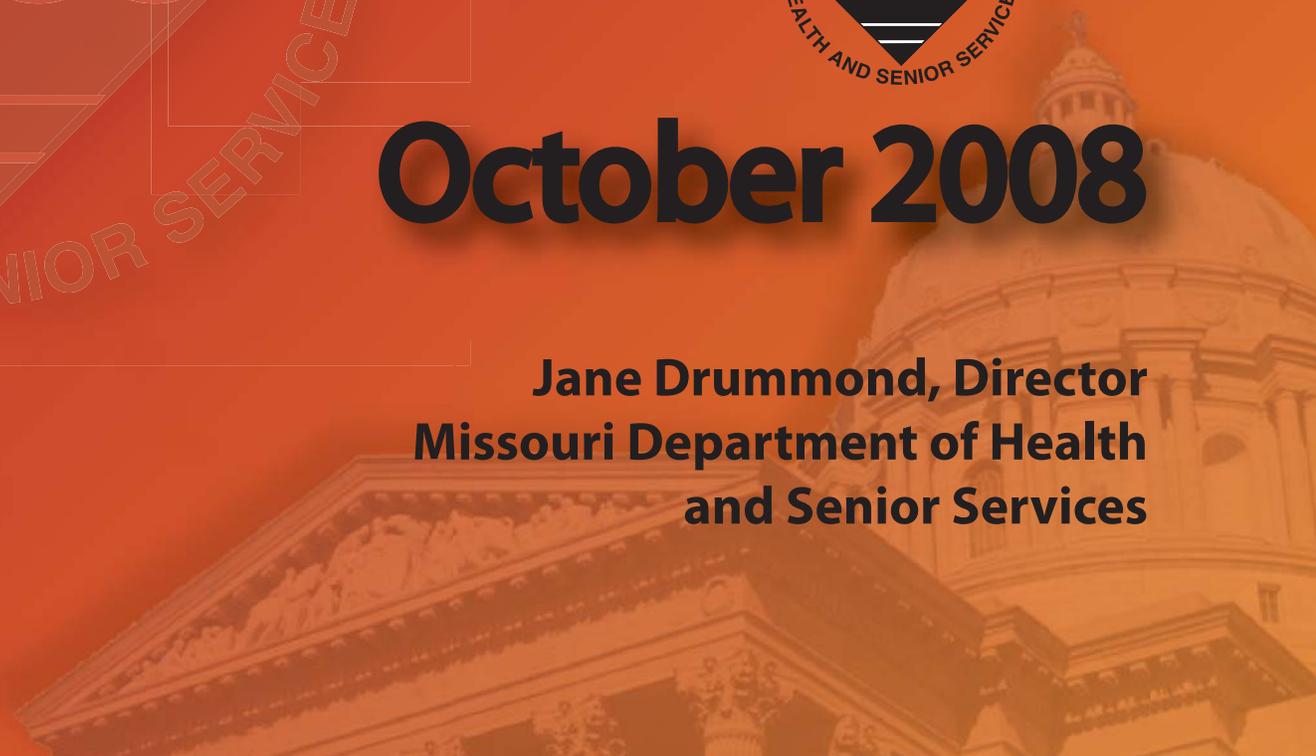


# Missouri Chronic Kidney Disease Task Force



**October 2008**

**Jane Drummond, Director  
Missouri Department of Health  
and Senior Services**



*DEDICATION  
TO*

*ROBERT W. WHITLOCK, MSSM, MHA, LCSW*

*CHAIRMAN  
CHRONIC KIDNEY DISEASE TASK FORCE*



This final report is dedicated to Robert (Bob) Whitlock, chairman of the task force until his untimely death on July 20, 2008. He was a primary force behind the creation of this task force. As director of the Missouri Kidney Program for 14 years, he saw the need for early recognition and prevention of chronic kidney disease. It is unfortunate that he will not see the benefits that patients will have from the work of this task force. His forethought, advice and wisdom will be greatly missed.

*“We have to build intellectual bridges with all health professions to shift our collective thinking away from ‘waiting for kidneys to fail’ to strategies for intervention and prevention, particularly with regard to diabetes, hypertension and obesity.”<sup>1</sup>*

*Robert W. Whitlock*



# Missouri Chronic Kidney Disease Task Force Report and Recommendations to the Missouri General Assembly October 2008

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Brochure provided at end of report:  
*eGFR and CKD: Estimated Glomerular, Filtration Rate and Chronic Kidney Disease*



# Acknowledgments



The Missouri State Legislature is only one of a handful of state legislatures that has had the foresight to create a task force to examine the problems caused by chronic kidney disease (CKD) and to make recommendations for its prevention. At this time only five states have completed this task. The Missouri State Legislature is to be applauded for its prudence, which is in keeping with the verse that is printed on the dome of Missouri's State Capitol, "*Where There Is No Vision, The People Perish.*"

Physicians and other health care professionals involved in the treatment of CKD were appointed by Jane Drummond, the director of the Missouri Department of Health and Senior Services (DHSS), to serve on the task force. Bob Whitlock, director, Missouri Kidney Program (MoKP), was selected as the chairperson. Michael Young, DO, was chosen to serve as vice chairperson. Legislators were appointed by The Honorable Rod Jetton, Missouri's Speaker of the House of Representatives, and The Honorable Michael Gibbons, President Pro Tem of the Senate.

Sincerest appreciation is extended to Michael Young, DO, FAOCI, who assumed the role of chairperson, and to Douglass Takashi Domoto, MD, JD, who assumed the responsibility of writing the report following Bob's death. This report would not be possible without their assistance.

## **TASK FORCE MEMBERS**

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# Executive Summary





# Executive Summary

According to the National Institutes of Health (NIH), “The best hope for reducing the human and economic costs of end-stage renal disease lies in prevention.”<sup>2</sup>

Chronic kidney disease (CKD), which leads to renal failure, is a public health issue for Missouri. In the year 2007, there were 6,467 Missourians living with chronic kidney disease (CKD) Stage 5, which is an advanced stage. In 2007, 2,079 new cases were diagnosed with CKD Stage 5. The Missouri CKD Task Force believes that CKD meets A. C. Schoolwerth’s definition of a public health issue and requires “a broad and coordinated public health approach ... to meet the burgeoning health, economic, and societal challenges of CKD.”<sup>3</sup>

Kidney failure does not happen overnight. Unfortunately, there are few if any symptoms in the early stages of kidney disease. Symptoms usually show up late in the process. Kidney failure is the end result of a typically gradual breakdown of kidney function. The most common causes of kidney failure are diabetes and high blood pressure.

CKD, when left untreated, progresses to either dialysis or transplantation. The estimated cost of maintaining a patient on dialysis is \$65,000 per year. CKD patients who are on dialysis are eligible for Medicare coverage. When treated early and dialysis is prevented, the cost savings to Medicare is \$250,000 per patient. The NIH estimates that the “overall estimated Federal savings from recent improvement in preventing kidney disease is approximately \$1 billion per year.”

In today’s fast-paced, demanding, and cost-conscious healthcare environment, it is important to evaluate the cost effectiveness of any program. Patient education is an arena where research has documented cost effectiveness. For example, every \$1 spent on patient education across chronic illnesses saves \$3 to \$4 in medical costs.

Today CKD can be detected much earlier than 30 years ago. Blood tests measuring serum creatinine can be used to diagnose CKD, and, used in combination with a patient’s other risk factors, determine the presence of or stage of CKD. The earlier stage of diagnosis, the greater the chance of preventing the patient from progressing to dialysis or transplantation.

Steps to prevent the development and progression of CKD are well known, widely accepted, and achievable. Aggressive management of diabetes, hypertension, and cardiovascular disease is critical to the success of preventing CKD. The most important goal is to control blood pressure.



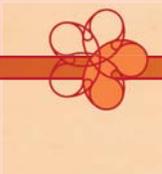
Weight loss, smoking cessation, treating cholesterol or dyslipidemia, and lowering uric acid level when high are other measures that help preserve renal function. These measures also help prevent the development and progression of cardiovascular disease.

The authors recommend the following public policy approaches to preventing CKD:

1. Universally use and recognize the estimated glomerular filtration rate (eGFR);
2. Conduct basic CKD screening that includes blood pressure monitoring to assure detection of CKD in Stages 1 – 3, earlier stages, versus Stages 4 and 5;
3. Provide CKD education to primary care providers;
4. Engage public and private insurers and payers;
5. Increase funding for CKD education; and
6. Increase collaboration among interested parties.

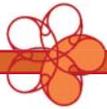
The Missouri State Legislature was prudent in its foresight to appoint a task force to study the magnitude of CKD as a public health problem. Now is the time to continue taking steps to address CKD as a public health problem. The task force proposes recommendations for early intervention and treatment for CKD. The potential cost benefits are obvious. Action is needed now to intervene successfully.





# Legislative Mandate





# Legislative Mandate

The Chronic Kidney Disease Task Force was created in 2008 under RSMo 192.632 (as part of Senate Bill 577). Outlined below is the statutory mandate for the composition of the task force along with the charge to the task force.

