



Missouri Kidney Program



2014



Annual Report

UNIVERSITY of MISSOURI HEALTH SYSTEM

MISSOURI KIDNEY PROGRAM

SCHOOL OF MEDICINE

October 22, 2014

This was the fifth year at the helm for Leanne Peace whose leadership team must take credit for steering the Program to 16% (\$250,000) funding increase for FY13/14 through the national financial downturn.

Budget frustrations started with a 28 percent reduction in 2009, then a devastating 48% cut in 2011. Stringent measures were called for and taken with having to lay off some of the staff and to prune some of the programs like cost containment research. We were able to keep the direct patient care cost at 80-85% of budget and still help a number of needy Missourians with renal disease. This year our Administrative cost was 17%.

The year had many upsides as well. The Centralized Drug Program was able to assist 1,409 people to receive over \$4.5 million of lifesaving medications. Others received help with transportation to and from dialysis, nutritional assistance, and insurance premiums. In the final analysis over 1,440 Missourians suffering from renal disease were helped. Although this is less (13%, compared to 25%) than in past years we are happy to be able to reach out to so many people who have no other support.

My wish is for a brighter and healthier future for Missouri kidney patients and MoKP continues to strive for a full restitution of state appropriations. MoKP continues to advocate and educate on behalf of Missouri kidney patients to their fullest capacity. Prevention education classes for patients and families are essential to delay the progression of kidney disease, and to make informed treatment choices. Professional education is provided to healthcare professionals, updating them on the best CKD treatment practices. Organ donation awareness efforts inform Missourians about the vital need of transplantation.

If you have questions about the information in this report or about the program in general, please contact the Missouri Kidney Program office.

Sincerely,



James D. Campbell, PhD
Chair, Advisory Council





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HISTORY

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 to 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 FY13/14 was \$1,697,500. The Missouri Kidney Program provided assistance to approximately 1,440 patients through facility agreements with 164 participating facilities. Patients typically have more than one assistance category.



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).

Goals

- 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 includes 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.

FY14 Executive Committee Members.

Chair - James Campbell, PhD
Vice Chair - Mark Wakefield, MD
Immediate Past Chair - Michael Young, DO

FY 13/14 Advisory Council Dates: Oct. 29, 2013; Feb. 27, 2014; June 26, 2014

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.



Missouri Kidney Program Staff from left to right:

Back row: Leanne Peace, Lionelle Miller, Tammy Turner,
Melissa Robertson

Front row: Patricia Lutz, Cynthia Murray, Jordan Peace



MoKP is fortunate to have wonderful, dedicated staff. This past year, we had stable staffing of 4.5 employees, plus a student worker of approximately 10 hours per week. In addition, we host a Family Support Division Eligibility Specialist, and pay half of her salary.

In FY13/14 our administrative costs were only 17% of total expenditures, which is comparable or less than the average administrative expenses of other health and social service providers.

STATUS OF CHRONIC KIDNEY DISEASE IN MISSOURI

Missouri is somewhat unique with regard to Chronic Kidney Disease. It is estimated that 1 in 9 Missourians are at risk for CKD, which is higher than the national average. This may be attributed to a number of factors including the general aging of the population, and the tendency of CKD to be slanted toward the last trimester of life. The highest rate of increase is in the elderly population, specifically those older than 75. In addition, CKD affects minorities, persons with diabetes, obesity and hypertension. It is unlikely this trend will change in the foreseeable future, thus the number of Missourians experiencing CKD will increase.

