# Missouri Kidney Program 2012 ANNUAL REPORT



# UNIVERSITY of MISSOURI HEALTH SYSTEM

MISSOURI KIDNEY PROGRAM SCHOOL OF MEDICINE

#### 2011-2012 was a year of struggle and strife for Missouri Kidney Program,

#### but we are still here!

During May 2011 in the last weeks of the Missouri legislative session, Missouri Kidney Program was handed an unexpected and devastating budget reduction of 48%. Shock and disbelief was shared by all across the kidney community. The working budget for the next fiscal year was reduced back to 1980's level of appropriations. Consequently, our important educational programs along with the essential direct assistance services for patients, plus MoKP staffing level were deeply impacted.

MoKP staff and the Advisory Council's Financial Committee had only a few weeks to strategize the future of MoKP's mission and services, now having to live within the new restricted appropriation. After much calculations and deliberations, it was decided to stay true to our core assistance program. MoKP continued to offer patients medication assistance through our Centralized Drug Program. The insurance coverage assistance did continue, but was drastically reduced. Transportation, nutritional supplements, and coverage for Medicare premiums were eliminated. Patient education would continue with free educational classes, but operated out of the Columbia office. Thus the St. Louis and Springfield education offices were closed. As a result of losing almost half of the state funding, half of the programs were terminated. Ultimately 387 patients lost services, and 4.5 loyal employees lost their positions.

During the past year, we have slowly recovered from the shock, and work hard to provide over 1,400 patients with vital assistance. In addition our important mission of prevention and patient education continues. We remain committed to assisting and educating Missourians with kidney disease.

If you have questions about this report, or MoKP in general, please contact our office.

Respectively,

Prome Peace

Leanne Peace, MSW, MHA

Director



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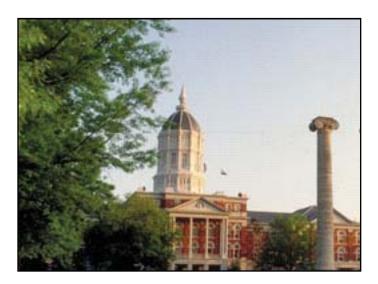
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#### HISTORY AND LEGISLATIVE AUTHORITY

In March 1968, the Missouri Legislature appropriated \$100,000 to the University of Missouri - 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 the University of Missouri, was chosen by the Missouri Legislature to develop the state renal disease program. The MoRMP agreed to absorb the administrative costs so all state dollars could be targeted for direct patient care.

In 1973, the United States Congress passed Public Law No 92-603, extending Medicare coverage to ESRD patients after a three-month waiting period. This made treatment available to nearly everyone and has vastly increased the number of ESRD patients receiving therapy. Also, in 1976 the Regional Medical Programs were phased out, making it necessary to identify another organization to administer the program. The Missouri Kidney Program (MoKP) was established and an advisory council was formed to provide oversight as the MoRMP Regional Advisory Group had done in the past.

From 1977 --2009, the Missouri Kidney Program also has sponsored cost-containment research and demonstration projects aimed at increasing the cost-effectiveness of patient care. This important program was temporarily discontinued due to budget reductions. In 1983 a statewide pre-dialysis education program was begun. These unique programs serve as national models for other state kidney programs. In fact, the National Kidney Foundation adopted the educational curriculum and program of the MoKP, and is training affiliates across the United States to use the "People Like Us - Live" program. The annual state appropriation for the FY 11/12 was \$1,455,000. The Missouri Kidney Program provided assistance to approximately 1,467 patients through facility agreements with 153 participating facilities.



#### MISSION AND GOALS

#### **Mission**

The mission of the Missouri Kidney Program (MoKP) is to help to meet the educational needs, and to promote the physical and mental well-being of eligible Missouri residents with Chronic Kidney Disease (CKD).

#### <u>Goals</u>

• To advocate for policies that ensure no Missourian is denied treatment for kidney failure because of inability to pay.

• To provide financial help to eligible Missourians to defray the in-direct medical expenses related to CKD Stage 5.

o Benefits range from medications,

transportation, and insurance premiums assistance depending on available funding.

