. I knew a dialysis patient once who was no longer able to work and became so depressed over bill collection notices that in spite of our best efforts, she chose to discontinue dialysis and die. We will never know how many people choose to forego dialysis to avoid burdening their families with high medical costs. The renal disease fund could help these Kansans.

And I've seen all this in several Kansas City dialysis facilities where the Missouri resident sitting in one chair receives Missouri Kidney Program assistance with transportation, medications, and insurance premiums while the needy Kansas resident sitting next to him or her receives nothing. The renal disease fund could help these Kansans.

To prolong kidney function, reduce complications, and save jobs, at risk individuals must be identified early, referred to nephrologists, renal dietitians, nephrology social workers, and to education programs like the Missouri Kidney Program's Patient Education Program. Kansas residents living in border cities attend Missouri Kidney Program classes but other Kansans cannot. Pre-treatment education offered by the Missouri Kidney Program helps attendees learn about kidney disease and options for treatment, improves attitudes and coping, and helps them choose less expensive treatments that allow them to keep their jobs. Facility staff report that patients who receive education prior to starting treatment ask more informed questions, are more active participants in their care, and are more adherent with their treatment prescription, all attributes that reduce cost of care. The renal disease fund could help these Kansans.

In conclusion, I am asking for your support of HB 2059 that would establish a renal disease fund to accept monies to assist persons with kidney disease pay for transportation, medications, and insurance premiums and to support early intervention screening and education programs. I want to thank you for your consideration of this extremely important legislation that has the potential to greatly help your neighbors and constituents who have or are at risk of developing kidney disease.

Respectfully submitted,

Beth Witten, MSW, ACSW, LSCSW
Missouri Kidney Program Patient Education Program
Life Options Rehabilitation Program

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Testimony re: HB 2059

House Health and Human Services Committee

Presented by Ronald R. Hein

on behalf of

National Kidney Foundation of Kansas and Western Missouri

January 30, 2001

Mr. Chairman, Members of the Committee:

My name is Ron Hein, and I am legislative counsel for the National Kidney Foundation of Kansas and Western Missouri. NKF KS/MO is a regional office of the National Kidney Foundation with a service area of the entire state of Kansas and the western portion of the state of Missouri. It's mission is to assist patients of kidney disease, and it fulfills this mission through numerous services including raising funds for research, providing direct patient care and treatment, providing of early intervention screenings, provision of a camp for children with kidney disease, including kids on dialysis, organ donation awareness and numerous other programs.

As many of you know, my wife, Julie, who also lobbies with me, donated a kidney to me in 1996, after my kidneys failed as a result of end stage renal disease caused by my diabetes mellitus. For her to give up one of her own functioning kidneys to give the gift of life to me was a loving and selfless act. I also serve on the Board of Directors of the NKF KS/Western MO. I have been appointed by the board to lobby on this bill, but I want to make clear that I am not receiving any remuneration and am offering my services and the services of my firm on a pro bono basis because I truly support the program established by HB 2059.

HB 2059 authorizes the KU Medical Center to implement a program to provide assistance for those in need of care and treatment for kidney disease. Medicare provides coverage for dialysis treatment and the expense of a kidney transplant, and covers certain drugs and services. However, Medicare does not cover all of the expenses that are necessary for the care and treatment of these individuals.

As a result, the National Kidney Foundation presented a proposal to reinstate a program which used to be on the books in Kansas. This proposal was considered by the Joint Healthcare Reform Legislative Oversight Committee during the interim, and they approved the introduction of the legislation that is now HB 2059.

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From 1970-1988, Kansas operated a program for the care and treatment of persons suffering from acute or chronic renal failure requiring dialysis. That program was funded, sporadically, from 1970 until 1984, with the legislature appropriating as much as \$136,662 (1973). In 1988, the legislature repealed the program, because of a weak commitment to the program by the legislature prompted, probably, by the advent of Medicare coverage which diminished some of the original program objectives.

The conferees following will describe the scope of this new kidney program, and explain why this program is vitally necessary. The passage of this bill will put the program in the Kansas Statutes, but will not mandate the appropriation of any funds for the program. The legislation does permit the KU Medical Center to receive grants and other gifts to fund the program, and, should the Legislature choose to appropriate monies, authorizes them to utilize such appropriations to implement the program.