1. There is hereby created a “Chronic Kidney Disease Task Force”. Unless otherwise stated, members shall be appointed by the director of the department of health and senior services and shall include, but not be limited to, the following members:
  - (1) Two physicians appointed from lists submitted by the Missouri state medical association;
  - (2) Two nephrologists;
  - (3) Two family physicians;
  - (4) Two pathologists;
  - (5) One member who represents owners or operators of clinical laboratories in the state;
  - (6) One member who represents a private renal care provider;
  - (7) One member who has a chronic kidney disease;
  - (8) One member who represents the state affiliate of the National Kidney Foundation;
  - (9) One member who represents the Missouri kidney program;
  - (10) Two members of the house of representatives appointed by the speaker of the house;
  - (11) Two members of the senate appointed by the president pro tem of the senate; and
  - (12) Additional members may be chosen to represent public health clinics, community health centers, and private health insurers.
2. A chairperson and vice chairperson shall be elected by the members of the task force.
3. The chronic kidney disease task force shall:
  - (1) Develop a plan to educate the public and health care professionals about the advantages and methods of early screening, diagnosis, and treatment of chronic kidney disease and its complications based on kidney disease outcomes, quality initiative clinical practice guidelines for chronic kidney disease, or other medically recognized clinical practice guidelines;



- (2) Make recommendations on the implementation of a cost-effective plan for early screening, diagnosis, and treatment of chronic kidney disease for the state's population;
  - (3) Identify barriers to adoption of best practices and potential public policy options to address such barriers;
  - (4) Submit a report of its findings and recommendations to the general assembly by August 30, 2008.
4. The department of health and senior services shall provide all necessary staff, research, and meeting facilities for the chronic kidney disease task force.
  5. The provisions of this section shall expire August 30, 2008.

## **TASK FORCE MISSION**

Task force members identified the mission as follows:

1. Defining the target as:
  - a. The public: the “invisible” people – those in Stages 1 and 2, the early stages of CKD, who are “undoctored” or “underdoctored”
  - b. Health care professionals – primary care – family practice doctor, general practice doctor, internal medicine doctor, advance practice nurse, physician’s assistant
2. Identifying the components of the tasks for screening, diagnosis, and early treatment of chronic kidney disease (CKD) and its complications including:
  - a. A plan to educate
  - b. A plan for implementation
  - c. Identify barriers to best practices
  - d. Identify public policy options to address barriers
3. Determining the specific components to work on which are:
  - a. Public education and awareness
  - b. Health care professional education and awareness
  - c. Early detection
  - d. Early treatment
  - e. Document burden, including financial consequences
  - f. Recommend best practices
  - g. Identify barriers to implementation
  - h. Identify public policy options to address barriers



# TASK FORCE ACTIVITIES

The task force met as a whole on the following dates.

- January 17, 2008
- February 28, 2008
- June 9, 2008

The subcommittees met separately on the following dates.

- Provider Education and Treatment Subcommittee
  - \* April 24, 2008
  - \* June 26, 2008
  - \* April 16, 2008
- Patient and Public Education Subcommittee
  - \* April 22, 2008
  - \* April 28, 2008
- Screening and Early Detection Subcommittee
  - \* March 27, 2008
  - \* April 17, 2008

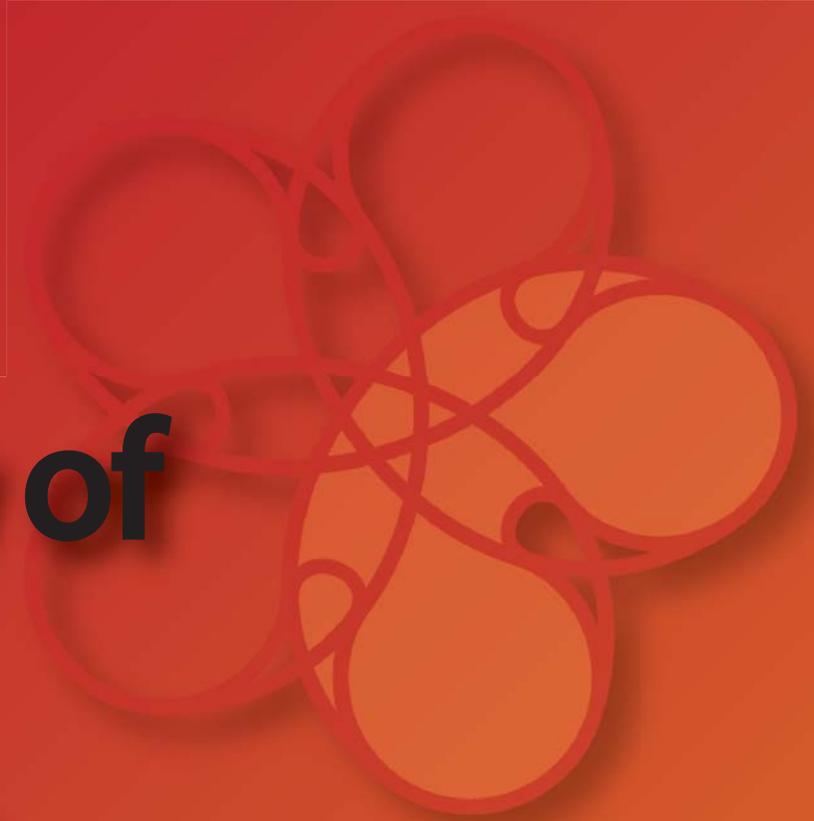
Subcommittee chairs and members of DHSS staff met on the following dates.

- July 31, 2008
- August 21, 2008

Minutes of all meetings are available upon request.



# Overview of Chronic Kidney Disease



# Overview of Chronic Kidney Disease

## The Importance of Kidneys

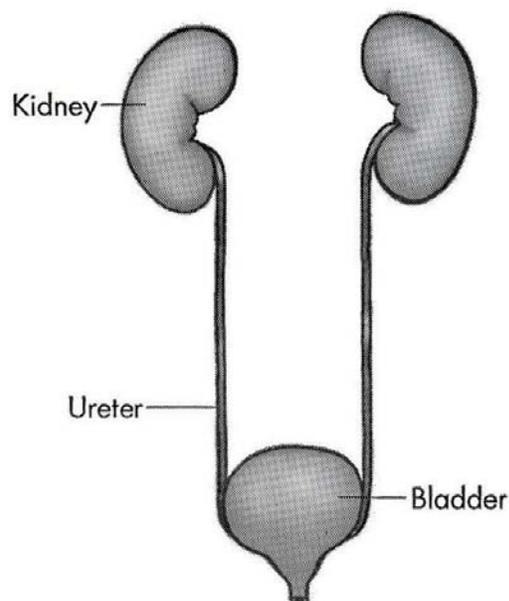
The following information was adapted from *Getting Ready for a “New Normal”: A Helpful Guide for Starting Dialysis*.<sup>2</sup>

People don't usually think about their kidneys. Generally speaking, the kidneys and how they work are a mystery to most. People usually have two kidneys, even though one is all that is needed to live a healthy life. Unlike heart or lungs, which have more noticeable functions (the heart beats to pump blood and the lungs expand and contract when breathing in and out), the kidneys perform their important work without being noticed.

The major job of the kidneys is to remove waste products and excess fluid from the body through the urine. The kidneys also produce hormones that affect the function of other organs. For example, a hormone produced by the kidneys called erythropoietin (or EPO) helps the body make red blood cells. Other hormones produced by the kidneys help control blood and how the body uses calcium.

The kidneys are powerful chemical factories that perform the following functions:

- ❖ Remove waste products from the body
- ❖ Remove drugs from the body
- ❖ Balance the body's fluids
- ❖ Release hormones that control blood pressure
- ❖ Produce a form of vitamin D that promotes strong, healthy bones
- ❖ Control the production of red blood cells.



Kidney failure does not happen overnight. In the early stages of kidney disease, there are few, if any, symptoms. Symptoms usually show up late in the process. Kidney failure is the end result of a typically gradual breakdown of kidney function. The most common causes of kidney failure are diabetes and high blood pressure. As kidneys fail, blood urea nitrogen (BUN), a substance which comes from the breakdown of protein in the foods eaten, rises, as does the level of creatinine (a measure of kidney function) in the blood. Some patients may also have nausea, vomiting, a loss of appetite, weakness, increasing tiredness, itching, muscle cramps (especially in the legs), and anemia (a low blood count).

### Stages of Kidney Disease

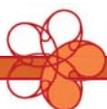
CKD has been divided into five stages. They are determined by the eGFR, the rate at which the kidneys remove waste products from the bloodstream. The eGFR is a calculation based on serum creatinine (a measure of kidney function), a patient's age, gender, and whether the patient is African American. The five stages of eGFR follow:

- Stage 1. eGFR greater than 90 ml/min with other evidence of kidney damage
- Stage 2. eGFR between 60 and 89 ml/min with other evidence of kidney damage
- Stage 3. eGFR between 30 and 59 ml/min
- Stage 4. eGFR between 15 and 29 ml/min
- Stage 5. eGFR less than 15 ml/min

Early recognition of CKD would not be as important if there were not steps available that slow the progression and even prevent eventual kidney failure. The more important steps that slow progression are:

1. Control of blood pressure,
2. Reduction of protein excretion if present in the urine,
3. Control of blood sugar if diabetic, and
4. Avoidance of certain medications harmful to the kidneys.