• To provide and support the CKD education of Missourians:

- o To promote public awareness and prevention of CKD.
- o To help select an appropriate treatment for kidney failure and to encourage active participation in their medical care.
- o To provide continuing education seminars to the professional disciplines working with the CKD population.

• To increase public awareness of the need for organ donation, and to encourage kidney donations for transplantation.

• To collaborate with other organizations on efforts to prevent kidney disease.

• To promote efforts to delay or avoid the onset of kidney failure for those who have CKD which will reduce associated cost of care.

• To foster the exchange of medical, technical and administrative information among programs and professionals who treat people with CKD.

# ADVISORY COUNCIL

Deep appreciation goes to our Missouri Kidney Program Advisory Council and Executive Officers. Our Council is a multi-disciplinary body and meets at least three times per year. Council membership include individuals with appropriate knowledge and experience representing interested agencies and health care disciplines. Every effort is made to provide diverse disciplinary and geographic representation. In addition, one member each of the Missouri House of Representatives and Senate is appointed to the Council.

#### FY11 Executive Committee Members:

Chair - Michael Young, DO Vice Chair - James Campbell, PhD Immediate Past Chair - Venkataraman Ramachandran, MD

#### FY 2012 Advisory Council Dates:

Nov. 3, 2011 Feb 26, 2012 June 28, 2012



Back Row: James Campbell, Michael Young, Jim Hafner, Rachel Covington, Mimi Korth

Front Row: Pam Beauford, Leanne Peace, Karen Turner

#### **ADMINISTRATION & STAFF**

The Missouri Kidney Program is administered by a director which is traditionally appointed by the Dean of the School of Medicine, in consultation with the Advisory Council. Leanne Peace is the current director, serving since 2009. She is responsible for hiring and supervising the MoKP staff and for implementing the goals, objectives and policies of the program as authorized by the Missouri Legislature, the Dean and the Advisory Council.

#### **Staffing**

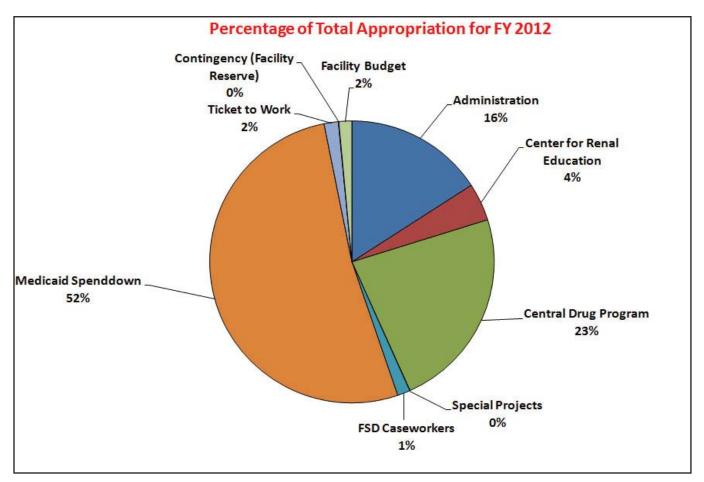
With the FY11/12 budget reduction, there was a loss of programs, and thus positions. Unfortunately 4 full-time employees were let go; we lost a secretary position, a coordinator position, and 2 health educators. Our technology employee was reduced to half time, and a contracted FSD worker who worked half time returned to the county office.

The remaining staff total was 4.5 employees, down from 8.8 in the previous year. In FY11/12 administrative costs were only 16% of total expenditures, which is below the average administrative expenses of other health and social service providers.

#### FISCAL REPORT

Missouri Kidney Program began FY11/12 with a reduction in our state appropriations of \$1.3 million or 48%. Our operating budget starting July 1 2011 was 1,455,000, down from the previous year of 2,793,890. This followed a mid-year reduction of 27% in Oct. of 2009.

