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Press Release (FOR IMMEDIATE RELEASE)

News from the Coalition for Supportive Care of Kidney Patients

Richmond, VA, November 14, 2016: The Gordon and Betty Moore Foundation has awarded the Mid-Atlantic Renal Coalition (MARC), a Quality Insights company, a 15-month grant to support the development of evidence-based best practices for delivering person-centered palliative care to patients with chronic kidney disease. The program, named the *Pathways Project*, will develop tools to establish pathways to conservative non-dialytic management, palliative care throughout the continuum of kidney disease, and dialysis withdrawal for those patients who choose to stop dialysis.

The Pathways Project builds on the work of the Coalition for Supportive Care of Kidney Patients (CSCKP) has been sponsoring since 2005. Dale Lupu, MPH, PhD and Alvin Moss, MD, Chairperson of the CSCKP, are Co-Principal Investigators. Dr. Lupu is Associate Research Professor at George Washington University and principal of Daleview Associates and Dr. Moss is Professor of Medicine at West Virginia University. Together, they have significant experience bringing palliative and supportive care to many communities and settings.

The Pathways Project addresses a need to offer conservative management to suitable patients with chronic kidney disease or end stage renal disease. “We know that for some elderly patients with multiple comorbidities there may be limited survival advantage with dialysis and that these patients may have a better quality of life with conservative management,” explains Dr. Moss. “But the pathway for these patients is not clearly defined or understood.” It is also known that about 20% of patients withdraw from dialysis each year and having these conversations with patients is challenging and often difficult for the dialysis center staff. “We hope that tools and

resources can be assessed and developed to facilitate this important aspect of patient-centered care,” states Dr. Lupu. The Pathways Project will also focus on timely delivery of primary and specialty palliative and supportive care for the entire continuum of care.

MARC is convening a Technical Expert Panel representing nephrology, palliative care, hospice, communication, policy as well as experts who have accomplished change in other care settings. The Institute for Healthcare Improvement will serve on the panel and will facilitate and support the work of identifying best practices and making those operational for the CKD environment.

The CSCKP has the vision to offer palliative care to everyone with chronic and end-stage kidney disease, from the time of diagnosis through end of life and bereavement. Informed, supported patients and families receive the care they want. Dr. Lupu says, “There is so much need for more supportive care. Patients are hungry for it, staff want to provide it, nephrologists and nurses are eager to improve their skills. Now we’re going to be able to help them do that.”

The Gordon and Betty Moore Foundation fosters path-breaking scientific discovery, environmental conservation, patient care improvements and preservation of the special character of the Bay Area. Visit <https://www.moore.org/> and follow @MooreFound.

To learn more about the CSCKP visit <http://kidneysupportivecare.org>