



Missouri Kidney Program



2016

Annual Report





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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. 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.

In addition to its direct charge, the Missouri Kidney Program sponsored cost-containment research and demonstration projects aimed at increasing the cost-effectiveness of patient care. This important program began in 1977, but was discontinued in 2009 due to budget reductions. In 1983, MoKP began a statewide pre-dialysis education program. 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. MoKP continues with these prevention and group educational classes throughout the state.

Throughout the years MoKP continues to advocate for and provide a voice for MO citizens with kidney failure. MoKP partners with many agencies and resources, so that kidney issues, along with prevention and education, can be heard. MoKP has a listserv for all social workers across the state. This is our interactive communication mode where information is disseminated and shared with clinic social workers, enabling them to pass information on to patients in a timely manner.

The annual state appropriation for the FY15/16 was \$1,697,500. The Missouri Kidney Program provided assistance to approximately 1,407 patients through facility agreements with 174 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 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.
 - Benefits range from medications, transportation, and insurance premiums assistance depending on available funding.
- To provide and support the CKD education of Missourians:
 - To promote public awareness and prevention of CKD.
 - To help select an appropriate treatment for kidney failure and to encourage active participation in their medical care.
 - 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 two times per year. Council membership includes individuals with appropriate knowledge and experience representing interested agencies, health care disciplines, and kidney consumers. 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. Our council meetings were available via conference call to accommodate our long distance members.



Standing from left: Jim Hafner, Bridget Andrews, Chad Iseman. Sitting from left: Mark Wakefield, Leanne Peace, Jim Campbell. Not pictured: Pam Beauford, Tammy Turner, Valerie Hardesty, Steve Moore, Cheryl Ibrahim, Mimi Korth, Prashanth Podaralla, Tingting Li, Sue Emmert, Ted Groshong, Michael Young, Mike Arrowood, Debbie Ulm and Caleb Rowden.

FY16 Executive Committee Members.

Chair - Mark Wakefield, MD

Vice Chair - Preethi Yerram, MD

Immediate Past Chair - James Campbell, PhD

FY 15/16 Advisory Council Dates: Nov. 5, 2015, and June 23, 2016.

ADMINISTRATION & STAFF

The Missouri Kidney Program is administered by a director, traditionally appointed by the Dean of the School of Medicine. Leanne Peace is the current director, serving since 2009. The director's responsibilities include hiring and supervising of the MoKP staff and implementing the goals, objectives and policies of the program as authorized by the Missouri Legislature, the Dean, and the Advisory Council.

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 MO HealthNet Eligibility Specialist, and pay half of her salary. Having an in-house Eligibility Specialist, who can streamline MHN applications, renewals and problem issue, is an important service to patients, MoKP, and to kidney providers.

In FY15/16 our administrative costs were 18% of total expenditures, which is comparable or less than the average administrative expenses of other health and social service providers.

Standing from left:
Valerie Hardesty,
Carlee Johnson,
Lionelle Miller, and
Melissa Krapf. Sitting
from left: Tammy
Turner, Leanne Peace,
and Cynthia Murray.





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 11,850 Missourians that have reached CKD Stage 5 or End-stage Renal Disease 8,113 (68.5%) are on dialysis (7,004 on Hemodialysis, 1,109 on Peritoneal Dialysis), and 3,706 (31.5%) Missourians have a kidney transplant. There were 2,203 new chronic kidney patients needing renal replacement therapy last year. (USRDS, 2016) MoKP is able to provide assistance to only those with limited income. 12 % of Missouri ESRD patients is a significant drop compared to 20% just a few years ago.

COMMENTS FROM MOKP PATIENTS

"I am very pleased with MKP and the staff. I would not be able to stay as healthy as I am without them. This program and the professional, courteous people in the office are a life saver for me and my family who loves me."

"It's an excellent program to which if it hadn't existed my family and I would be lost without."