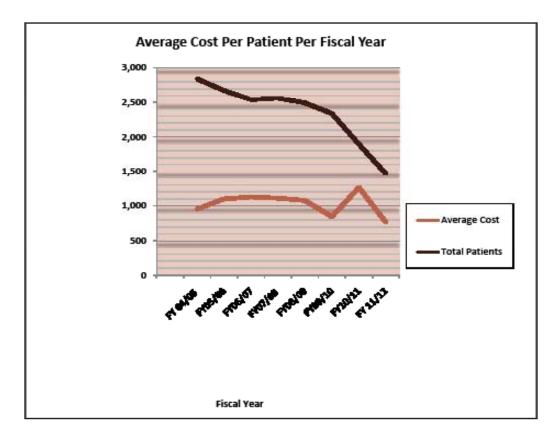
During FY 11/12, Missouri Kidney Program was still able to assist 1,467 eligible CKD Stage 5 kidney patients with expenses related to dialysis, transplantation or post-transplantation follow-up care. The average cost per patient provided by MoKP in FY 11/12 was \$769.

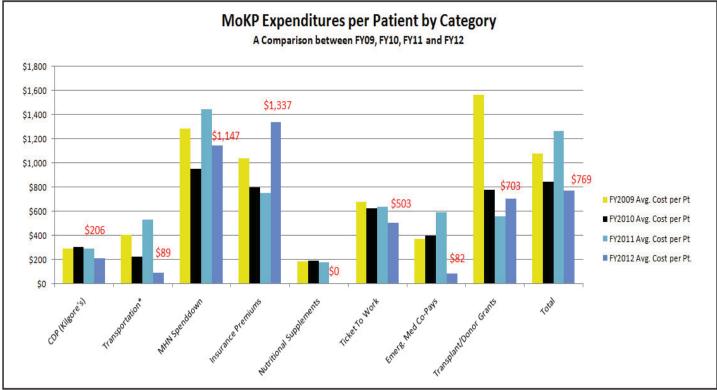


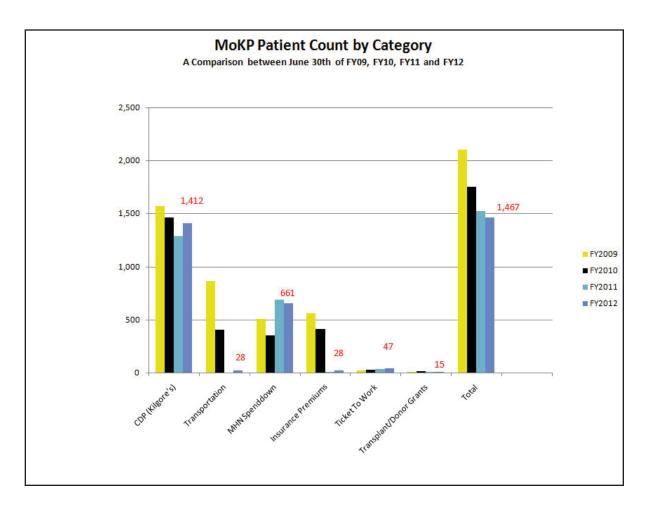
#### MISSOURI KIDNEY PROGRAM APPROPRIATIONS HISTORY

Fiscal Year	Net Appropriation	Percent Change from Past Year
FY 79/80	\$2,277,559	
FY 80/81	\$2,316,726	1.72%
FY 81/82	\$2,151,566	-7.13%
FY 82/83	\$2,052,051	-4.63%
FY 83/84	\$1,987,781	-3.13%
FY 84/85	\$3,646,902	83.47%
FY 85/86	\$3,899,873	6.94%
FY 86/87	\$3,919,258	0.50%
FY 87/88	\$3,924,151	0.12%
FY 88/89	\$3,926,945	0.07%
FY 89/90	\$3,936,595	0.25%
FY 90/91	\$3,839,661	-2.46%
FY 91/92	\$3,605,322	-6.10%
FY 92/93	\$3,801,264	5.43%
FY 93/94	\$3,692,093	-2.87%
FY 94/95	\$3,802,855	3.00%
FY 95/96	\$3,878,912	2.00%
FY 96/97	\$3,977,690	2.55%
FY 97/98	\$4,057,243	2.00%
FY 98/99	\$4,161,082	2.56%
FY 99/00	\$4,244,304	2.00%
FY 00/01	\$4,329,190	2.00%
FY 01/02*	\$3,621,407	-16.35%
FY 02/03*	\$3,761,018	3.86%
FY 03/04	\$3,896,271	3.60%
FY 04/05	\$3,896,271	0.00%
FY05/06	\$3,896,271	0.00%
FY06/07	\$3,896,271	0.00%
FY07/08	\$3,896,271	0.00%
FY08/09*	\$3,701,457	-5.00%
FY09/10*	\$2,710,870	-26.76%
FY10/11	\$2,793,890	3.06%
FY11/12	\$1,455,000	-47.92%