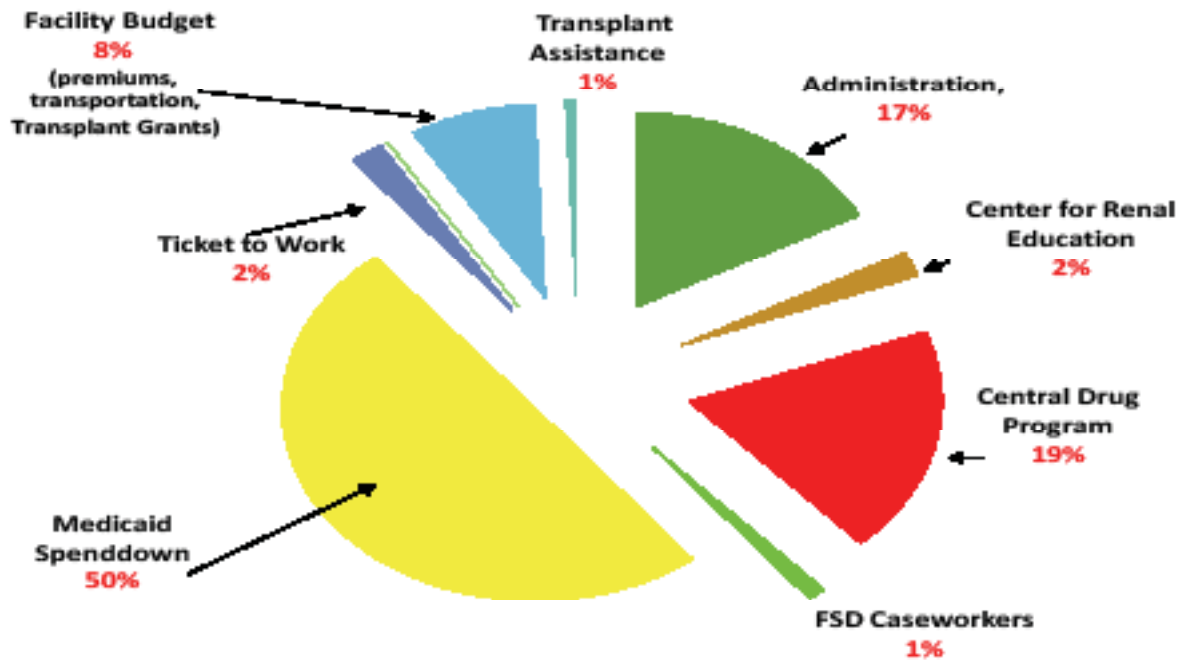
Of the 11,353 Missourians that have reached CKD Stage 5 or End-stage Renal Disease, 7588 (68%) are on dialysis (Heartland Network 2013 Annual Report), and 3,765 (32%) citizens have a kidney transplant. MoKP is able to provide assistance to only those with limited income of 13 % of Missouri ESRD patients, compared to 20% just a few years ago.

FISCAL REPORT

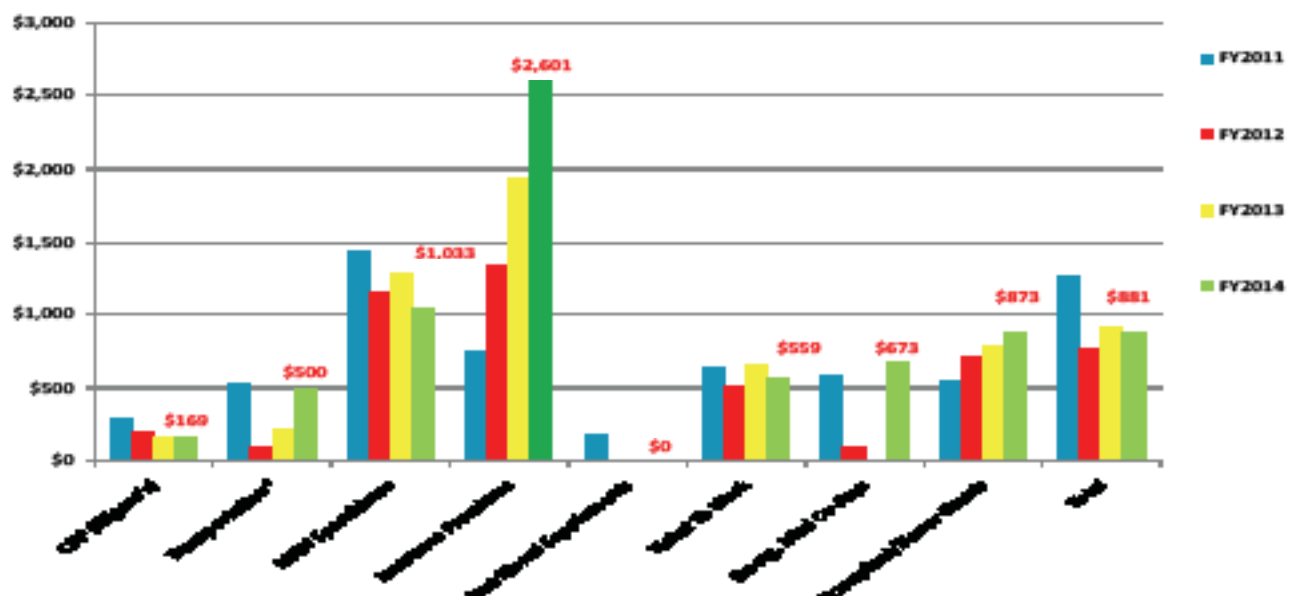
Missouri Kidney Program began FY13/14 with a stable state appropriations of \$1.75 million, with the usual 3% withhold from the Governor. We were fortunate to receive a slight increase of \$250,000 (16.7%) to our funding, to offset our previous year's amount of \$1,455,000. Our operating budget starting July 1, 2013 was \$1,697,500. We attribute this increase to our advocacy efforts directed to the Missouri Legislators explaining our patients' needs of transportation, premium coverage, and medication assistance.