It is important to note that these measures should be part of the routine care of patients with hypertension, diabetes, or early CKD and do not add greatly to the overall cost of care for these patients.



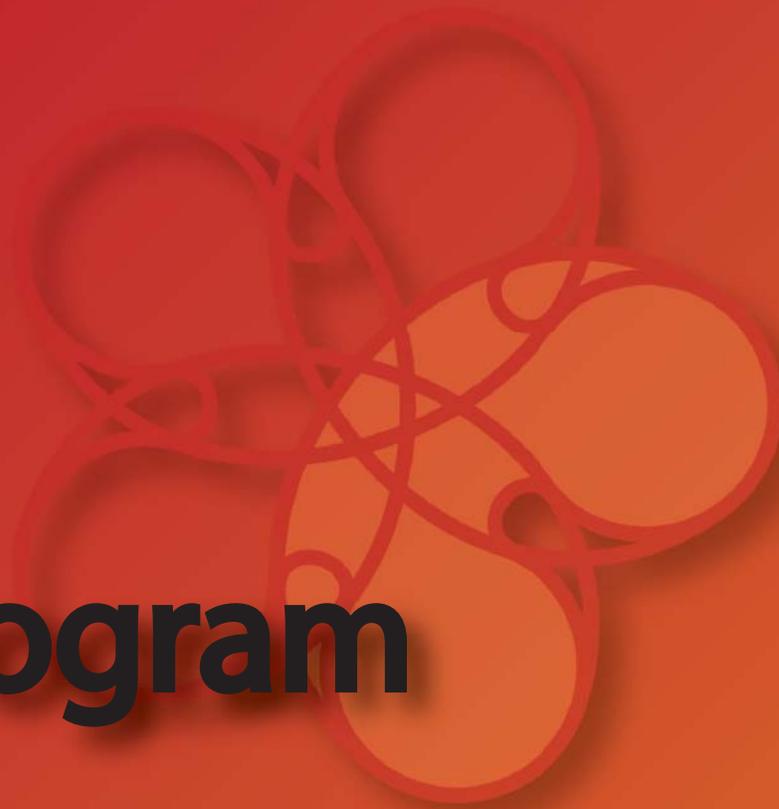
## **Prevention of Chronic Kidney Disease by Early Treatment**

Steps to prevent the development and progression of CKD are well known, widely accepted, and achievable. The most important goal is to control blood pressure. Blood pressure should be less than 130/80, and even lower in diabetics. Strict blood glucose control is important for diabetics. A blood test called hemoglobin A1c, which is an estimate of three-month average glucose, should be less than 7%.

Weight loss, smoking cessation, treating cholesterol or dyslipidemia, and lowering uric acid level when high are other measures that help preserve renal function. These measures also help prevent the development and progression of cardiovascular disease.



# Missouri Kidney Program





# Missouri Kidney Program

## History

In March 1968, the Missouri Legislature appropriated \$100,000 to the University of Missouri's (MU) Board of Curators for a state kidney program to assist Missouri's end-stage renal disease (ESRD) population with life-sustaining dialysis. The Missouri Regional Medical Program (MoRMP), a federally funded program administratively attached to MU, was chosen to oversee the development of the program. The MoRMP Regional Advisory Board authorized awards to both Washington University in St. Louis and to the Kansas City General Hospital in Kansas City. Thus, in fiscal year 1969, 17 Missouri ESRD patients, now referred to as in chronic kidney disease Stage 5, received state and federal assistance for dialysis at these two facilities.

Annual legislative appropriations have continued. Today, the Missouri Kidney Program (MoKP) is administratively located at the MU School of Medicine and is overseen by an advisory council comprised of multidisciplinary professionals and lay members of the CKD community. Additionally, one member each of the Missouri House of Representatives and Senate is appointed to the council. The net funding in fiscal year 2008 was near \$3.9 million that provided assistance to 2,563 CKD Stage 5 patients through contracts with 147 facilities.

## Mission

The mission of the MoKP is to help meet the medical, educational, and psychosocial needs of eligible Missouri residents who have chronic renal insufficiency or have had a renal transplant.

## Goals

To accomplish the mission, the MoKP is committed to:

- Ensure that no Missourian is denied treatment for CKD Stage 5 because of financial or social status.
- Ensure that treatment is of high quality and provided at a reasonable cost.
- Encourage home dialysis and transplantation when medically feasible.
- Encourage donations of kidneys for transplantation.
- Encourage and support research, demonstration, and prevention efforts designed to reduce the cost of care and/or delay the onset of ESRD.
- Maintain, in collaboration with other agencies, a data bank to aid in planning and evaluation of ESRD services.



- Foster the exchange of medical, technical, and administrative information among ESRD facilities.
- Encourage and support continuing education services for ESRD facility staff.
- Encourage and support experiences for ESRD patients.
- Actively cooperate and collaborate with other organizations in the prevention and treatment of ESRD.

## Services

Persons who have lost their kidney function must have either regular dialysis therapy or a transplant to survive. Most Missourians with kidney failure are eligible for Medicare and/or Medicaid; however, these sources do not cover all treatment-related costs, such as co-insurance, drugs, and transportation. MoKP utilizes its funds to assist eligible kidney patients with expenses related to hospitalization, dialysis, transplantation, and post-transplant follow-up. Direct medical expenses, as well as take-home medications, nutritional supplements, transportation, co-insurance premiums, and transplant assistance with unusual or special circumstances are potential reimbursable services.

### Center for Chronic Kidney Disease Education

Providing education services to both patients and professionals in the CKD community is an integral and important component of services offered by MoKP. The Center for Chronic Kidney Disease Education serves as a national model for state kidney programs.

### Professional Education

The professional education component of the Center for Chronic Kidney Disease is designed to provide accredited continuing education programs for Missouri's multidisciplinary CKD Stage 5 facility staff and physicians while avoiding the expense of long-distance travel.

### Patient Education

Education is provided to Missouri residents with CKD, their families, and friends through the award-winning Patient Education Program (PEP). The PEP began in 1983 as a cost containment grant to evaluate whether patients who were provided unbiased education prior to the need for dialysis would be more likely to select less costly options, including home dialysis or transplantation. It is designed to help those who attend to learn more about kidney disease, options for treatment, and how to live well with kidney disease. In addition to having educated over 2,000 Missouri patients and their families to date, the PEP was used as the model for the National Kidney Foundation's People Like Us, Live! Program and is available across the country. The Missouri PEP currently targets Stage 3 CKD patients.



In today's fast-paced, demanding, and cost conscious healthcare environment, it is important to evaluate the cost effectiveness of any program. Patient education is an arena where research has documented cost effectiveness. For example:

- Every \$1 spent on patient education across chronic illnesses saves \$3 to \$4.<sup>3</sup>
- Patients who receive early education are less likely to start dialysis urgently, more likely to start as an outpatient, and spend fewer days in the hospital.<sup>4</sup>
- Patients who receive early education score significantly higher on mood, lower on anxiety, and have better mobility and functioning.<sup>5</sup>
- An early education program increases the use of fistulas, the access guidelines recommended for hemodialysis, and patients are better nourished when dialysis starts.<sup>6</sup>
- Patients who have early education are more likely to choose peritoneal dialysis.<sup>7</sup>
- Blue-collar workers are the most at risk for losing their jobs due to kidney failure. Those who have multidisciplinary education before starting treatment are more likely to keep their jobs.<sup>8</sup>

## **Future**

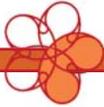
As a leader in the CKD community both locally and nationally, MoKP continues to participate in building the future by helping shape it in a way that benefits its ultimate reason for being, which is, simply, helping the CKD patients and their families acquire a better quality of life in whatever form that may be. That can only be done by closer communication and constant collaboration between other like-minded organizations, agencies, treatment facilities, professionals, and the CKD clients themselves.



# A Public Health Issue in Missouri



# A Public Health Issue in Missouri



According to Schoolwerth, Engelgau, et al. (p. 1), an issue must meet the following four criteria to be determined a public health issue:

1. “The health condition must place a large burden on society, a burden that is getting larger despite existing control efforts;
2. “The burden must be distributed unfairly (i.e., certain segments of the population are unequally affected);
3. “There must be evidence that upstream preventive strategies could substantially reduce the burden of the condition; and
4. “Such preventive strategies are not yet in place.”<sup>9</sup>

The MO CKD Task Force agrees that CKD “meets these criteria for consideration as a public health issue... [and agree that]...a broad and coordinated public health approach will be necessary to meet the burgeoning health, economic, and societal challenges of chronic kidney disease.”<sup>9</sup>

## Definition and Risks

The National Kidney Foundation (NKF) defines CKD as the persistent and usually progressive reduction in glomerular filtration rate (GFR) of less than 60 ml/minute/1.73 m<sup>2</sup> (body surface area) for three months or more and/or the presence of protein or albumin in the urine at an excretion rate of over 30 mg per gram of urinary creatinine.<sup>10</sup>

The risk of CKD is eventual kidney failure, that is, CKD Stage 5. Patients with CKD Stage 5 require renal replacement therapy, which is usually chronic dialysis or, for some, kidney transplantation. Organ availability remains a major limitation for transplantation.