\*=Mid Year Cuts







#### **MoKP Patient Demographics**

The reduction of funding and programs had a negative impact on the number of kidney patients we could assist. Our data reveals that 387 patients were dropped from MoKP assistance programs, the majority of these were dialysis patients, not transplant patients. At the end of FY11/12, our current patient demographics revealed we served 1,171 patients, 402 were transplant patients, and 769 were dialysis patients. The majority of our patients are urban residents. The male patients numbered 624, compared to female 547.

#### SERVICES AND PROGRAMS

MoKP's primary area of focus in FY11/12 was providing medication and immunosuppressive assistance. It was decided there would be no cuts in our medication assistance through Kilgore's Medical Pharmacy. In addition, patients who are actively using Kilgore's will be reviewed to determine future insurance premium assistance eligibility.

With the huge budget reduction, the following services were affected starting July 1, 2011:

- Elimination of our nutritional supplement program.
- Elimination of any transportation assistance to dialysis or transplant appointments.
- Elimination of Medicare premium reimbursement.
- Elimination of any insurance premiums assistance to patients not actively using Kilgore's.
- Reduction in transplant/living donor grants, maximum of \$500. (increased to \$1,000 in Feb. 2012)
- Eliminating patient/staff education assistance. (temporarily re-open Jan-May 2012)
- Reducing financial eligibility asset limit to \$15,000 from \$30,000.

In addition, MoKP changed our internal operations, and reduced our mailings. We instructed all social workers to retrieve their reports from our database to reduce postage costs and workload.

#### Medication Assistance through the Centralized Drug Program

MoKP continued to provide the same high quality medication assistance to eligible dialysis and transplant patients in FY11/12. Our formulary includes close to 400 "kidney related" oral medications, which are shipped to our patient's homes or to their dialysis unit. Kilgore's Medical Pharmacy of Columbia remains as our state-wide mail-order pharmacy. Kilgore's submits bills to all insurance payors (Medicare Part B and Part D, MO HealthNet, private insurance, and any 3rd party insurance companies) for \$5,834,421 worth of medications, Since MoKP is the payor of last resort, our medication expense in FY 11/12 was only \$256,789. During FY 1/12 we were able to assist 1,412 patients with an average cost of \$206.

#### **Insurance Premiums**

For those patients that are on our medication program, we were still able to assist a very few with insurance premium assistance. MoKP determines if it was cost-effective to pay for the insurance costs over the costs of the medications. This is typically the case with transplant patients. In FY 11/12, MoKP was able to assist 28 patients with insurance costs of a yearly average cost of \$1,337, totaling \$37,446

#### Mo Healthnet Spend Down

MoKP considers MHN to be important and necessary insurance coverage, as it assist "near poor" patients with many different vital medical needs. MoKP's purchasing this coverage for the patient or "paying in" MHN Spend Down allows "first day-first dollar" coverage for dialysis or transplant costs, physician costs, medication costs, and in-home services. Indirectly dialysis units, nephrologists, and hospitals also benefit from MoKP's payment of MHN Spend Down coverage. In FY11/12, MoKP helped 661 by paying in their Spend Down amounts for an average of \$1,147 per patient per year. This totaled \$758,341,000 which made up 52% of MoKP's budget.

#### Ticket to Work Health Assurance

In FY11/12 MoKP was able to help 47 disabled Missourians with kidney disease with insurance coverage by paying their MHN Ticket to Work premium. The average annual cost of these premiums was \$503. The total expense in this category was \$23,658. TWHA is a state and federal program that allows disabled patients to be employed without the risk of losing their health benefits. These working patients are able to purchase MHN coverage for a small monthly premium.