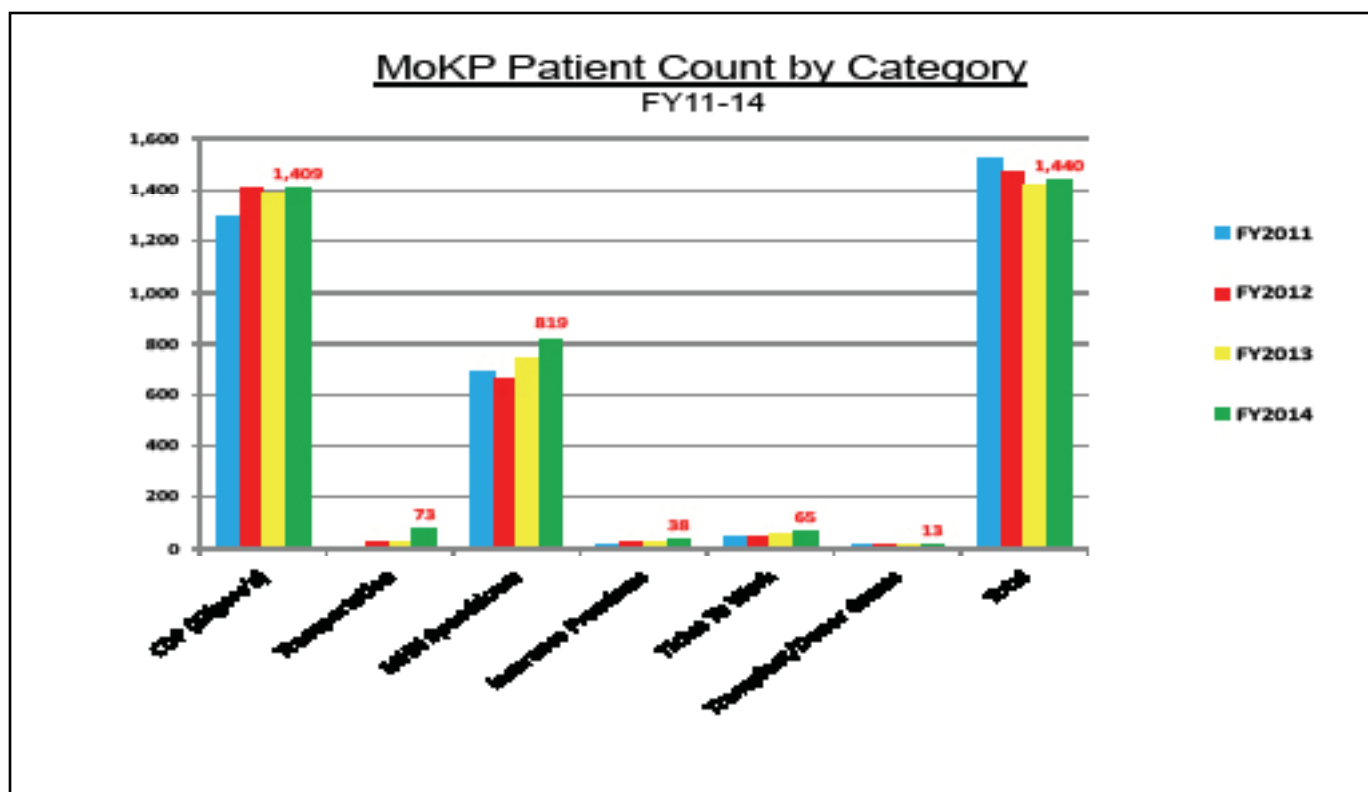
During FY 13/14, Missouri Kidney Program was still able to assist 1,440 eligible CKD Stage 5 kidney patients with expenses related to dialysis, transplantation or post-transplantation follow-up care. The average cost per patient provided by MoKP in was \$881.