Cardiovascular disease is the major cause of death in patients with CKD especially if they are at CKD Stage 5. Cardiovascular disease frequently contributes to the progression of CKD, which in turn, can worsen cardiovascular disease. It is more likely that the patient will die from cardiovascular disease than that the patient will progress to dialysis. Thus, early recognition and treatment of CKD has beneficial consequences for other major diseases.



## Incidence and Prevalence

In the United States, it is estimated that there were over 26 million people over age 20, with various stages of CKD, or roughly one in nine adults. Another 20 million are at risk for CKD.<sup>11</sup> Since 2002, there have been over 100,000 new cases of CKD Stage 5 each year.<sup>12</sup> At this time there are over 450,000 patients on chronic dialysis, and by the year 2015 as many as 680,000 patients will require treatment for kidney failure. The incidence rate of new cases is expected to grow. By 2015, it is estimated that 135,000 new cases of CKD Stage 5 patients will occur each year. The aging population plus the rising prevalence of diabetes account for much of this increase.

CKD usually remains asymptomatic until later stages. Thus, many patients are not aware that they have it. Though the number of people with CKD increases, awareness lags behind. Only 11.5% of men and 5.5% of women with CKD Stage 3 were aware that they had kidney problems.<sup>13</sup>

These numbers would be higher but for the estimated mortality rate of 20% per year of patients with CKD Stage 5. Kidney disease is the ninth-leading cause for overall mortality in the United States. However, this is an underestimation since CKD is often a comorbid condition, a condition that a patient has at the same time as another condition or disease. For CKD patients, the comorbid condition, such as heart disease and stroke, is often a more common cause of death.

**Table 1. Stage 5 CKD Patients, December 2007**

Age	Number
19 and younger	37
20 – 49	1,366
50 – 59	1,436
60 – 69	1,528
70 and older	2,100
<b>Total</b>	<b>6,467</b>

Source: Heartland Kidney Network, Annual Report 2007, p. 64

In Missouri, in the year 2007, there were 6,467 patients with CKD Stage 5 (Table 1). St. Louis County, followed by, Jackson, St. Louis city, Greene, and St. Charles counties, have the highest prevalence (number living with the disease) at 1,553; 922; 861; 245; and 241 patients, respectively. There were 2,079 new cases reported in 2007 (Table 2).

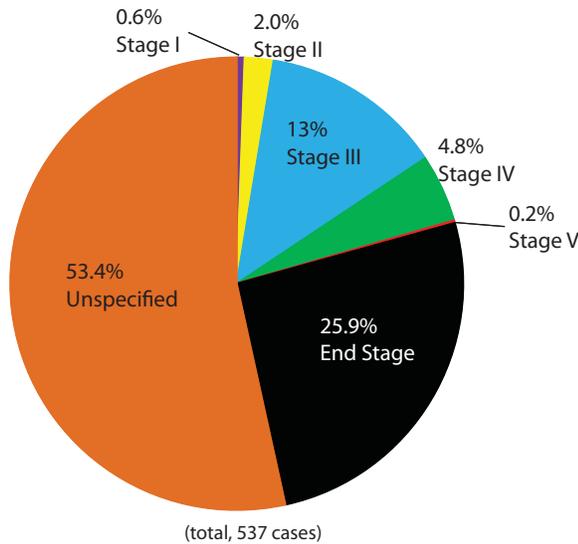
**Table 2. Newly Diagnosed Stage 5 CKD Patients, December 2007**

Age	Number
19 and younger	23
20 – 49	332
50 – 59	406
60 – 69	513
70 and older	805
<b>Total</b>	<b>2,079</b>

Source: Heartland Kidney Network, Annual Report, 2007, p. 63

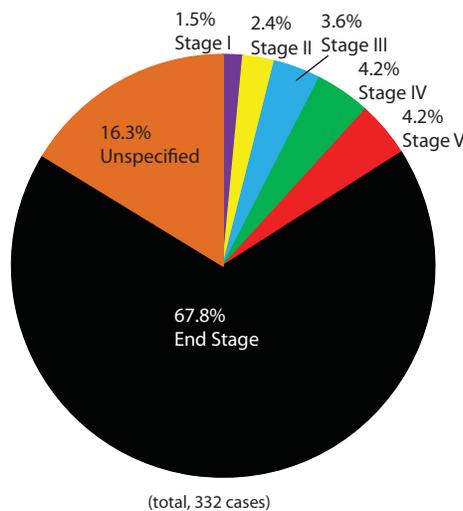


**Figure 1. Stage of CKD Emergency Department Visits in Missouri, 2006**



Source: Missouri Department of Health and Senior Services, Bureau of Health Informatics, Patient Abstract System.

**Figure 2. Stage of CKD for Inpatient Hospitalizations in Missouri, 2006**



Source: Missouri Department of Health and Senior Services, Bureau of Health Informatics, Patient Abstract System.

In 2006, there were 537 emergency department visits for CKD, and 25.9% of these visits were for end stage renal disease, the phrase formerly used to describe their condition (Figure 1).

The number of inpatient hospitalizations for CKD was 332, and 67.8% inpatients suffered end stage renal disease (Figure 2). The total case number of CKD is not available but may be as high as 11% of the population. Many more have risk factors for CKD.

CKD will eventually progress to the point of requiring dialysis or a transplant. As the primary reason, chronic renal failure (ICD-10 code, N18) led to the death of 374 Missourians in 2006

(Table 3). Of these deaths, 290 (77.6%) were white, 79 (21.1%) were Black/African American, and 5 (1.3%) were among individuals of other races. As the non-primary reason, chronic renal failure also contributed to the deaths of an additional 1,201 Missourians in 2006. In addition, unspecified renal failure (ICD-10 code, N19) led to the death of 495 Missourians as the underlying cause and contributed to the deaths of 1,903 Missourians (Table 1). In total, renal failure led to or contributed to 3,973 Missouri deaths in 2006.

**Table 3. Death from Renal Failure in Missouri, 2006**

Death	Chronic renal failure (N18)				Unspecified renal failure (N19)			
	White	Black	Other	Total	White	Black	Other	Total
Primary reason								
Number	290	79	5	374	443	49	3	495
Percent (%)	77.5	21.1	1.3	100	89.5	9.9	0.6	100
Non-primary reason								
Number	944	249	8	1201	1668	222	12	1903
Percent (%)	78.6	20.7	0.7	100	87.7	11.7	0.6	100

Source: Missouri Department of Health and Senior Services, Bureau of Health Informatics, Missouri Vital Statistics.



## Risk Factors

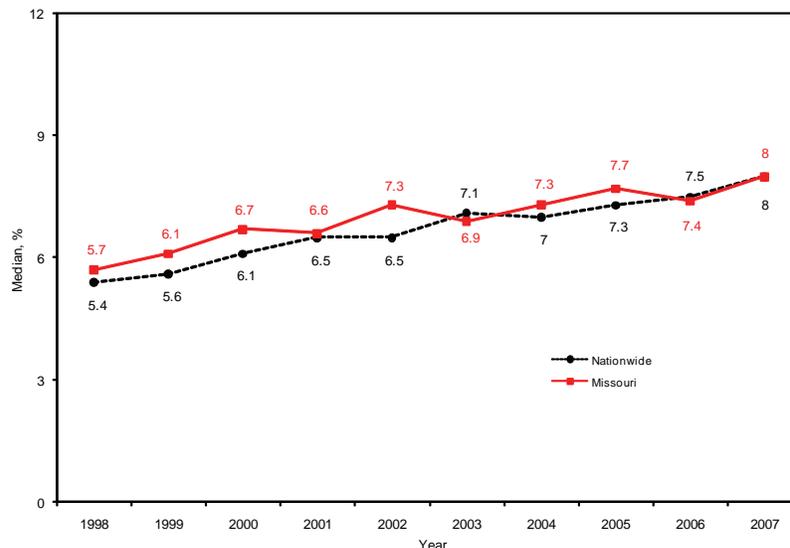
Risk factors for CKD can be classified as those that are modifiable and those that cannot be changed. The factors that cannot be changed include:

1. Age; it is estimated that we lose 10% of renal function for every decade over 50 years of age.
2. Race/ethnicity; in descending order African Americans, Native Americans, Asian Americans, and Hispanics have a higher incidence than whites for developing CKD Stage 5.
3. PKD and other renal diseases are hereditary. Heredity cannot be influenced.

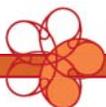
The biggest single risk factor for CKD is diabetes; both type 1 and type 2. More than 40%-45% of patients on dialysis have diabetes. Hypertension is the second-most common cause for CKD Stage 5. Good blood pressure control and good blood glucose control will delay or forestall the progression of renal failure. Thus, even with hereditary diseases that one cannot control, one can still control the high blood pressure that frequently accompanies these diseases. In Missouri, prevalence of diabetes and hypertension has gradually increased within the past ten years, as it has nationwide (Figures 3 and 4), and African Americans showed higher rates of diabetes and hypertension compared with whites or with the nation as a whole (Figures 5 and 6).

Polycystic kidney disease (PKD) is another relatively common cause of CKD. The prevalence of Missourians with PKD is believed to be as great as 1 in 500 and as few as 1 in 1,000. As of 2006, Missouri had a population of 5,842,713. Therefore, it is estimated that approximately 9,000 Missourians have PKD. It is estimated nationally that 5%-8% of people on dialysis have PKD. Thus, it is estimated approximately 500 people of the 6,500 on dialysis in Missouri have PKD.