#### **Transportation**

MoKP eliminated this assistance for FY11/12, but allowed one month transition assistance so that patients, families and social workers could help organize other resources. We assisted 83 patients during this temporary transition of an annual cost per patient of \$89.

#### Patient and Staff Education

MoKP was pleased to re-open our Patient and Staff Education assistance program mid-year. The award was capped at \$250 per request, but different requests could be submitted per clinic. Common expenses for patient education were purchasing reading and video materials, or even items for a dietary/fluid contest. Staff education expenses could be used for professional membership fees, journal subscriptions, or conferences. In FY11/12 MoKP approved 121 requests and spent \$22,337 in this category.

#### Transplant / Donor Grant Assistance

This grant can be awarded to a Missouri kidney transplant recipient or their living donor, who experiences financial hardship directly related to the surgery or recovery process. The transplant social worker submits these grants after the surgery is over. The Transplant Grant assistance program was allotted \$10,000 for the year, and each grant was limited to \$500. However by mid-year it was increased to \$1,000. MoKP assisted 17 patients; 13 transplant recipients, and 4 living kidney donors with an average grant of \$703.

# PATIENT EDUCATION PROGRAM

The budget reduction for FY11/12 downsized MoKP's Center for Chronic Kidney Disease Education, with the workforce reduction of two health educators and their home offices. However, funding was set aside to continue with our Patient Education Program (PEP) classes, coordinated out of the Columbia office and organized by contracted employees. These free classes for patients and families prove 6 hours of educational information on kidney function, dietary, coping, financial

issues, and all of the treatment options. In FY 11/12, a total of 7 PEP classes were offered in St. Louis and Kansas City. Approximately 100 patients and guests attended. Future goals will be to provide PEP classes throughout the state.

#### LEGISLATIVE EFFORTS

MoKP hosted a Kidney Awareness Day at the Missouri Capitol on March 21, 2012. A coalition of kidney patients and advocates were recognized on the House Floor by Representative Chris Kelly, and received a Resolution announcing March as Kidney Awareness month. There were kidney educational displays from National Kidney Foundation, and MoKP. Legislators were visited and cupcakes were provided courtesy of Kilgore's.





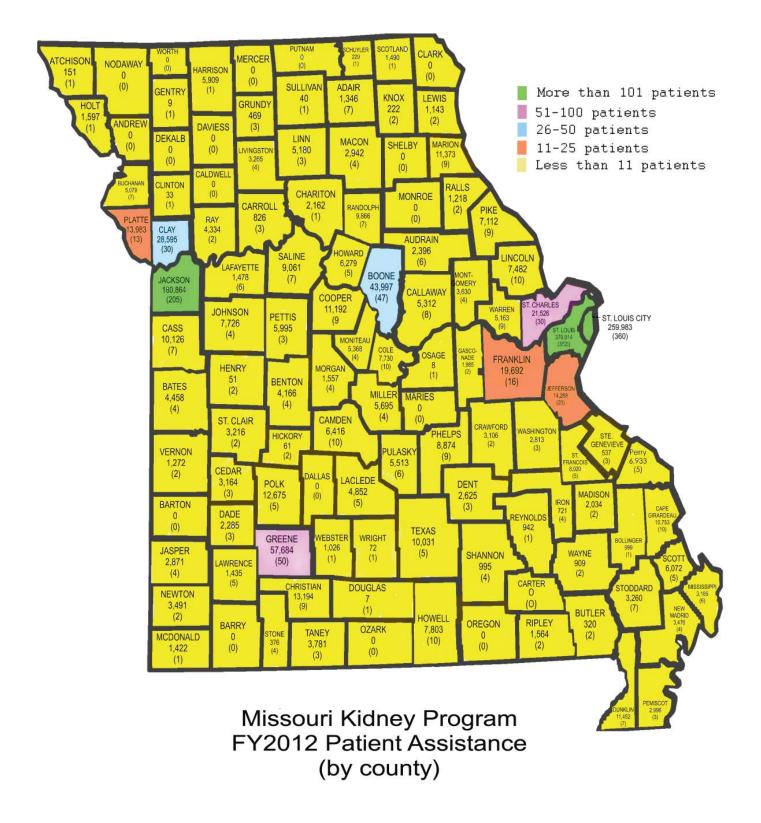
MoKP participates on the Governor's Organ Donation Advisory Committee, and attended their April 17, 2012 Organ Awareness day at the Capitol. Organ donation and transplant education was provided to legislators. Governor Jay Nixon signed a Proclamation noting April as Organ Awareness month.