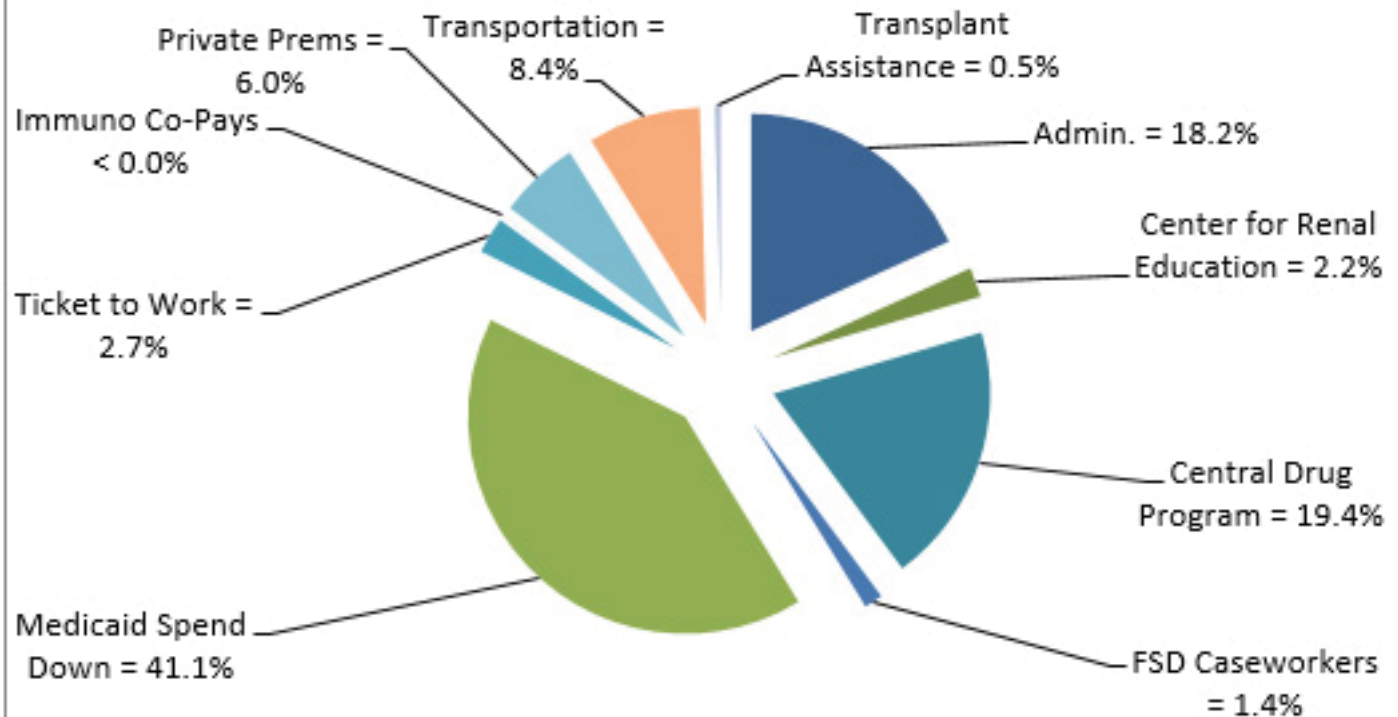
"I just am so thankful for the Missouri Kidney Program and all the help I get from them. I don't know what I would do without their help."