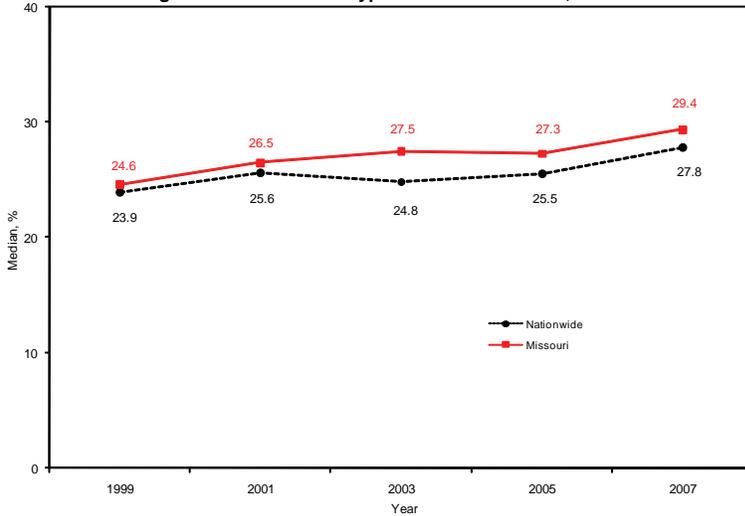
Figure 3. Prevalence of Diabetes in Missouri, 1998-2007



Source: Centers for Disease Control and Prevention and Missouri Department of Health and Senior Services, Behavioral Risk Factor Surveillance System.

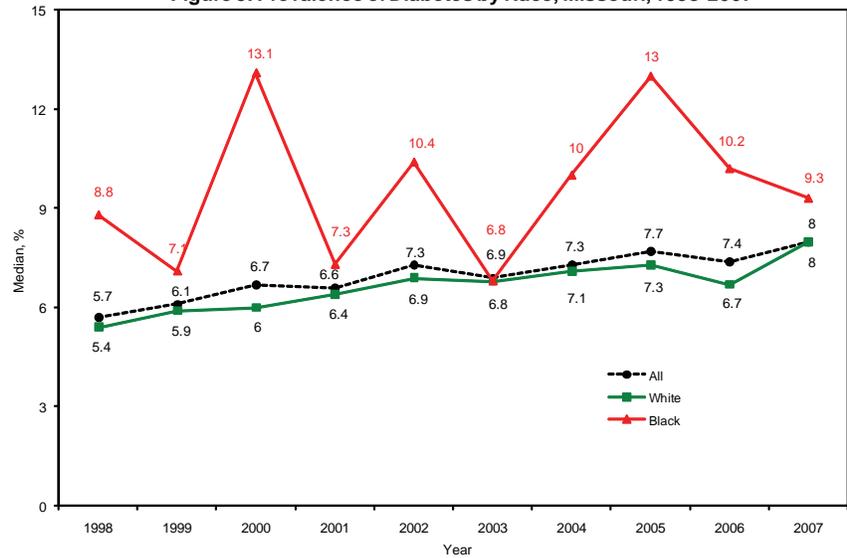


**Figure 4. Prevalence of Hypertension in Missouri, 1999-2007**



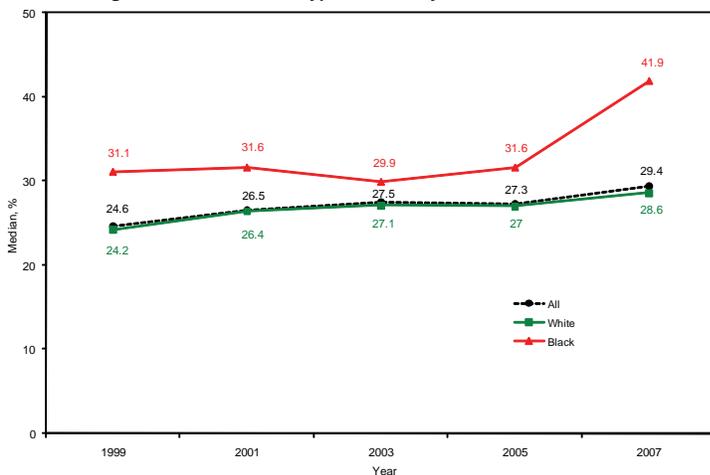
Source: Centers for Disease Control and Prevention and Missouri Department of Health and Senior Services, Behavioral Risk Factor Surveillance System.

**Figure 5. Prevalence of Diabetes by Race, Missouri, 1998-2007**



Source: Centers for Disease Control and Prevention and Missouri Department of Health and Senior Services, Behavioral Risk Factor Surveillance System.

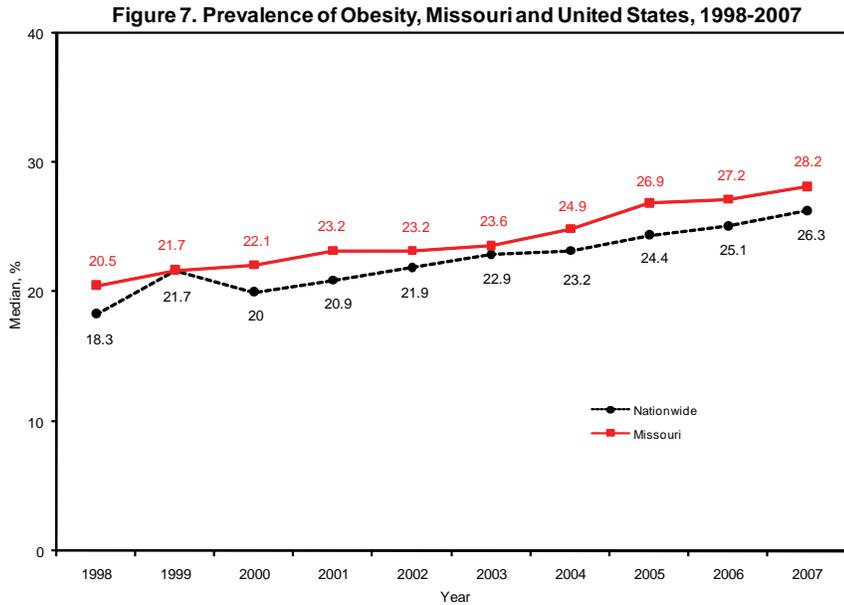
**Figure 6. Prevalence of Hypertension by Race, Missouri, 1999-2007**



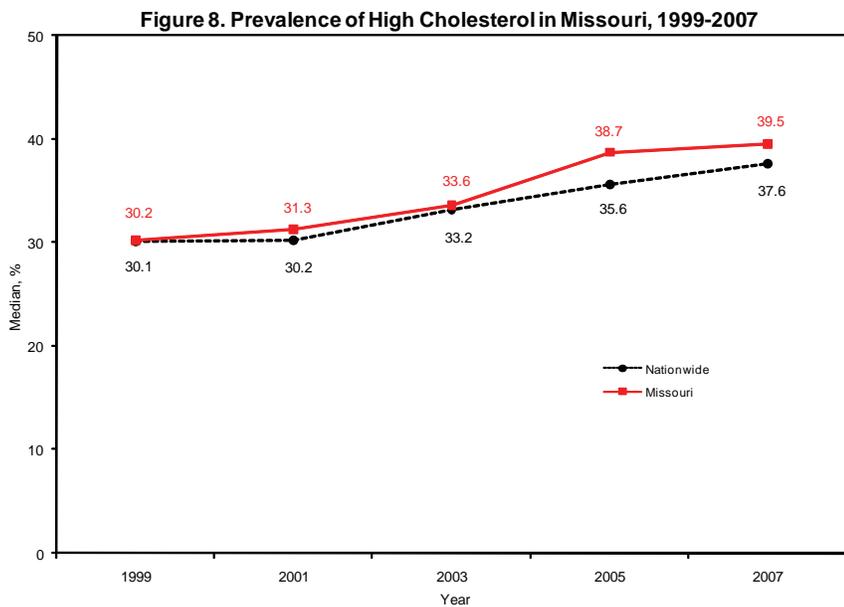
Source: Centers for Disease Control and Prevention and Missouri Department of Health and Senior Services, Behavioral Risk Factor Surveillance System.



Obesity and high cholesterol are also important risk factors for CKD. Obesity and high cholesterol are being recognized as a national epidemic. Prevalence of obesity and high cholesterol have also increased gradually within the past ten years for both the nation and in Missouri (Figures 7 and 8). African Americans displayed higher rates of obesity (Figure 9), but whites showed higher rates of high cholesterol (Figure 10). As more people have these risk factors, the incidence of CKD will increase.