Ultimately, if this legislation is approved by the 2001 Legislature, we would approach the House Appropriations Committee, the Senate Ways and Means Committee and the Governor seeking funding for this program. We know that funds are extremely tight and that such appropriation request may not be successful immediately, but we also know that, as you will hear from other conferees, funding for this program can greatly improve outcomes of dialysis patients and others in end-stage renal disease, and that such improved outcomes can result in decreased healthcare costs, and improved health that can result in the patients being more productive. By improving outcomes and keeping people productive, there is also a commensurate increase in tax collections resulting from such improved health.

I urge you to support HB 2059.

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

Testimony in Pursuit of a Kansas Kidney Program
Thursday, September 21, 2000
Scott Solcher, MD, FACP

Thank you very much for allowing me to testify in favor of a state kidney program.

I will briefly describe kidney failure and treatment with dialysis. I will also discuss issues that prevent patients from maximizing their treatment, which in turn lead to poorer health, increased hospitalizations and earlier death. I believe a Kansas kidney program can improve outcomes by facilitating patients' ability to receive pre-dialysis education, improving awareness of renal disease, providing transportation to dialysis, supplying medicines, and providing childcare assistance. Improved outcomes include better health, fewer hospitalizations, and longer life.

BACKGROUND INFORMATION

Kidney Failure

The most common cause of kidney failure is diabetes. The second leading cause is high blood pressure. Fortunately kidney failure is treatable. Kidney failure can be a slow process or a very rapid one. The symptoms may at first be subtle with loss of energy, vigor, or appetite. Symptoms progress to severe fatigue, weakness, vomiting, and profound itching. Often there is water overload with swelling in patient's legs or lungs. These symptoms are caused as toxins (poisons) increase in the bloodstream when the patient does not have adequate renal function. Kidney failure can be treated with either dialysis or transplantation. Virtually all patients who receive a transplant require dialysis while waiting for a kidney due to the complexity and time required for transplant evaluation.

Hemodialysis

Hemodialysis is blood dialysis performed at a dialysis unit. It typically requires three weekly sessions that last four hours each. Eighty-five percent of patients with end stage renal disease in the United States use this modality. Each session is typically associated with significant fatigue, especially in the elderly. Hemodialysis is, in essence, an attempt to fit a weeks worth of kidney function into three, four-hour treatments. With hemodialysis, the patient's blood must be transferred to the dialysis machine. In order to do so, an artificial conduit is surgically placed. Ideally the conduit is present in the patient's forearm several months prior to beginning hemodialysis. If there is not enough time prior to the initiation of dialysis, a temporary catheter must be placed in a vein. Typically the large jugular vein in the neck is used. Catheters are associated with increased rates of infection and the quality of dialysis is generally poorer.

Peritoneal Dialysis

Peritoneal dialysis is the modality that the other fifteen percent of patients use. In this procedure, patients place approximately two liters of dialysate fluid in the abdominal cavity around the stomach. The fluid is infused through a special catheter placed through the abdominal wall. Toxins diffuse into this fluid, with other chemicals diffusing from the fluid into the blood stream. The fluid is then drained. This procedure must be done four to five times daily, every single day. Although peritoneal dialysis allows more flexibility for some patients, it is an enormous amount of work.

Lifestyle Restrictions

Regardless of how patients dialyze, they have multiple lifestyle restrictions. Included are restrictions of the amount of any fluid they drink, as well as limitations in salt, potassium, and phosphorus intake. These limitations affect every meal and change every aspect of a patient's eating habits. Their lifestyle is additionally burdened by twelve to sixteen hours required weekly for hemodialysis and twenty-eight to thirty-five hours required weekly for peritoneal dialysis. Finally, while many of the most severe symptoms of renal failure improve with dialysis, many persist. The most prominent is fatigue. Weakness, itching, and loss of appetite can also continue. While dialysis in general does a good job of clearing poisons; it not like having adequate kidney function.