MoKP Appropriation by Category in FY14



MoKP Expenditures per Patient by Category FY 11-14





MISSOURI PROGRAM ASSISTANCE

To receive MoKP assistance, kidney patients must be United States citizens residing permanently in Missouri, or aliens lawfully admitted for permanent residence in the state. Patients must be CKD Stage 5, and meet an income/asset eligibility requirement for MoKP benefits; however any Missourian is eligible to attend our free patient education programs. For details of our financial guidelines, go to: <http://som.missouri.edu/mokp/Guidelines.htm>.

MoKP Patient Demographics

At the end of June 30, 2014, our current patient demographics revealed we served 1,207 Missouri patients, a slight increase from last year. From this number 434 (36%) were transplant patients, and 772 (64%) were dialysis patients. The majority of our patients are urban residents. The male patients numbered 649 (54%) compared to 558 (46%) females.

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%
FY12/13	\$1,455,000	0.00%
FY13/14	\$1,697,500	16.67%

* = Mid-Year Cuts

SERVICES AND PROGRAMS

MoKP's primary area of focus in FY13/14 was to continue to provide routine medication and immunosuppressive assistance. Those patients who are actively using Kilgore's were reviewed to determine insurance premium assistance eligibility. In addition, we re-opened transportation assistance to assist our patients with the burdens of transportation to dialysis treatments.

Average Patient Assistance in FY14

Assistance	# of Patients assisted	Average cost \$
Medications	1,409	\$169
Transportation	73	\$500
Private Insurance Premiums	38	\$2,601
Medicaid Spend Down	819	\$1,033
Ticket To Work	65	\$559
Transplant or Donor Grant	13	\$873
Emergency Medications	2	\$673
Total	1,440	\$881

Medication Assistance through the Centralized Drug Program

MoKP continued to provide the same high quality medication assistance to eligible dialysis and transplant patients in FY13/14. 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 \$4,720,160 worth of medications. Since MoKP is the payer of last resort, our medication expense in FY13/14 was only \$237,950. During FY13/14 we were able to assist 1,409 patients with an average cost of \$169.



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 FY13/14, MoKP was able to assist 38 patients with insurance costs of a yearly average cost of \$2,601, totaling \$98,826.

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, transportation and in-home services. Indirectly dialysis units, nephrologists, and hospitals also benefit from MoKP’s payment of MHN Spend Down coverage. In FY13/14, MoKP helped 819 patients by paying in their Spend Down amounts for an average of \$1,033 per patient per year. This totaled \$845,737, which made up 50% of MoKP’s budget

Ticket to Work Health Assurance

In FY13/14 MoKP was able to help 65 disabled Missourians with kidney disease with insurance coverage by paying their Ticket to Work premium. The average annual cost of these premiums was \$559. The total expense in this category was \$36,314. 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 was able to re-open this important benefit so that patients can attend their life sustaining dialysis treatments or transplant appointments. This assistance is only available to patients not eligible for Missouri’s Non-Emergent Medical Transportation program managed through LogistiCare. In FY13/14, MoKP was able to assist 73 patients with an average cost of \$500 for an actual total of \$36,491.