FISCAL REPORT

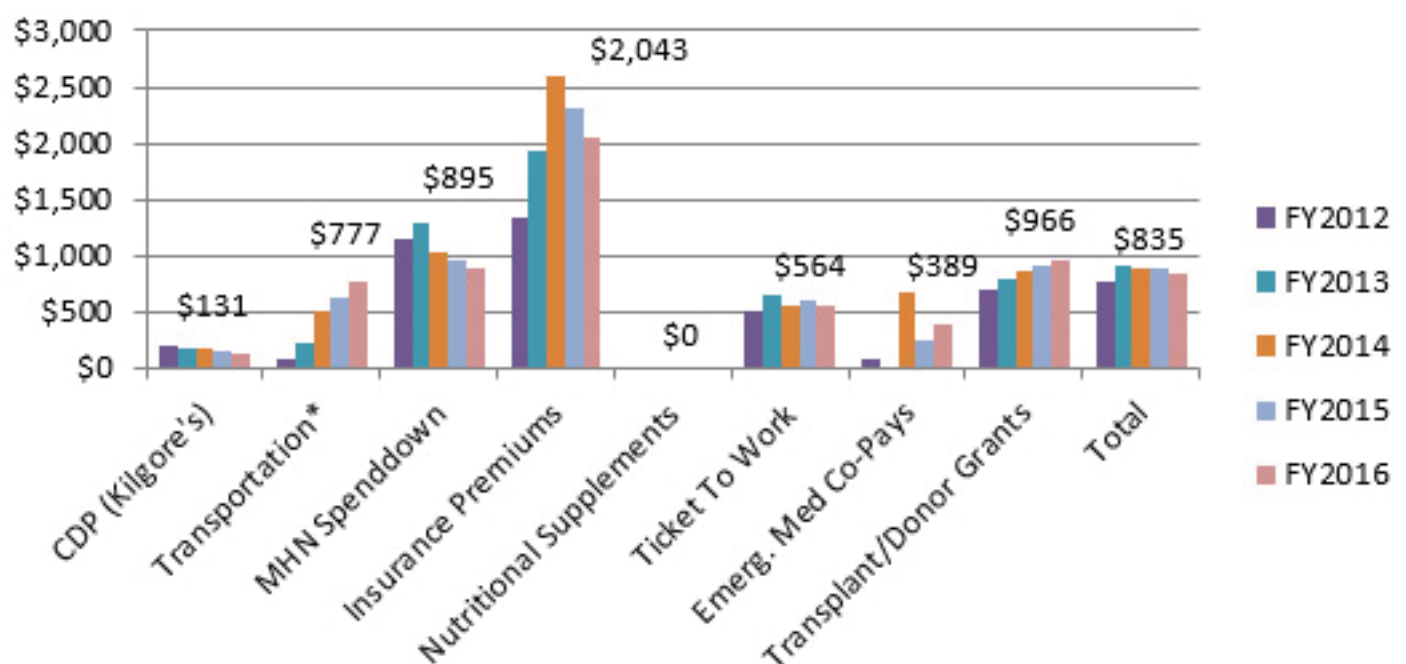
Missouri Kidney Program began FY15/16 with a stable state appropriations of \$1.75 million, with the usual 3% withhold from the Governor. Our operating budget starting July 1, 2015 was \$1,697,500. We have maintained a slight increase since 2013, of \$250,000, which was due to our advocacy efforts after our 48% budget cut in 2011.