Clearly the diet and time schedule is difficult to adhere to. In addition to the dialysis sessions and dietary restrictions, dialysis patients on average take nine different medicines, with many patients taking 15 or 20. The schedules for these medicines are very difficult for anyone to manage correctly.

HOW A KANSAS KIDNEY PROGRAM WILL ASSIST DIALYSIS PATIENTS

Early Intervention and Pre-dialysis Education

Early intervention is critical. The Kansas Foundation for Medical Care studied patient's initiation of dialysis and published their preliminary results in 1998. They compared patients who were referred early to a nephrologist versus patients who were referred late to a nephrologist. Patients who saw a nephrologist greater than sixty days prior to the initiation of dialysis were considered early referrals. Late referrals were those patients who saw a nephrologist for the first time less than sixty days before starting dialysis. Their findings included the following.

- Patients who were late referrals were twice as likely to die within two years than early referrals.
- Patients who were late referrals were more likely to start hemodialysis than early referrals.

I have spoken already of the number of medicines taken by the average dialysis patient. Many of these medicines must be taken up to four times daily, and costs generally range from twenty to one hundred twenty dollars per medicine monthly. For the average patient taking nine medicines daily, the costs can be staggering. Often patients simply do not have adequate income to pay for their medicines after rent and food.

Noncompliance with most medicines taken by dialysis patients leads to adverse outcomes. Common medicines include blood pressure lowering agents, phosphorus lowering medicines, blood thinners, and heart medicines. The literature is extensive and clear that lack of compliance with these medicines will lead to poorer outcomes with more strokes, heart attacks, clotted dialysis accesses, hyperparathyroidism requiring surgery, and a host of other complications. These complications lead to greater expense and early death.

It is documented that transplant patients with low incomes are twice as likely to experience a failure of the transplanted kidney and to return to dialysis after one year and after five years versus patients with adequate income.

A Kansas kidney program will make an enormous difference by assisting patients unable to pay for their medicines, whether they have a transplant or are on dialysis. Again, if compliance were improved, patients' outcomes would be better with less hospital costs.

Childcare

Childcare is an absolutely crucial issue for some patients. This issue is not well documented simply because it is less common. Childcare requirements affect parents as well as grandparents who are responsible for the care of children. In my experience, inadequate childcare arrangements always lead to missed dialysis treatments. This in turn increases mortality.

Lack of childcare is a barrier to better health care that can be removed with a Kansas kidney program.

IMPROVED OUTCOMES WITH IMPROVED COMPLIANCE

It is critical to point out that not only does poorer compliance lead to poorer outcomes but also that improved compliance leads to improved outcomes. Data from 1998 show increased medical compliance and increased perception of social support improved mortality. Patients were twenty percent less likely to die. A Kansas Kidney Program could replicate these findings.

- Patients who were late referrals spent twice as many days in the hospital than early referrals.
- Other studies have shown that patients who were late referrals were unable to choose peritoneal dialysis over hemodialysis as often as early referrals.
- Late referrals are more likely to need a venous catheter to start dialysis, increasing the risk of infection and decreasing the quality of their dialysis.
- Finally, initiation of dialysis in patients who were referred late has been documented to cost five times as much compared to those patients who were referred early.

Late referral also does not enable for pre-dialysis education and treatment. Kidney disease can often be slowed with appropriate dietary education and blood pressure control. Anemia can be corrected with blood hormone. Bone disease can be prevented with dietary changes and medicines. Blood that has too much acid can be improved with therapy. All of these issues can be addressed with timely referral and education.

A Kansas kidney program could increase pre-dialysis education and facilitate early referral. In doing so, patients would feel better, live longer, and initiate dialysis less expensively.

Transportation

Transportation is a major factor in a patient's noncompliance with their dialysis schedule. Many patients do not or cannot drive themselves to and from dialysis, and transportation can be extremely expensive. Problems with transportation frequently lead to missed or shortened dialysis sessions. Compliance to the dialysis regimen has been well studied, and patients live longer if they complete all of their thirteen or fourteen dialysis treatments each month. Here are facts illustrating the importance of compliance to the dialysis schedule:

- Patients who miss one or more hemodialysis session monthly are 25% more likely to die than other patients on dialysis.
- Patients who shorten three or more dialysis sessions monthly are 20% more likely to die than other patients on dialysis.