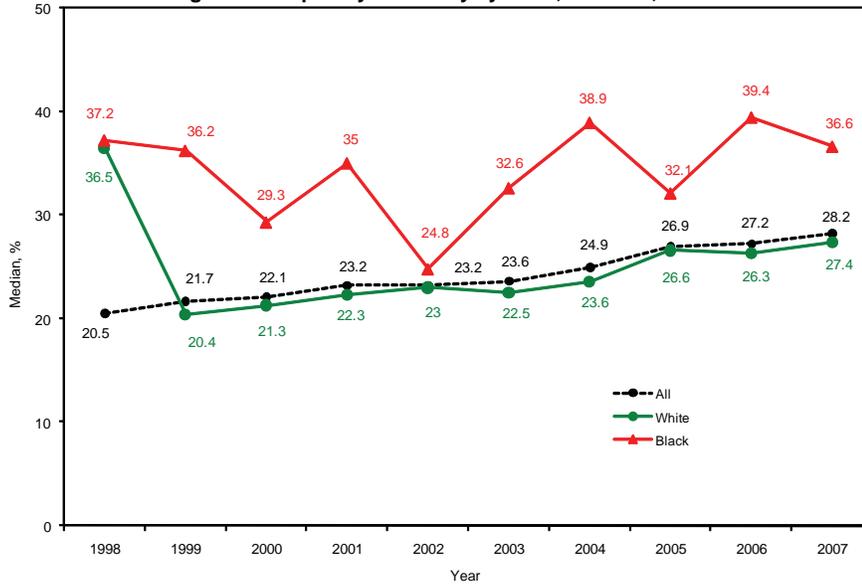
Source: Centers for Disease Control and Prevention and Missouri Department of Health and Senior Services, Behavioral Risk Factor Surveillance System.



Source: Centers for Disease Control and Prevention and Missouri Department of Health and Senior Services, Behavioral Risk Factor Surveillance System.

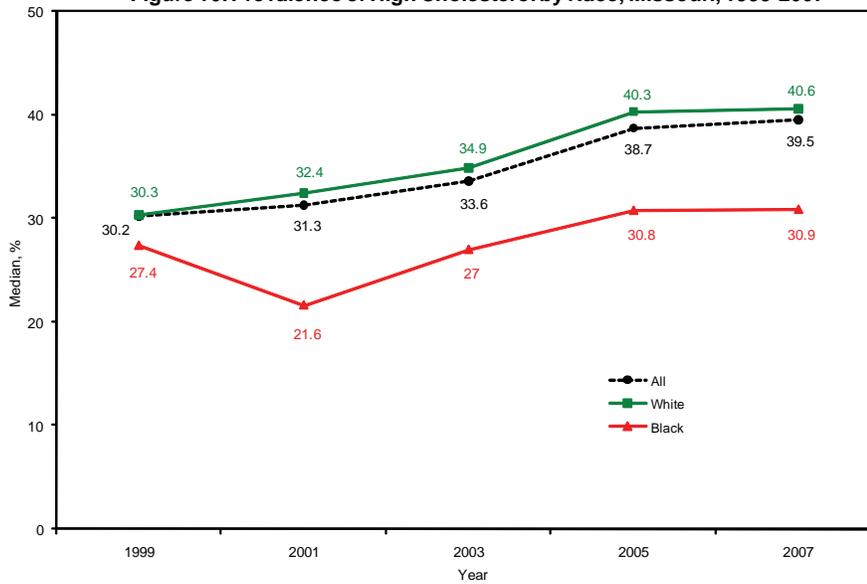


**Figure 9. Frequency of Obesity by Race, Missouri, 1998-2007**



Source: Centers for Disease Control and Prevention and Missouri Department of Health and Senior Services, Behavioral Risk Factor Surveillance System.

**Figure 10. Prevalence of High Cholesterol by Race, Missouri, 1999-2007**



Source: Centers for Disease Control and Prevention and Missouri Department of Health and Senior Services, Behavioral Risk Factor Surveillance System.



## Costs and Cost Comparisons

The cost of kidney disease is enormous. CKD Stage 5 patients are about 1.1% of the Medicare population, but it is estimated that they use 6.4% of Medicare dollars. Expenditures in 2005 for example were over \$31 billion and have only increased since then. CKD is the eleventh-most costly chronic medical condition. It is estimated that the savings to Medicare for each CKD Stage 5 patient who does not progress to dialysis is \$250,000 per year.<sup>14</sup> Dialysis care costs the federal government and secondary payers about \$65,000 per patient per year. “Published U.S. government data estimates the total health care cost burden of a dialysis patient at \$65,000 annually, with dialysis services representing approximately 25% of this cost, while the cost of hospitalizations, drugs and physician fees make up more than 50%.”<sup>15</sup>

In comparison, the cost to treat a CKD patient per year is about \$4,700. CKD patients are more likely to require more medications, more office visits, and more hospitalizations than other patients with chronic diseases.<sup>16</sup>

The National Kidney Foundation of Kansas and Western Missouri and the Missouri Kidney Program screened 13,000 individuals using the “Kidney Early Evaluation Program” (KEEP®). Costs were approximately \$45 per screened person or \$45,000 per 1,000 persons screened. Demographic and epidemiological strategies can be developed to identify those areas containing the highest number of potential high-risk patients. Screening should begin there. If 4,000 people could be screened in one year, the cost would be \$180,000. Assuming that approximately 50% of those with CKD could be brought into early treatment, the cost saving in later years is staggering.

A hypertensive patient could be managed with a proven ace inhibitor for as little as \$50 per year. The potential cost/benefit ratio is obvious. Diabetic patients are more expensive, perhaps \$500 per year on average. However, the long-term savings also speak for themselves. Savings can be measured not only in dollars spent but in quality of life and reduced illness and death.

One cost that should also be considered is lost productivity. The 2007 U.S. Renal Data Retrieval System (USRDS) Annual Data Report provides the employment status of U.S. patients 18-54 years old by age, gender, race, and diagnosis from data collected on the Centers for Medicare and Medicaid Services (CMS) Form 2728. Table C.15 provides the following information about employment status of CKD Stage 5 patients at [http://www.usrds.org/2007/ref/C\\_pt\\_char\\_07.pdf](http://www.usrds.org/2007/ref/C_pt_char_07.pdf):

- Working full time, 8.4%
- Working part time, 1.8%
- Homemaker, 5.1%
- Retired (age/preference), 38.2%
- Retired (disabled), 18.4%
- Medical leave, 3.0%
- Student, 1%
- Unemployed, 19.3%
- Missing, 4.8%



Meanwhile, the Heartland Kidney Network reports in Table 8 on p. 93 of the Annual Report, that of the 2,146 patients aged 18-54, only 503 are employed full time or part time. Another 67 patients attend school full time.<sup>12</sup>

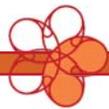
Patients with CKD Stage 5 who are unable to work receive federal SSI payments. Standard payments, excluding any state supplements are as follows: 1) SSI individual: \$637; 2) SSI couple (both disabled): \$956. For additional perspective, the estimated Average Monthly Social Security Benefits Payable in January 2008 were:

- All retired workers, \$1,079
- Aged couple, both receiving benefits, \$1,761
- Widowed mother and two children, \$2,243
- Aged widower alone, \$1,041
- Disabled worker, spouse, and one or more children, \$1,690
- All disabled workers, \$1,004



# Barriers to Prevention





# Barriers to Prevention

## **1. Lack of universal recognition of eGFR**

CKD is identified primarily by the eGFR. Recognition of the eGFR by all participants (patients and health care providers) is seen as a major barrier to the early detection of CKD. Recognition must first occur at the clinical pathology laboratories that measure serum creatinine. Several years ago there was resistance by clinical laboratories to provide eGFR when the serum creatinine was reported. Large national laboratory chains now provide eGFR. Not all hospital and local laboratories provide this information.

## **2. Failure by all medical providers in the clinical setting to measure blood pressure**

Data from the National Ambulatory Medical Care Survey in 2003 and 2004 report that blood pressures were measured in only 56% of all office visits for patients age 18 or older. Internists, general practitioners, and cardiologists measure blood pressure about 85% of the time. Patients with high blood pressure had their blood pressure measured 93% of the time; in other words, 7% of the time it was omitted. Other sub-specialty practices only measure blood pressures 35% of the time.<sup>17</sup>

The task force recommends that blood pressures be taken at all clinic visits by all medical practitioners. Other than equipment costs and the minimal time needed to measure blood pressure, there is little added expense for this routine procedure. Educational programs are needed to increase the routine measurements of blood pressures by all practitioners.

## **3. Lack of insurance reimbursement for routine screening**

Insurance plans pay for some preventative programs such as mammograms, Pap smears, and colonoscopies. Not all plans pay for routine blood tests and urine tests unless there is a primary diagnosis. These routine tests, such as a basic metabolic panel and urinalysis, should be covered in all insurance plans as part of a routine health screen, even if there is not a primary diagnosis.



#### **4. Workforce shortage of nephrologists**

By 2005 there is projected to be a shortage of 200,000 nephrologists in the United States. Approximately 340 nephrologists complete their training annually while approximately 240 are retiring. In addition, the number of patients with later stage chronic kidney disease is increasing more rapidly than ever before.<sup>18</sup>

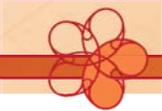
#### **5. Lack of funding to support continuing medical education for providers on screening, early recognition and early treatment of CKD**

Currently the NKF has a symposium on CKD Stage 5 for primary care physicians but has limited funding to provide additional educational programs on the importance of early screening for and diagnosis of CKD.