Transplant or Living 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 a grant request after the surgery is over. The Transplant Grant assistance program grant was limited to \$1,000. MoKP assisted 13 patients; 4 transplant recipients, and 9 living kidney donors with an average grant of \$873, for an actual total cost \$11,350.

CHRONIC KIDNEY DISEASE EDUCATION

Patient Education Program (PEP)

These free classes for patients and families provide 6 hours of unbiased CKD educational information on kidney function, dietary, coping, financial issues, and all of the treatment options. In FY 13/14, a total of 12 PEP classes were offered in St. Louis, Central MO and Kansas City. There were 122 attendees (72 patients and 50 guests) at these educational group classes. Future goals will be to provide PEP classes throughout the state.

Since 2012, MoKP has contracted with 2 local Nephrology Social Workers to be our PEP Coordinators for the St. Louis area, and the Kansas City area. These coordinators handle the logistics of arranging the settings, speakers, plus marketing these classes to healthcare providers

Community Education

MoKP participates and exhibits in community health fairs and awareness programs throughout the state. This past year we reached out to the Senior Citizen Centers throughout the state, and provided CKD in-services and educational materials to numerous centers.

Professional Education

MoKP also attended and exhibited at 2 primary care conferences, and numerous kidney related conferences throughout the state, providing information on the updated changes to the CKD staging process, along with MoKP services.



RESEARCH OPPORTUNITY

MoKP has partnered with Amy Waterman, PhD of UCLA and has been awarded a DHHS grant for Social and Behavioral Interventions to Increase Solid Organ and Tissue Donation. Our 3 year grant is titled: **“Improving Low-Income End Stage Renal Disease patients’ Transplant Knowledge: A Case Management Trial”**. At the end of FY14, we began the recruitment process and offering the opportunity for MoKP patients to participate in this research study.

Abstract:

Deceased donor kidney transplant (DDKT) and living donor kidney transplant (LDKT) offers patients improved quality-of-life and length of life compared to remaining on dialysis. Unfortunately, research has shown that patients on dialysis are inconsistently educated about LDKT, particularly patients who are members of racial minority groups and those who are socioeconomically disadvantaged. There is a complex set of potential risks and benefits to be weighted regarding whether to get an LDKT, particularly for patients facing many practical and financial barriers to transplant. With dialysis providers reporting that they have limited time to educate complex patients, their educational practices are most commonly recommending that patients get evaluated for transplant and learn more at transplant centers. To help all low-income patients make informed LDKT decisions, a more comprehensive case-management program may be needed to supplement the minimal transplant education provided with dialysis centers

The aims of the grant are:

1. To understand the transplant decision-making and educational needs of low income kidney patients who previously chose to remain on dialysis or pursue DDKT and LDKT.
2. Compared to dialysis center education only, to conduct a randomized controlled trial to assess the effectiveness of mailed transplant education and intensive telephone case management on improving patients’ knowledge of the risks and benefits of LDKT, informed LKDT decision-making, and satisfaction with their treatment choice.
3. To conduct a cost-effectiveness assessment of the impact of the mailed education and and the intensive case management on increasing LDKT knowledge.
4. To examine how known patient, family, and healthcare system barriers to LDKT act alone and in combination with the educational programs to affect low-income patients’ LDKT knowledge and decision-making.