A Kansas kidney program could aid in transportation for patients. Reliable transportation would lead to better compliance to the dialysis schedule. Better compliance decreases mortality.

Medicines

SUMMARY

Kidney failure requiring dialysis is a life-changing event with complicated, expensive treatment. A program that improves early referral and pre-dialysis education will make a difference. A program that ensures transportation will be available to dialysis will make a difference. A program that ensures patients will be able to purchase their medicines will make a difference. A program that ensures adequate childcare is available will make a difference. A program that can provide these things makes fiscal sense. There is a wonderful opportunity here to make the lives of Kansans on dialysis better, and I ask you to please help them.

Thank you very much for allowing me to speak.

References

Early Referral

Roubicek, C, et al, Timing of nephrology referral: Influence on mortality and morbidity. *AJKD*, 2000 Jul;36(1):35-41.

Arora, P, et al, Prevalence, predictors, and consequences of late nephrology referral at a tertiary care center. *JASN*, 1999, Jun;10(6):1281-6.

Spivey G, et al, ESRD pilot study: timing of referral to nephrologists. *QIJ* 1998 March:5-6.

Obrador GT, Pereira BJ, Early referral to the nephrologist and timely initiation of renal replacement therapy: a paradigm shift in the management of patients with chronic renal failure. *AJKD* 1998 Mar;31(3):398-417.

Schmidt, RJ, Domico, JR, Sorkin, MI, Hobbs, G, Early referral and its impact on emergent dialyses, health care costs, and outcome. *AJKD* 1998 Aug;32(2):278-83.

Ellis, PA, Reddy, V, Bari, N, Cairns, HS, Late referral of end-stage renal failure. *QJM*, 1998 Nov;91(11):727-32.

Ifudu O, Dawood M, et al, Excess morbidity in patients starting uremia therapy without prior care by a nephrologist. *AJKD* 1996 Dec;28(6):841-5.

Campbell, JD, et al, The timing of referral of patients with end-stage renal disease. *Dialysis and Transplantation*, 1989 Dec;18(12):660-685.

Compliance

Howard AC, et al, Targeted intervention to improve compliance in an urban hemodialysis population. *Nephrol News Issues* 1999 Feb;13(2):27, 31-4.

Leggat JE, et al, Noncompliance in hemodialysis: predictors and survival analysis. *AJKD* 1998 Jul;32(1):139-45.

Kimmel, PL, et al, Psychosocial factors, behavioral compliance, and survival in urban hemodialysis patients. *KI* 1998 Jul;54(1);245-54.

Bander SJ, Walters BA, Hemodialysis morbidity and mortality: links to patient non-compliance. *Curr Opin Nephrol Hypertens* 1998 Nov ;7(6):649-53.

Latham, CE, Obstacles to achieving adequate dialysis dose: compliance, education, transportation, and reimbursement. *AJKD* 1998 Dec;32(6 Suppl 4):S93-5.

Kimmel PL, et al, Behavioral compliance with dialysis prescription in hemodialysis patients. *JASN* 1995 Apr;5(10):1826-34.

Morduchowicz G, et al, Compliance in hemodialysis patients: a multivariate regression analysis. *Nephron* 1993;64(3):365-8.

O'Brien ME, Compliance behavior and long-term maintenance dialysis. *AJKD* 1990 Mar;15(3):209-14.

Wolcott DL, et al, Treatment compliance in end-stage renal disease patients on dialysis. *AJKD* 1986;6(5):329-38.

Kalil, RS, et al, Patients with a low income have a reduced renal allograft survival. *AJKD* 1992 Jul;20(1):63-9.

The USRDS dialysis morbidity and morbidity study: Wave 2. *AJKD* 1997 Aug;30(2), Supplement:S67-S85.

Cost Effectiveness

Obrador GT, Pereira BJ, Early referral to the nephrologist and timely initiation of renal replacement therapy: a paradigm shift in the management of patients with chronic renal failure. *AJKD* 1998 Mar;31(3):398-417.