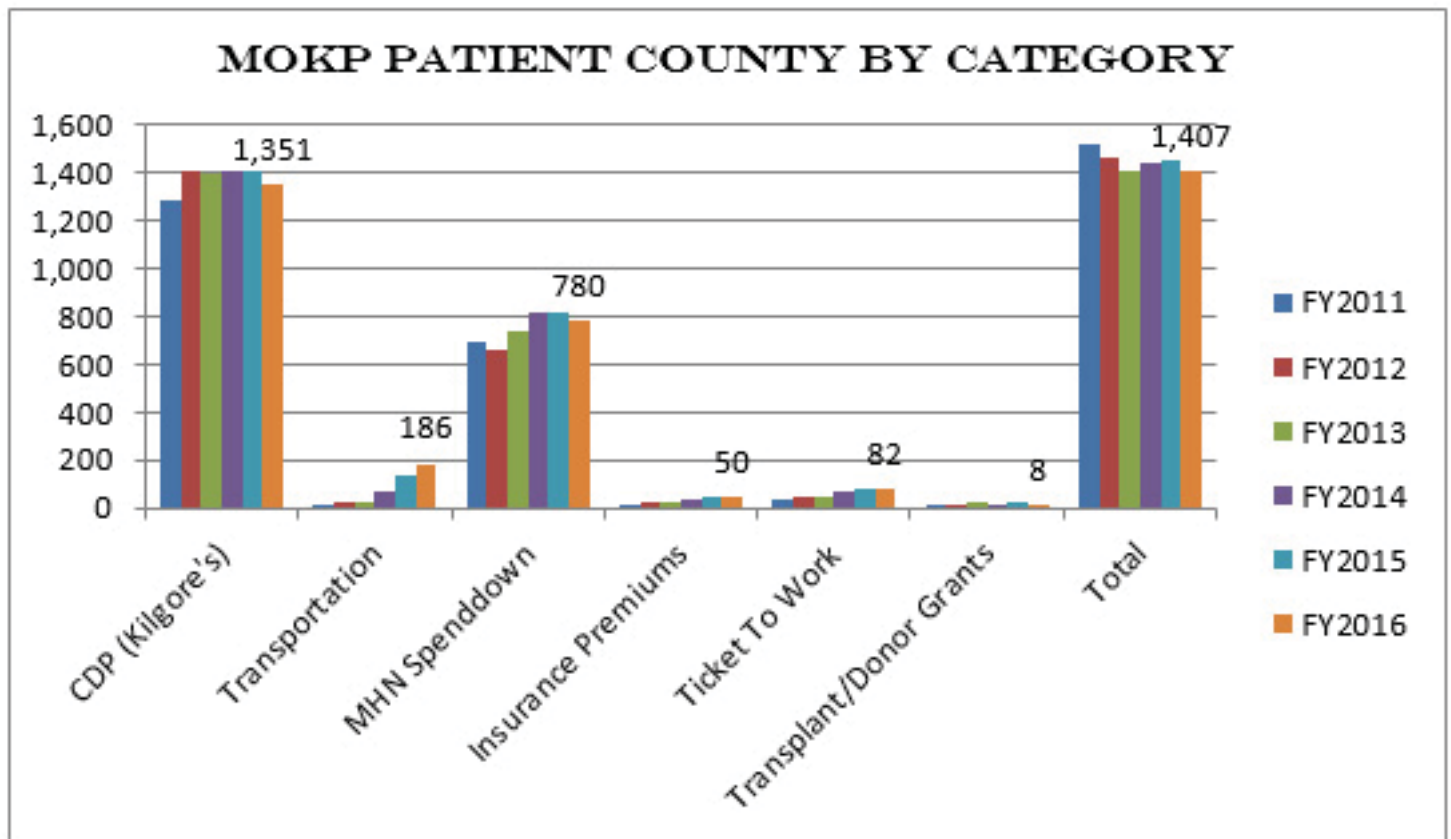
During FY 15/16, Missouri Kidney Program was able to assist 1,407 eligible CKD Stage 5 kidney patients with expenses related to dialysis, transplantation, and post-transplantation follow-up care. MoKP provided assistance with an average cost of \$835.

MOKP APPROPRIATION BY CATEGORY FY16



MOKP EXPENDITURES PER PATIENT BY CATEGORY





MISSOURI KIDNEY PROGRAM ASSISTANCE

MoKP Eligibility

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 on dialysis or have a kidney transplant. In addition they must 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

During the FY15/16 fiscal year, we assisted 1,407 patients with benefits, or 12% of the MO ESRD population. A snapshot picture of our caseload taken on June 30, 2016, showed our patient caseload of 1,166, a slight decrease from last year. From this number 415 (36%) were transplant patients, and 751 (64%) were dialysis patients. The majority of our patients are urban residents. The male patients numbered 641 (55%) compared to 528 (45%) females. Our racial demographics reveal African Americans make up 56% of our caseload, compared to 40% are Caucasian. Hypertension is the prominent diagnosis for renal failure for our patients, and diabetes is second.

