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WASHINGTON REPRESENTATIVE

LEGISLATIVE RECOMMENDATIONS FISCAL YEAR 2016

NephCure Kidney International is the only organization committed exclusively to support research seeking the cause of the potentially debilitating kidney disease Focal Segmental Glomerulosclerosis (FSGS) and the diseases that cause Nephrotic Syndrome, improve treatment, and find a cure. NephCure is driven by a panel of respected medical experts and a dedicated band of patients and families.

FSGS occurs when the kidney's glomeruli become scarred. The damaged filters allow protein to leak into the urine, and prolonged leakage can lead to kidney damage and failure. Patients with kidney failure must undergo dialysis or receive a kidney transplant. Unfortunately, FSGS returns in 30-40% of patients who receive a transplant. FSGS is the most common cause of steroid resistant NS in children, and it is a leading cause of kidney failure in children. In addition, African Americans are impacted at a five times greater rate than the general population. The causes of FSGS are unknown and there is currently no cure.

NephCure asks Congress to support the following FY16 recommendations:

• Provide \$32 billion for the National Institutes of Health (NIH).

• Provide \$2.02 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and support FSGS/NS research opportunities. Cure Glomerulonephropathy (CureGN) is an important study with the goal of supporting precision medicine development for NS.

• Provide \$286.206 million for the National Institute on Minority Health and Health Disparities (NIMHD) and support FSGS/NS research opportunities through grant and training programs.

• Support rare disease research at the National Center for Advancing Translational Sciences (NCATS). The NEPTUNE Study, part of the Rare Diseases Clinical Research Network, is a collaboration of NIH, NephCure and university partners to pool resources and find a cure.

• Include FSGS/NS as a disease eligible for study in the Defense Peer-Reviewed Medical Research Program in the FY16 Defense Appropriations bill.