Schmidt, RJ, Domico, JR, Sorkin, MI, Hobbs, G, Early referral and its impact on emergent dialyses, health care costs, and outcome. *AJKD* 1998 Aug;32(2):278-83.

Hornberger JC, The hemodialysis prescription and cost effectiveness. Renal Physicians' Association Working Committee on Clinical Guidelines. *JASN* 1993 Oct;4(4):1021-7.

Campbell, JD, et al, The timing of referral of patients with end-stage renal disease. *Dialysis and Transplantation*, 1989 Dec;18(12):660-685.

HIGH PHOSPHORUS FOODS

Some people with kidney disease may develop an elevated level of phosphorus in the blood which could cause changes in the structure of the bones. Your physician or dietitian will tell you if you need to avoid the following foods in order to lower phosphorus in your diet.

LIMIT THE FOLLOWING FOOD ITEMS

DAIRY

Milk, cheese, yogurt, ice cream, pudding

MEAT AND MEAT SUBSTITUTES

Liver (and organ meats)
Cheese
Fish (salmon and flounder)
Peanut butter
Egg yolk (3/week limit)
Bratwurst/Hotdogs

STARCHES

Whole grain bread and cereals (i.e. Cherrioes, wheat bran cereals)
Quick Cream of Wheat (regular okay)
Oatmeal

VEGETABLES

Dried beans (lima beans, broad beans, navy beans)
Dried peas
Soybeans
Lentils
Broccoli
Brussell sprouts
Mushrooms

SOUPS

Cream Soups

ADDITIONAL FOODS

Cocoa
Chocolate
Seeds (sunflower, pumpkin, and sesame)
Baking powder and Baked products (pancake or waffle, bran muffin/cornbread, cakes)
Molasses
Brown sugar
Nuts
Soda pop (Coke, Pepsi, Mr. Pibb, Dr. Pepper, Strawberry soda)
Beer

Please Note: Make sure you also take your calcium and/or phosphate binder consistently as prescribed

Prepared by:
Kansas City Dialysis and Transplant
Kansas City, Missouri

HIGH POTASSIUM FOODS

The following foods contain 250 mg or more of potassium per normal serving (1/2 cup), and are considered high in potassium.

MEAT SUBSTITUTES

Dried Beans:

- Butter Beans
- Lima
- Navy
- Kidney
- Pinto
- Pork and Beans
- Dried Peas

MISCELLANEOUS

- Salt Substitute
- Molasses
- Brown Sugar
- Black Licorice

STARCHES

Bran cereal concentrate

VEGETABLES

- Avocado
- Bamboo Shoots
- Brussels Sprouts
- Carrots, raw
- Greens, beet
- Kohlrabi
- Leeks
- Parsnips
- Potatoes:
 - Baked
 - French Fried
 - Instant
 - Mashed
 - Mixes
- Spinach
- Squash
 - Acorn
 - Winter
- Succotash
- Sweet Potato
- Tomato, raw
- Tomato, sauce

JUICES

- Orange Juice
- Prune Juice
- Tomato Juice
- V-8 Juice Cocktail

FRUITS

- Apricots
- Bananas
- Cantaloupe
- Coconut
- Honeydew
- Kiwi Fruit
- Mango
- Nectarine
- Orange
- Papaya
- Persimmon
- Tangelos
- Dried Fruits

From: Now You're Cooking!
Missouri-Kansas Council on Renal Nutrition

HIGH SODIUM FOODS

DAIRY PRODUCTS

Blue Cheese
Buttermilk
Cottage Cheese
Processed Cheese
Processed Cheese Spreads

FAT

Bacon Drippings
Ham Fat
Salt Pork

MEAT

Canned & Packages Main Dishes (Chili, Ravioli, Stew)
Canned Meats & Fish
Cured Meat (Bacon, Corned Beef, Ham)
Frozen Meat Dishes
Frozen TV Dinners
Pickled Meats
Pot Pies
Processed Meats (Dried Beef, Luncheon Meats, Sausage & Frankfurters)

