

FSGS RESEARCH FUNDING TO REDUCE END-STAGE RENAL DISEASE TALKING POINTS FOR AUGUST LOCAL VISITS

Background: August is a good time to engage in grassroots advocacy while legislators are in their local districts and states. Schedule a meeting with your Representative and Senators, or attend their events, and relay the message below. Follow up with their staff to thank them for their time and reiterate the underlined ‘asks.’

The team leader should be a constituent of the Congressional office you are visiting and should begin the meeting by introducing themselves, stating their neighborhood, and letting the other group members introduce themselves as well.

- Thank you for taking the time to see us today.
- NephCure is the only non-profit organization exclusively devoted to supporting research on the causes for and treatment of focal segmental glomerulosclerosis (FSGS) and nephrotic syndrome (NS).
- FSGS occurs when the filters of the kidney (the glomeruli) become scarred. The damaged filters allow protein to leak into the urine, a condition called NS. This condition destroys kidneys, forcing patients to undergo dialysis or receive a kidney transplant. Many patients who receive a kidney transplant often have to go back on dialysis when FSGS returns in the transplanted kidney. Approximately 13,600 Americans suffer from end stage renal disease as a result of FSGS. African Americans are impacted at a rate five times greater than the general population. The causes of FSGS remain a mystery and no known cure exists for this devastating disease.
- {Tell your FSGS/NS story.}
- ESRD is among the most costly chronic diseases to manage. In 2012, Medicare expenditures on ESRD increased by 3.2 percent to \$28.6 billion, accounting for 5.6 percent of total Medicare spending¹. In addition, ESRD impacts the veteran population; nearly 30,000 veterans suffer from ESRD and an additional 3,000 veterans are expected to reach ESRD each year. This costly disease contributes to the significant growth in federal health spending.
- NS is a rare disease syndrome, yet it is responsible for approximately 12% of all cases of end-stage renal disease (ESRD) and up to 20% of ESRD in children, at an annual cost in the U.S. of \$3 billion. Research on FSGS and NS will lead to better treatments and ultimately delay and reduce the number of patients that require dialysis.
- In this climate of debt reduction, discovering better treatment options for FSGS and NS will reduce cases of ESRD and lead to significant savings in Medicare. Please support the following:
 - Provide \$32 billion for NIH in the FY16 Labor-HHS-Education Appropriations Bill
 - Include FSGS in the Defense Peer-Reviewed Medical Research Program in the FY16 Defense Appropriations bill

¹ U.S. Renal Data System,USRDS 2014 Annual Data Report