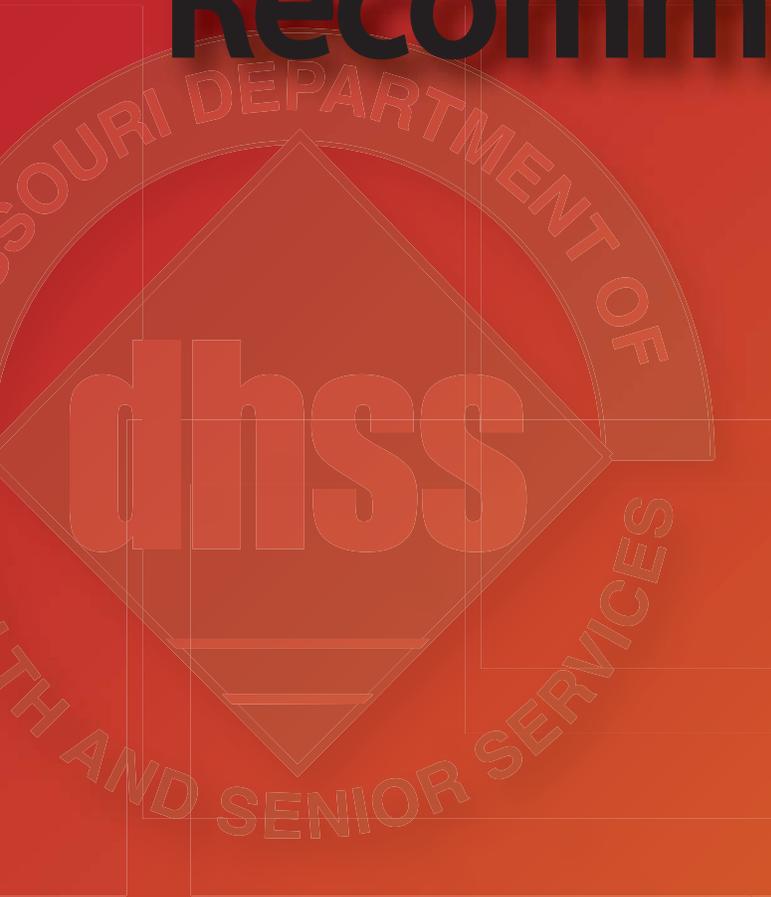
#### **6. Lack of funding for patient education in the early stages of CKD**

Current funding supports patient education for CKD in Stage 5. However, funding for educating patients about the importance of early screening, diagnosis and management of CKD is limited.





# Public Policy Recommendations





# Public Policy Recommendations

## 1. Universally use and recognize the eGFR.

- All clinical laboratories doing business in Missouri should compute and report the eGFR every time a provider orders a serum creatinine or when the creatinine is part of a metabolic panel.
- Payers and insurers should require that all serum creatinine determinations for their members and dependents automatically include the eGFR.
- The Department of Health and Senior Services should monitor the clinical laboratories to determine if reporting eGFR has become standard practice when a serum creatinine is ordered. After a year, if reporting eGFR does not become standard practice across the state for all laboratories, the Missouri State Legislature should amend the statutes to require all creatinine laboratory reports to include eGFR values.
- Educational tools for providers should be utilized in explaining the eGFR to patients.

The widespread use of eGFR is critical for moving forward with early detection. The American College of Pathologists has indicated that it now supports the reporting of eGFR with all laboratory results that include a serum creatinine. Several labs in Missouri have already converted or are in the process of converting to this automatic reporting of the eGFR. The task force applauds this practice with great enthusiasm. However, the task force recognizes the need for a massive educational program to accompany this milestone.

The task force developed a tri-fold educational brochure that simply but thoroughly explains the relationship of the eGFR to the serum creatinine and the interpretation of these data in a way that helps patients understand the stages (see “Brochure” at the end of this report).



The task force recommends collaborating with the Missouri State Medical Association, the Missouri Association of Osteopathic Physicians, the Federally Qualified Health Centers (FQHCs), and any other organizations of primary care providers, including physician assistants and advanced practice nurses, to reach out to as many patients as possible who are at risk.

Ancillary information can also be web based for those medical offices and providers that are able to use the web as an educational tool.

The task force has begun preliminary discussions with the Heartland Kidney Coalition concerning a collaborative networkwide educational program to increase awareness of CKD. The coalition's extensive capabilities for various methods of distributing information could be an important tool.

The task force also recommends working with the public sector through the Department of Health and Senior Services programs on heart disease, stroke, and diabetes to explore mutual ways of disseminating information.

In summary, the task force believes the wide acceptance and understanding of the eGFR is absolutely critical in early identification and successful intervention in CKD.

## **2. Conduct basic CKD screening that includes blood pressure monitoring to assure detection of CKD in Stages 1 – 3 versus Stages 4 and 5.**

- Medical care providers must inform patients of their risk, screen those at risk, and then inform patients of the results of their screening.
- The basic metabolic profile (chem. 7 panel) should be the screening test done on all those at risk for CKD. In addition, in line with the State of Missouri Consensus Screening Guidelines for Pre-diabetes and Diabetes in a Medical Setting,<sup>19</sup> which recommends screening for diabetes starting at age 45 for the general population (those without risk factors predisposing them to developing diabetes), the basic metabolic profile should be a screening test done on all persons starting at age 45.
- Public and private insurers, payers, and other organizations that offer disease management or quality improvement initiatives targeted at people with diabetes, hypertension, or cardiovascular disease should give greater emphasis to chronic kidney disease prevention, screening, and management.

One request of the legislature was to examine ways that Missourians could have better access to low-cost but high-yield screening to detect CKD or the risk factors for CKD earlier in their lives. In addition to age, these risk factors include diabetes, hypertension, and obesity. The task force considered a wide array of existing and proposed schema.



Screening programs can be divided into two categories, depending on the population to be screened. First, screening programs can be directed at the general population. Groups such as hospitals, churches, or other community organizations that provide screening such as blood pressure checks at health fairs are screening the general population for basic health risks. Second, other screening events such as the “Kidney Early Evaluation Program” (KEEP®) screen those at risk for kidney disease--anyone 18 years and older with high blood pressure, diabetes, or a family history of kidney disease. KEEP has been offered by the National Kidney Foundation of Kansas and Western Missouri and the Missouri Kidney Program with great success in many locations. The prime target of this screening program is the “walking wounded,” or those persons who have early disease and are not aware of its presence. However, the general population was also included. One important value of such screening programs is to increase public awareness.

KEEP is designed to raise awareness about kidney disease among high-risk individuals and to provide free testing and educational information so that kidney disease and its complications can be prevented or delayed. Along with a comprehensive health risk appraisal, KEEP provides three simple tests that determine kidney function--blood pressure measurement, blood testing, and urine testing. Those screened are offered the opportunity to discuss their health and to review results with on-site physicians. All participants with risk factors are referred to local physicians and program staff conduct follow-up with them three months later.

The KEEP screenings in Missouri are to be applauded and celebrated. Although CKD itself was not often identified, the volume of screening data (over 13,000 cases) indicated that over 52% of all of those screened had one or more health risk factors that put them at risk for CKD. Not surprisingly, approximately one third of that 52 % had no knowledge of their health risks. Protocol includes follow-up, which is an essential part of any screening program.

With minimal medical sophistication such programs can be replicated. They measure height and weight to calculate body mass index, a measure of obesity. They can do waist measurements, one indicator of “metabolic syndrome,” which is a precursor to diabetes mellitus. Blood pressures can be measured. With additional medical/technical help, blood tests and urine samples can be obtained. These would be used to check glucose and serum creatinine in the blood and the presence of protein in the urine. However, these screening programs are more likely to detect people with hypertension or early diabetes and not people who have kidney disease. Regardless, screenings to identify people at risk for developing (or who may already have) the conditions that lead to CKD can be beneficial. The task force suggests providing funding to the MoKP to create, distribute, and offer training on a tool kit or a how-to plan for community groups that would like to conduct such screening programs.

The task force feels that screening is best done by the primary care physician and other medical providers. Medical care providers should inform patients of their risk, screen those at risk, and inform patients of the results of their screening. Directing screening to those who have one or more risk factors for CKD will lead to early detection of CDK and appropriate intervention to delay its progression. That is, screening of patients already known to have diabetes, hypertension,



and/or heart disease is more likely to detect those with early stages of CKD. All patients at high risk for CKD should have the basic metabolic profile (chem. 7 panel). In addition, a baseline comprehensive panel should be obtained for all individuals at age 45, just as diabetes screening should start at 45 for those with no other risk factors.

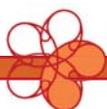
The task force recommends developing short, simple screening protocols and distributing them to primary care providers to direct them to screen in the most efficient manner. With additional funding, the MoKP could develop and distribute the protocols and provide necessary trainings in collaboration with nephrologists.

Encouraging more screening and follow-up could take other approaches as well. If funding were available, perhaps contractual arrangements with existing resources could make more screenings available in high-risk areas of the state. Perhaps partnerships with FQHCs could be found if funding could be directed toward their already stretched budgets.