VEGETABLES*

Canned Mushrooms
Pork-N-Beans
Sauerkraut
Tomato Puree (Tomato Paste is low in sodium)
Tomato Sauce

*All canned vegetables contain salt and should be used in moderation

SOUPS

Bouillon Cubes or Granules
Canned Soups
Dehydrated Soup Mixes

SEASONINGS

Celery Salt
Garlic Salt
Lite Salt
Meat Tenderizers
Monosodium Glutamate
Onion Salt
Sea Salt
Soy Sauce

MISCELLANEOUS

Baking Soda
Biscuits & Pancake Mix
French & Italian
Salad Dressings
Olives
Packaged Seasoned Mixes (Gravy, Spaghetti, Sauces)
Pickles
Salted Crackers
Salted Popcorn
Salted Nuts & Seeds
Salted Snack Foods (Corn Chips, Potato Chips, Pretzels)
Seasoned Croutons
Stuffing Mixes
Snack Food Dips

**Testimony to
Healthcare Reform Legislative Oversight Committee**

**Presented by: Wendy Funk Schrag, LMSW
Renal Care Group of the Midwest**

Good afternoon. My name is Wendy Funk Schrag and I am a dialysis social worker. I work for Renal Care Group of the Midwest which provides hemodialysis, peritoneal dialysis and home hemodialysis for around 500 patients in the state of Kansas in the following cities: Wichita, Arkansas City, Hutchinson, Newton, Liberal, Dodge City, Chanute, Great Bend, Hays and Emporia. We cover a wide area of the state and have both an urban and rural population. I have been employed as a dialysis social worker with this agency since May, 1990. I also have had the privilege of talking with many other dialysis staff and patients through volunteer work with the National Kidney Foundation Council of Nephrology Social Workers and lectures I have given throughout the country about rehabilitation for people with kidney disease.

As a dialysis social worker for the past ten years, I have seen some great advances which have helped our patients cope with the physical aspects of kidney disease. A few examples of these advances include better anti-rejection medications for transplant anti-rejection, continuous cycling peritoneal dialysis and home hemodialysis which offer patients more variety in dialysis modalities to choose from to fit with their lifestyles, dialysis exercise programs to help patients gain strength, new drugs available for anemia management. However, the basic problems which I have assisted patients with since I started working in this field and often cause the greatest stress for our patients remain: the financial burden associated with kidney disease, loss of personal identity replaced by patient identity, and family stress. I continue to hear from people on dialysis that they are not pursuing kidney transplant because they can't finance their dental work to be considered for a transplant and can't afford anti-rejection medications once Medicare would stop paying for them.

Around 25% of the U.S. dialysis patient population under age 65 is employed. This leaves the remaining 75% reliant on their disability income as their sole means of financial support. This amount usually ranges anywhere from \$400-1,000 a month. I would estimate that most of the 120 patients I serve as social worker who receive disability income get \$600-900 per month. They are living above the amount that would qualify them for public assistance through Medicaid, so they are not able to get assistance with the cost of medications, transportation to dialysis treatment, or their Medicare Part B insurance premium. Much of my time as a dialysis social worker is spent doing financial assistance applications to such agencies as the Salvation Army, Red Cross, National Kidney Foundation, Kansas Dialysis Association and pharmaceutical indigent drug companies to help patients manage their medical and non-medical expenses. All of these organizations have limits. Only the pharmaceutical indigent drug companies offer ongoing assistance for those patients who qualify for those medications they offer. It is not unusual for a dialysis patient to be on 9-12 different medications. If someone has to

make a choice between paying rent or buying food and buying medications, the medications will be the item not purchased. Dialysis patients put themselves at risk for hospitalization and even death by not adhering to their medication regime. Hypertension is a common cause of kidney failure. One patient recently came to his dialysis treatment with blood pressure so high we had to send him to the hospital after his dialysis treatment because we were afraid he may have a stroke. This patient has a history of not taking his blood pressure medication because he doesn't have enough money each month to purchase all his medications. So, Medicare ends up paying for a hospital stay for him instead.