MISSOURI KIDNEY PROGRAM APPROPRIATIONS HISTORY

Fiscal Year	Net Appropriation	Percent Changed 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%
FY14/15	\$1,697,500	0.00%
FY15/16	\$1,697,500	0.00%

* = Mid-Year Cuts

SERVICES AND PROGRAMS

MoKP's primary area of focus in FY15/16 was to provide renal medication and immunosuppressive assistance. Those patients who are actively using Kilgore's are considered for insurance premium assistance eligibility. In addition, MoKP provides transportation assistance to assist our patients with the burdens of transportation to dialysis treatments.

Assistance	# of Patients Assisted	Average Cost \$
Medications.....	1,351.....	\$131
Transportation.....	186.....	\$777
Private Insurance Prens.....	50.....	\$2,043
Medicaid Spend Down.....	780.....	\$895
Ticket to Work Prens.....	82.....	\$564
Transplant/Donor Grant.....	8.....	\$966
Emergency Medications.....	2.....	\$389
TOTAL	1,407	\$835

Medication Assistance through the Centralized Drug Program

MoKP continued to provide the same high quality medication assistance to eligible dialysis and transplant patients in FY15/16. Our formulary includes over 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 submitted bills to all insurance payers (Medicare Part B and Part D, MO HealthNet, private insurance, and any 3rd party insurance companies) for a total of \$3,696,707 worth of medications for FY15/16.

Since MoKP is the payer of last resort, and closely manages insurance coverages our medication expense in FY15/16 was only \$177,534. During FY15/16 we were able to assist 1,351 patients with an average cost of \$131 per patient. This cost per patient is an overall decrease from the previous year, and we attribute this to our highly competitive contract award which started July 1, 2015. In addition to this direct medication assistance, we also assist our patients with enrollment into the optimal Medicare Part D plan, which covers most of their medications. During this process, we will refer and help with enrollment to appropriate state resources.

We partner with CLAIM, Missouri's State Health Insurance Program, to keep informed on Medicare coverages and changes. Our Coordinators are CLAIM Counselors, which greatly benefits our MoKP patients, all kidney patients, and providers as they encounter insurance questions. We share any Medicare news and programs that can affect ESRD clients with the social workers. We provided assistance to 1,187 MO contacts with Medicare Part D enrollments, Low Income Subsidy/Medicare Saving Programs and MO HealthNet referrals.



Insurance Premiums

For those patients that are on our medication program, we were able to assist a few patients with insurance premium assistance. MoKP determines if it is cost-effective to pay for the insurance costs versus the costs of the medications. This is typically the case with transplant patients, who are now eligible to get coverage through the Affordable Care Marketplace plans. In FY15/16, MoKP was able to assist 50 patients with insurance costs. The yearly average cost was \$2,043 per patient, totaling \$102,182.

Mo HealthNet (MHN) Spend Down

MoKP considers MHN to be important and necessary insurance coverage, as it assists “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 benefit from MoKP’s payment of MHN Spend Down coverage. In FY15/16, MoKP helped 780 patients by paying in their Spend Down amounts for an average of \$895 per patient per year. This totaled \$697,733, which made up 41% of MoKP’s budget.

Ticket to Work Health Assurance (TWHA)

In FY15/16, MoKP was able to help 82 disabled Missourians with kidney disease with insurance coverage by paying their Ticket to Work premium. 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. The average annual cost of these premiums was \$564 per patient. The total expense in this category was \$46,249.

Transportation

MoKP provides transportation so patients can attend their life sustaining dialysis treatments or transplant appointments. MoKP re-opened this important benefit in 2012, and it was the highest growing assistance category in FY15/16. This assistance is only available to patients not already eligible for Missouri’s Non-Emergent Medical Transportation program managed through LogistiCare. In FY15/16, MoKP was able to assist 186 patients with an average cost of \$777 per patient, for an actual total of \$143,170.

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 is limited to \$1,000. MoKP assisted six kidney transplant recipients and two living kidney donors with an average grant of \$966 per patient, for an actual total cost \$7,725.

CHRONIC KIDNEY DISEASE EDUCATION

Patient Education Program (PEP)

These free classes for patients and families provide six hours of unbiased CKD educational information focusing on kidney function, dietary, coping, financial issues, and all of the treatment options. In FY15/16, a total of 13 PEP classes were offered in St. Louis, Central MO and Kansas City. There were 108 attendees (77 patients and 31 guests) at these educational group classes. Future goals will be to provide PEP classes throughout the state or deliver this education in video or webinar formats.