### **3. Reimburse for CKD screening tests and assure that results are communicated to patients.**

- Insurance plans should pay for the basic metabolic profile (chem. 7 panel) and urinalysis as part of a preventive health screen for all individuals starting at age 45, even if there is not a primary diagnosis.
- Insurance plans should pay for the basic metabolic profile (chem. 7 panel) and urinalysis as on-going screening and diagnostic tests for on all those at risk for CKD.
- Payers, insurers, and other organizations should remind patients and providers to obtain regular screenings for chronic kidney disease including urine microalbumin and estimated GFR from serum creatinine.
- Public and private insurers should use patient-level eligibility and claims data to identify people who are at risk of or diagnosed with chronic kidney disease.

According to the U.S. Census, in 2007, there were 45 million uninsured people in the United States.<sup>20</sup> The task force believes that the number of uninsured people in Missouri is proportional to the national number. Programs to obtain coverage for the uninsured with health issues who remain above any assistance level but cannot afford regular health maintenance and medications must be found or created. It does little good to identify those at risk for CKD or its precursors, diabetes, hypertension, heart disease, and other chronic diseases if these patients do not have the means to control their disease at an early stage.



#### 4. Provide CKD education to primary care providers.

- Nephrologists should actively educate primary care providers and other health care professionals in their referral base regarding screening of patients at risk of developing CKD and the appropriate management of those in CKD Stages 1, 2, and 3 to delay or prevent progression to later stages.
- Education on CKD should include information about the importance of early screening for at-risk populations, the use of the eGFR to identify people with chronic kidney disease, stages of the disease, diagnosing the etiology of the disease, and evidence-based treatment guidelines for people with the disease. Education should be provided in a variety of settings including, but not limited to, health professional training schools, residency programs, continuing medical or nursing education programs, practice consultants, and quality improvement initiatives.
- Use and/or develop educational programs for health care providers to encourage them to become certified CKD educators.
- Chronic disease managers who manage patients with diabetes, hypertension, or cardiovascular disease should be cross-trained in the management of people with chronic kidney disease.
- Existing programs that provide disease management education and/or certification for diabetes, hypertension, or cardiovascular disease management should ensure that the curriculum includes information about prevention, screening, treatment, and self-management skills for people with chronic kidney disease.

With the anticipated shortage of nephrologists in the near future (see “Barriers,” p. 32), primary care providers must fully understand the risks for developing CKD, must learn the importance of eGFR and must use this laboratory result in their evaluation of patients at risk for CKD. It is only after clinical labs, hospitals, and medical providers use and inform patients of their eGFR that patients will also recognize the importance of this laboratory result. Primary care providers must also learn how to manage their patients in the early stages of CKD to prevent or delay the progression to later stages.

The National Kidney Foundation of Kansas and Western Missouri and the Missouri Kidney Program have developed a reference guide, *Early Detection, Diagnosis & Management of Kidney Disease Guidelines and Recommendations*, which is a very useful tool designed for primary care providers.<sup>21</sup> This guide has been reprinted several times, and there are only a handful of copies of the most recently revised edition available.



Early in its work, the task force spoke with the chair of the North Carolina Chronic Kidney Disease Task Force and explained the desire to establish a program in community colleges to teach health care professionals to become certified CKD educators (CKDEs). It would be similar to existing programs that train certified diabetes educators (CDEs). Just as CDEs are reimbursed for providing diabetes education, the CKDEs should be remunerated for monitoring and managing CKD patients, along with the comorbid diseases of diabetes and hypertension. Just as with weight control programs, self-directed citizens need interaction with others and encouragement – two things for which doctors have limited time. According to Dr. Ahmed Awad, a member of the Missouri CKD Task Force, Blue Cross and Blue Shield of New York does reimburse for this kind of teaching, paying between \$35 and \$50 to the NKF-sponsored effort for every patient educated. Missouri should collaborate with North Carolina in developing a CKDE program. If funding does not allow that, then the effort should be followed closely and considered as a model to be duplicated in Missouri if it appears successful in North Carolina.

### **5. Increase funding for CKD education.**

- Increase funding to the MoKP to develop and disseminate education to patients in early stages of CKD.

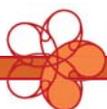
Key to the success of any efforts to reduce the progression of CKD is education. The general public must be made more aware of the risks of CKD. In addition to screening programs for the general public, other methods to increase awareness include public service announcements. Events sponsored by organizations with a primary interest in kidneys, such as the National Kidney Foundation, increase awareness. Web sites are helpful. The task force compiled a list of such web sites listed as “Resources,” on page 44 of this report.

Patients at risk for CKD and patients who already are in the first stages of CKD need education. A pamphlet was created for this purpose (Brochure: “eGFR and CKD”). The MoKP has had educational programs for medical providers for over 15 years. However, the focus of this program is toward patients with CKD Stage 5. In recent years, funding has allowed expansion for education of patients in CKD Stages 3 and 4 in a limited area of the state. Additional funds for the MoKP budget would allow this program to expand across the state.

Patients should become as familiar with eGFR as they are with their blood pressures, glucose readings if diabetic, or cholesterol level. As primary care providers learn the importance of eGFR and use this laboratory result in their evaluation of patients at risk for CKD, they must inform patients of their eGFR. Only then will patients recognize the importance of this laboratory result.

### **6. Increase collaboration among interested parties.**

When the task force began its work, it conducted a phone interview with Dr. Robert Falk, a leader of the North Carolina task force on CKD. One obvious conclusion the task force reached was that collaboration with other state task forces would have mutual benefits.



In addition, there are other interested parties. The National Kidney Foundation has been mentioned. The Heartland Kidney Network that oversees the Medicare ESRD (CKD Stage 5) program in Missouri as well as Kansas, Iowa, and Nebraska shares common goals and interests.

We have recently learned that Primaris has a grant to study this problem. Primaris is Missouri's Medicare quality improvement organization. The staff works with doctors, hospitals, home health agencies, nursing homes, and other healthcare professionals, as well as organizations, to promote the health and safety of older adults.

Various pharmaceutical companies have started educational programs for primary care physicians to increase awareness and offer guidelines for early preventative measures. For example, Abbott has started a lecture series. Preliminary steps to partner with them are underway.

### **Other Recommendations**

Other initiatives that will help recognize early CKD and slow or prevent its progression are possible. For example, some cities and at least one state (California) require restaurants to list the calories and fat content of the food they serve. This task force would support similar legislation in Missouri because obesity is a contributor of diabetes, hypertension, and CKD and is a major health problem in and of itself. Programs such as this, would increase awareness of the problem and to some extent reduce calorie and fat intake.

The task force firmly believes that education of individuals is a key to overcoming the growing burden of CKD, diabetes, obesity, and other chronic diseases in our state. The task force supports initiatives from the Department of Health and Senior Services, the Department of Elementary and Secondary Education, and the colleges of education from our many excellent universities to improve health education in our schools. As our late chairman, Bob Whitlock, said, "Education about health, diet and staying fit has to start early in life and become integrated into our early childhood educational system."<sup>1</sup>



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# RESOURCES

## Treatment of Chronic Kidney Disease Top Websites

### For providers:

- ✓ KDOQI guidelines (National Kidney Foundation)-  
[www.kidney.org/professionals/KDOQI](http://www.kidney.org/professionals/KDOQI).

### For Stage 1-3 CKD (goal: prevention/prolonging kidney function):

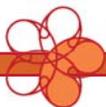
- ✓ National Kidney Disease Education Program - [www.nkdep.nih.gov](http://www.nkdep.nih.gov)
- ✓ National Diabetes Education Program - [www.ndep.nih.gov](http://www.ndep.nih.gov)
- ✓ National Institute of Diabetes, Digestive and Kidney Diseases - [www.niddk.nih.gov](http://www.niddk.nih.gov)
- ✓ MedlinePlus (diagnoses, drugs, and more) - [www.medlineplus.gov](http://www.medlineplus.gov)

### For Stage 4-5 (goal: preparing for treatment):

- ✓ Kidney School - [www.kidneyschool.org](http://www.kidneyschool.org)
- ✓ Scientific Registry of Transplant Recipients (data on transplant facilities) -  
[www.ustransplant.org](http://www.ustransplant.org)
- ✓ Transplant Living (all about transplant) - [www.transplantliving.org](http://www.transplantliving.org)
- ✓ Home Dialysis Central (home dialysis options, where offered, and more) -  
[www.homedialysis.org](http://www.homedialysis.org)
- ✓ Dialysis Facility Compare (facilities by city/state/zip/distance/, their hours,  
treatments, outcomes) - [www.medicare.gov/dialysis](http://www.medicare.gov/dialysis)

### Missouri residents:

- ✓ Missouri Kidney Program - [www.muhealth.org/~mokp](http://www.muhealth.org/~mokp)





Missouri Department of Health and Senior Services  
Bureau of Cancer and Chronic Disease Control (CCDC)  
PO Box 570, Jefferson City, MO 65102  
573-522-2860 or TDD 800-669-8819  
[www.dhss.mo.gov](http://www.dhss.mo.gov)

Missouri Department of Health and Senior Services.  
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Services provided on a nondiscriminatory basis.

Alternate forms of this publication for persons with disabilities may be obtained by contacting the  
Missouri Department of Health and Senior Services at 573-522-2860  
Hearing and speech impaired citizens telephone 1-800-735-2966. VOICE 1-800-735-2466.