I received a call recently from a frantic mother of one of our patients. She stated to me she is facing bankruptcy because she has been using her finances to help her son meet his expenses which has caused extreme hardship to herself. This patient transferred to our facility from Texas and has commented many times that it was much easier for him to manage financially there because Texas has a state kidney program which assisted him with expenses that we are not able to here. This situation is an example of the stress that a family faces with this disease.

The emotional impact of financial stress can not be underestimated. In preparation for this testimony, I looked over the list of patients for whom I provide services and who receive medication for depression. Approximately 15% of the patients at the largest clinic where I work receive medication for ongoing problems with depression. Only two patients who receive medication for depression are financially stable. The remaining patients all have ongoing financial stress. I don't think this is a coincidence but is an indicator of how much emotional hardship financial stress causes. I recently started a caregiver support group at one of our dialysis clinics. The group consists mainly of spouses and a few children of people on dialysis. Most of the spouses also have their own health problems to deal with and end up sacrificing their own health to help their spouse cope. Examples of this include not going to their own medical appointments because they need to save their gasoline for trips to dialysis, purchasing their spouse's medications but not their own, and quitting jobs in order to stay home to take care of their spouse. At my most recent meeting, a 65 year old man described how he had gone from a financially comfortable life prior to his wife's dialysis treatment to their current situation where they live on \$700 a month. Because of some non-monetary assets, they do not qualify for Medicaid. His wife requires someone to be with her all the time, so he is not able to work. He stated that when he was employed he had a high stress job, but the stress of dealing with his wife's illness and their financial difficulties caused him to experience extreme anxiety. He became so overwhelmed that he was not able to concentrate, kept forgetting things and was afraid he was going insane. He began wondering if he should put his wife in a nursing home because he didn't feel he was capable mentally of handling all the responsibilities of her care, plus trying to manage making ends meet. He is coping somewhat better now, thanks to some medication which he is taking and dealing with his stress at the support group meetings. I am getting this medication for him from an indigent drug program.

The nurses at our dialysis clinic have commented to me that they see a difference between those patients who receive pre-dialysis education and intervention and those who don't. Those who receive education and social work intervention prior to starting dialysis are less scared, anxious and depressed. It is very important to work with people before they get to the point where they are so ill that they lose hope that they can continue to work or maintain their prior lifestyle. They may not know options that are available to them and quit work or make other major life changes needlessly. It's also important to work with people prior to dialysis to help them learn how to take charge of their care and communicate with the health care team. Those people who are educated about their kidney disease can then be less focused on their illness and more focused on living. Educated patients are less likely to quit working or can become employed again. I see too many patients, who by the time they are referred to me for pre-dialysis education have already quit their jobs, become overwhelmed and depressed, and resigned themselves to the role of "patient." Patients who are able to maintain their employment are much different from unemployed patients. We offer an evening shift at a few of our clinics for patients who work. One of our dialysis technicians recently commented to me how different the patients are on the evening shift. She stated they are much more independent, self-assured people, less focused on their illness because they have other roles that they are still continuing in life. We need to work with people sooner to keep them involved in their prior activities as much as possible.

In summary, the needs I see the most among dialysis patients are the following:

- 1) transportation to and from dialysis and medical appointments
- 2) medication costs, both during dialysis and following transplantation
- 3) assistance with health insurance premiums
- 4) assistance with dental care in order to get prepared for a kidney transplantation
- 5) pre-dialysis education to assist in making the transition from health to adjustment to chronic illness

Thank you for your attention.

Robert Whitlock

**Executive Director
Missouri Kidney Program**



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Other States' Programs

- **23 states have state kidney programs**
- **TX, PA, MO provide comprehensive benefits similar to those requested**
- **Other states provide less comprehensive benefits**
- **Missouri Kidney Program budget for 2001 is \$4.1 million**



MoKP's Organizational Structure

- **Housed within Health Sciences complex of University of Missouri - Columbia**
- **Abides by University procedures and practices**
- **Operates under the guidance of a 16-member Advisory Council**
- **Maintains a staff of 11 FTE employees**