MoKP continues to contract with Beth Witten and Carol Newmark, two local nephrology social workers, to be the PEP Coordinators for the Kansas City and St. Louis area, respectively. These coordinators handle the logistics of arranging the settings, speakers, plus marketing these classes to healthcare providers.

In the spring of 2016, MoKP contracted with MHN case management department to direct mail our PEP educational class flyers to the addresses of those MHN clients who were diagnosed as CKD Stage 4. We are hoping this direct invitation will increase awareness and attendance in our CKD classes.

Patient Education Program (PEP) Comments

"I think all patients on Dialysis and who have kidney problems/disease should take this entire class. VERY HELPFUL INFORMATION!"

"I think this was the best presentation on this subject I have ever heard. I have a better understanding and appreciation for my doctors."

"I think this is an excellent way to learn about kidney disease especially for someone who has time before needing to go on dialysis."



Community Education

MoKP participates and exhibits in numerous community health fairs and awareness programs throughout the state. This past year we reached out to the Senior Citizen Centers and Health Departments throughout the state, and provided CKD in-services and educational materials to numerous centers. Hundreds of citizens have visited the MoKP booth and have received kidney disease, awareness, and prevention tips.

Professional Education

MoKP attended and exhibited at three primary care conferences, and several nursing and social work conferences throughout the state. Our exhibits provides information on the updated changes to the CKD staging process, prevention tips, along with MoKP class schedules and services.

RESEARCH OPPORTUNITY

MoKP partnered with Amy Waterman, PhD of UCLA and was awarded a HRSA grant for Social and Behavioral Interventions to Increase Solid Organ and Tissue Donation. The three year grant was titled: "Improving Low-Income End Stage Renal Disease patients' Transplant Knowledge: A Case Management Trial". FY15/16 was the final year of the research study, MoKP's role was to continue the educational mailings to participants. MoKP co-presented the poster at the National Kidney Foundation's Spring Clinical Meeting in Boston, MA. The first publication and data analysis are pending.

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.

LEGISLATIVE AWARENESS

MoKP hosted a Kidney Awareness Day at the Missouri Capitol on March 10, 2016. A coalition of kidney patients and advocates were recognized on the House Floor by Representative Caleb Rowden, announcing March as Kidney Awareness month. There were kidney educational displays and blood pressures were monitored. Legislators were visited and kidney facts along with blood pressure facts were distributed.