MoKP Exhibit in Capitol

# Advocating for MO HealthNet Spend Down Patients

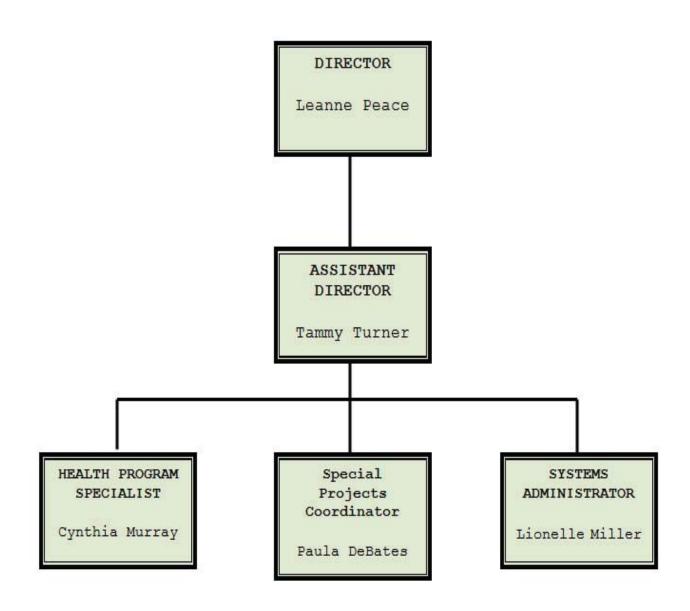
MoKP advocated throughout the year on behalf of the near poor chronically ill Missourians that have MHN Spend down coverage. In 2011, MO Dept. of Social Services' Family Support Division made a policy clarification on acceptable expenses for MO HealthNet Spend Down coverage. It was determined that the acceptable expenses will be the true patient responsibility, which is the final medical expense after all third-party payors. Dialysis and transplant patients were directly affected w/ loss of coverage for transportation, medical care, medications, physician bills, etc. MoKP partnered with other advocate groups in attending legislative hearings, MHN Oversight Committee meetings, plus letter- writing campaign to Governor Nixon, Legislators, and FSD. We were able to delay the implementation of this change until July 1, 2012. MoKP continues to support these patients and our kidney providers with FSD MHN Spend Down policy clarification information.



Dollars (Patients)

Pam Beauford, RN Administrator DCI Lee's Summit Kansas City, Missouri	Chris Kelly, JD Missouri Representative MO House of Representatives Jefferson City, Missouri
James Campbell, PhD Family and Community Medicine University of Missouri, Columbia	Mimi Korth, RD Renal Dietitian Fresenius Medical Care St Charles, Missouri
Rachel Covington Division President National Kidney Foundation of St. Louis, Missouri	Prashanth Podaralla, MD Nephrologist Hannibal, Missouri
Katrina Dinkel, MA Heartland Kidney Network 12 Kansas City, Missouri	Georges Saab, MD Nephrologist Washington University - St Louis St Louis, Missouri
Sue Emmert, RN Nurse Manager Freeman Hospital Joplin, Missouri	Karen Turner, MSW, LCSW DaVita St. Louis, Missouri
Cari Fears Patient Advocate St. Louis, Missouri	Tara Walker,RN Operations Manager Fresenius Medical Services Festus, Missouri
Janice Gentile Consumer Advocate Centertown, Missouri	Mark Wakefield, MD Transplant Surgeon University of Missouri - Columbia Columbia, Missouri
Ted Groshong, MD Pediatric Nephrologist University of Missouri - Columbia Columbia, Missouri	Michael Young, DO Nephrologist Jefferson City, Missouri
Jim Hafner, MSW Social Worker Davita - Northland Kansas City, Missouri	

# Missouri Kidney Program Staff Organization Structure FY11/12





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