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Kidney International

Saving Kidneys • Saving Lives

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### Legislative Agenda 115<sup>th</sup> Congress, 1<sup>st</sup> Session

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 (NS), 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 recommendations:

**Provide \$36 billion for the National Institutes of Health (NIH) for Fiscal Year 2018.**

**Provide a proportional increase 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 a proportional increase 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 academic partners to pool resources and find a cure.

**Continue to include FSGS as a disease eligible for study through the Defense Peer-Reviewed Medical Research Program** in the FY 2018 Defense Appropriations bill due to the impact of FSGS on veterans and military personnel.

### **Affordable Care Act Reform**

- **Please preserve basic patient protections from the *Affordable Care Act* including:**
  - prohibiting insurer discrimination against pre-existing conditions
  - allowing young adults to stay on their parents' insurance until the age of 26
  - establishing reasonable maximums for out-of-pocket costs
  - prohibiting annual and lifetime caps on insurance coverage

These protections have made it possible for chronic disease patients to obtain insurance coverage and protect them from stratospheric medical bills.