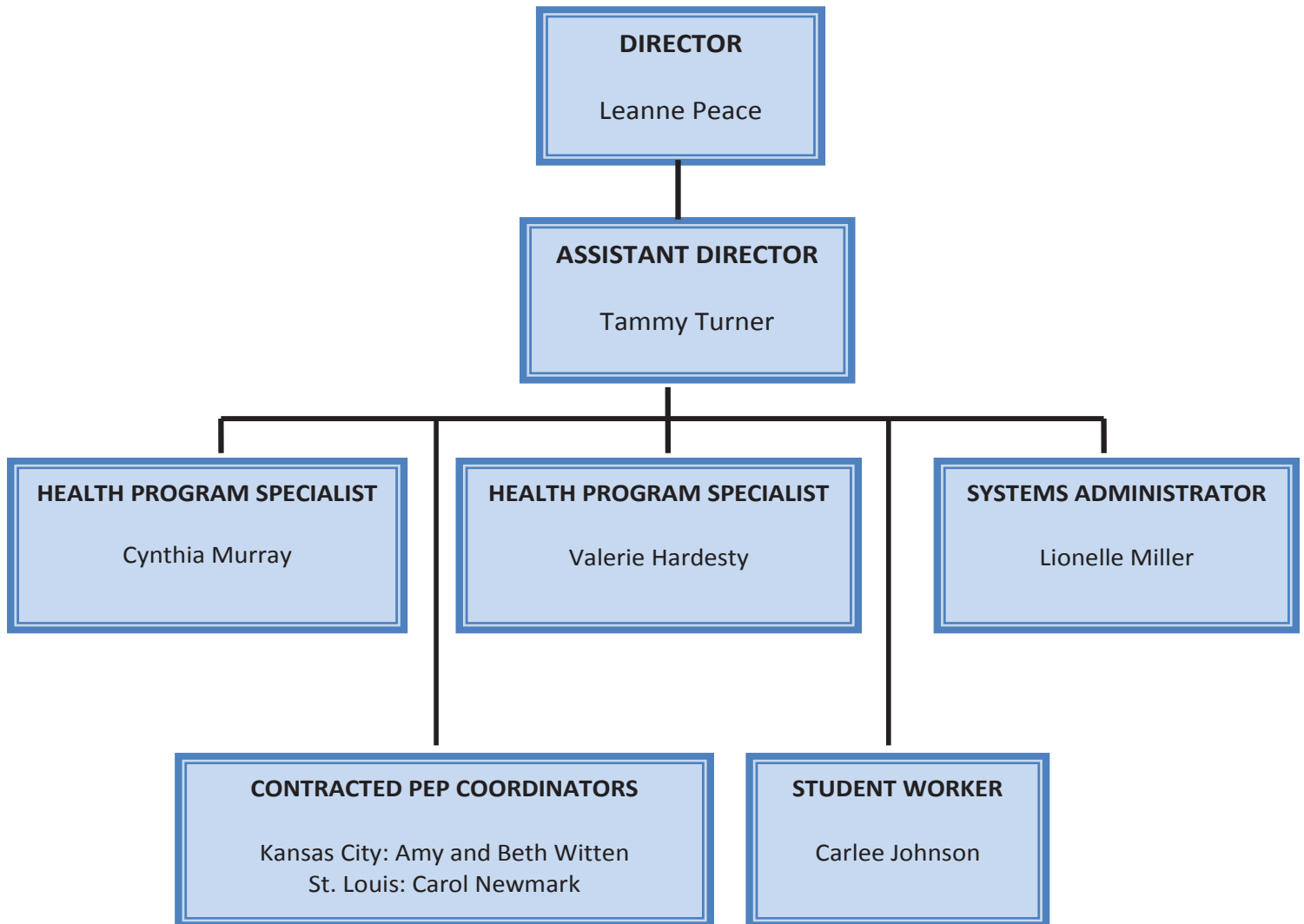


MoKP participates on the Governor's Organ Donation Advisory Committee, and attended their April 12, 2016 Organ Awareness Day at the Capitol. Organ donation and transplant education was provided to legislators. This year there was a Donor Recognition Ceremony, honoring all the deceased donors in Missouri.

MOKP ADVISORY COUNCIL FY 2016

Pam Beauford, RN Administrator DCI Lee's Summit Kansas City, Missouri	Caleb Rowden Missouri Representative MO House of Representatives Jefferson City, Missouri
James Campbell, PhD Family and Community Medicine University of Missouri, Columbia Columbia, Missouri	Mimi Korth, RD Renal Dietitian Fresenius Medical Care St Charles, Missouri
Chad Iseman Regional Director National Kidney Foundation of St. Louis, Missouri	Prashanth Podaralla, MD Nephrologist Hannibal, Missouri
Debbie Ulm Assistant Director Heartland Kidney Foundation 21 Kansas City, Missouri	Tingting Li, MD Nephrologist Washington University - St Louis St Louis, Missouri
Sue Emmert, RN Nurse Manager Freeman Hospital Joplin, Missouri	Bridget Andrews, MSW Renal Social Worker FMC St. Louis, Missouri
Mike Arrowood Patient Advocate Perry, Missouri	Cheryl Ibrahim Nurse Administrator Salem Memorial Hospital Salem, Missouri
Steve Moore Patient Advocate Fulton, 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
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Missouri Kidney Program
Staff Organization Structure
FY15/16





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