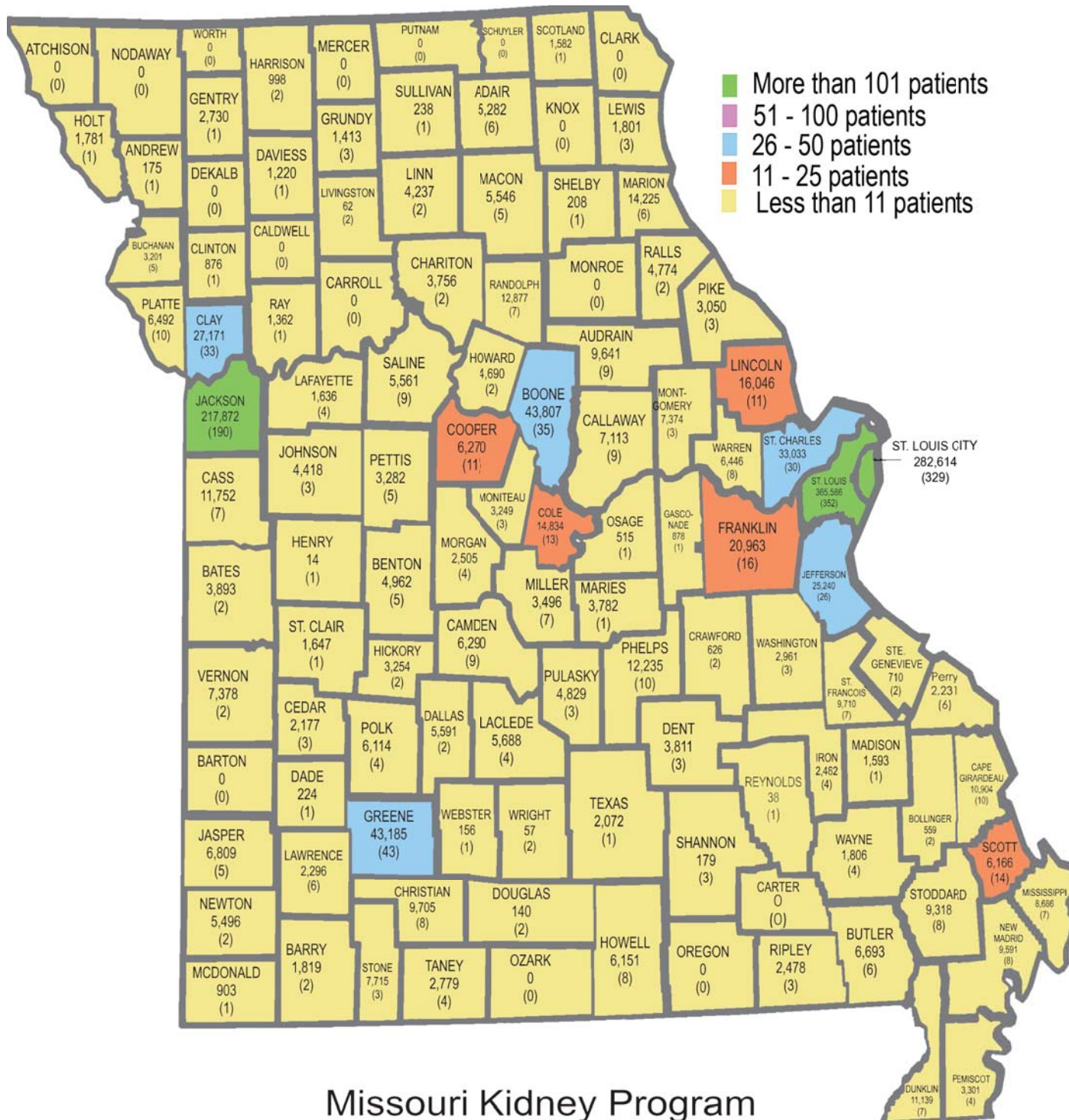
LEGISLATIVE AWARENESS

MoKP hosted a Kidney Awareness Day at the Missouri Capitol on March 27, 2014. A coalition of kidney patients and advocates were recognized on the House Floor by Representative Chris Kelly, announcing March as Kidney Awareness month. There were kidney educational displays from National Kidney Foundation, Dialysis Clinics, Inc, NxStage and MoKP. Legislators were visited and kidney facts along with blood pressure facts were distributed.





MoKP participates on the Governor's Organ Donation Advisory Committee, and attended their April, 15 2014 Organ Awareness day at the Capitol. Organ donation and transplant education was provided to legislators.