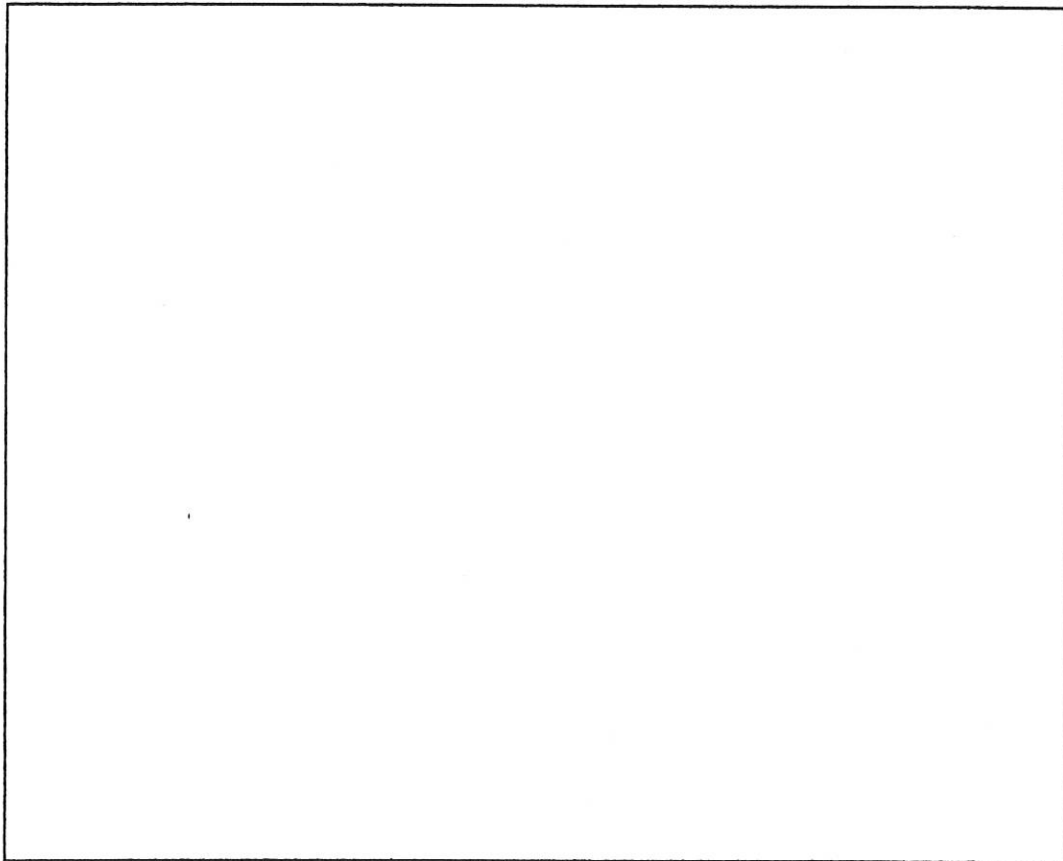
MoKP Patients & Services

- **MoKP has a means test to qualify for benefits**
- **MoKP serves the lowest 30% of Missouri residents with ESRD**
- **MoKP coordinates with other state departments & divisions**
- **MoKP is payer of last resort**
- **MoKP offers pre-treatment education**



Ways MoKP Reduces Costs

- **Competitive bidding for centralized drug program**
- **Contracting with university pharmacy, a public entity, entitled to lowest cost drugs through Public Health Services contract**
- **Billing patients' commercial insurance**
- **Developing computerized web based application and billing procedures**



MoKP Assistance Available

- **Will share forms, manuals, processes, procedures developed for MoKP**
- **Will consider selling or leasing computer database software designed for MoKP usage at below market value**



Conclusion

Why establish a Kansas Kidney Program:

- **To help people learn about risk factors for kidney disease and possibly prevent ESRD**
- **To help people learn about options for treatment to maximize productivity and quality of life**
- **To help people pay expensive indirect costs of treatment, improve adherence, and reduce morbidity and mortality**

As the Health and Human Services Committee , we hope that you will support us as we continue to advocate for establishment of a comprehensive state kidney program that would provide assistance with premiums, transportation, medications, nutrition supplements, and would offer early intervention screening and education. Thank you for your consideration.

We would be happy to respond to questions.