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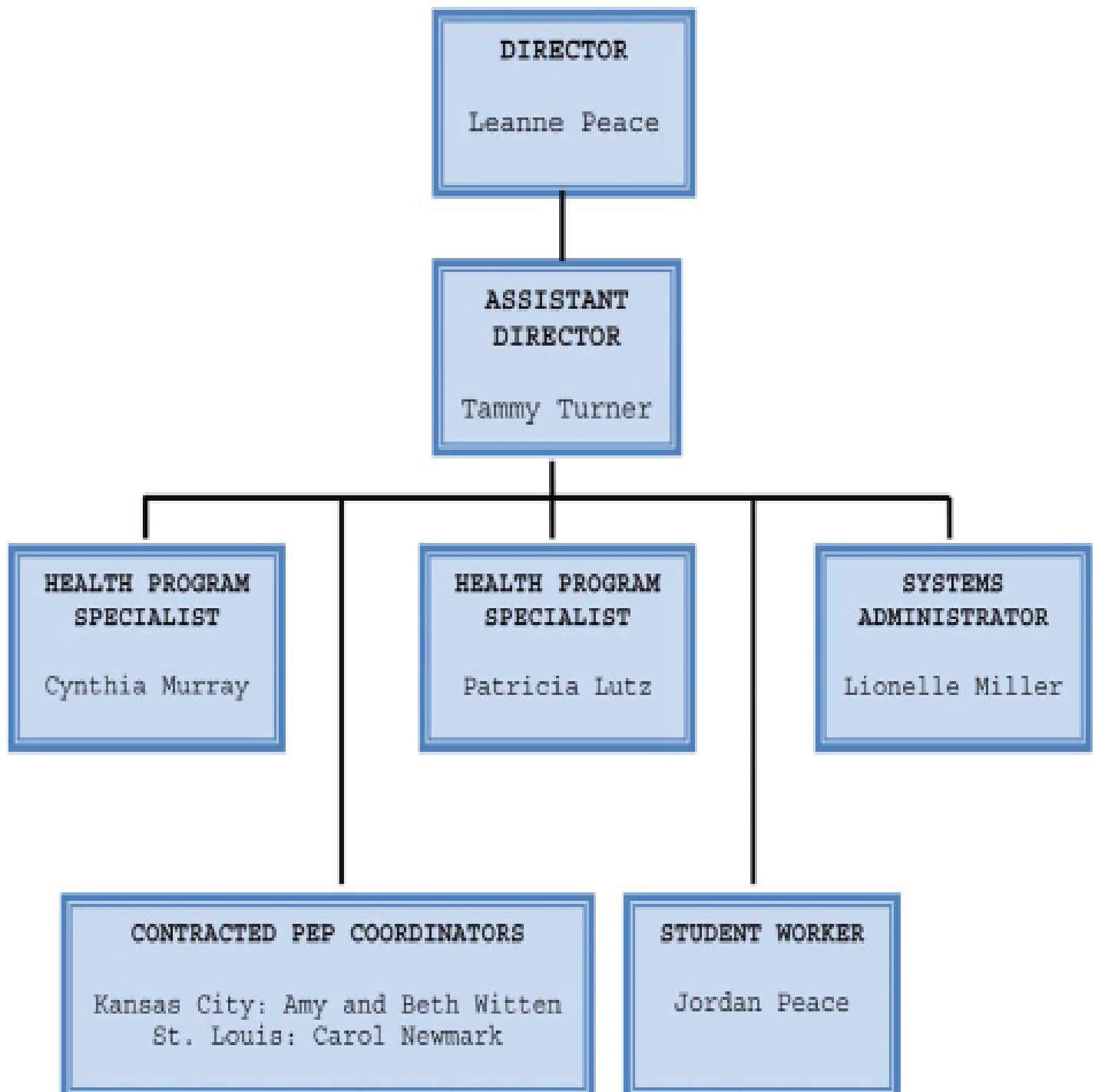
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Missouri Kidney Program
Staff Organization Structure
FY13/14





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