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March 31, 2015

The Honorable Tom Cole, Chair Subcommittee on Labor-HHS-Education Committee on Appropriations United States House of Representatives Washington, DC 20515 The Honorable Rosa DeLauro, Ranking Member Subcommittee on Labor-HHS-Education Committee on Appropriations United States House of Representatives Washington, DC 20515

Dear Chairman Cole and Ranking Member DeLauro:

On behalf of the American Society of Nephrology (ASN), and the 15,000 scientists, nephrologists, and other kidney health professionals the society represents, I am writing in support of the Friends of NIDDK advocacy coalition's request to have Barry I. Freedman, MD—an active and distinguished clinician-investigator whose research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)—testify during the House Appropriations Committee Subcommittee on Labor, Health and Human Services, and Education public witness hearing on Wednesday, April 29.

ASN is a member of Friends of NIDDK, which represents more than 40 NIDDK stakeholders committed to advancing the Institute's research. Friends of NIDDK works to educate members of Congress about the scientific advances made through the Institute's ongoing research and the critical importance of increased federal funding for future scientific initiatives. The fifth largest institute at the National Institutes of Health (NIH), NIDDK conducts and supports medical research and research training on diabetes and other endocrine and metabolic diseases; digestive diseases, nutritional disorders, and obesity; and kidney, urologic, and hematologic diseases. Collectively these are some of the most common, yet costly diseases.

For example, more than 20 million Americans have kidney disease and nearly 650,000 of them have kidney failure, or end-stage renal disease (ESRD). In 1972, Congress made a commitment to treat all Americans with kidney failure through the Medicare ESRD Program—the only health condition Medicare automatically provides coverage for regardless of age or disability. At an annual cost of \$35 billion—more than NIH's entire \$30 billion budget—the ESRD Program represents nearly 7% of Medicare's budget even though ESRD patients represent less than 1% of the Medicare population. Despite the staggering burden of kidney disease, NIH investments in kidney research are less than 1% of total Medicare costs for patients with kidney disease (\$585 million vs. \$80 billion in 2014).

ASN believes these numbers underscore the need for bolstering investments in NIDDDK. NIDDK investigators like Dr. Freedman are collaborating and using innovative technology for research that would improve patient care and yield significant federal savings. Dr. Freedman is John H. Felts, III Professor and Chief of Nephrology at Wake Forest Baptist Medical Center. He is listed in Best Doctors in America and US News and World Report's Top Doctors, and his research—which focuses on genetic causes of kidney and cardiovascular disease, hypertension and type 2 diabetes, particularly in African-Americans; as well as clinical outcomes in chronic kidney disease and after kidney transplantation—is featured in NIDDK's 2015 report on "Recent Advances & Emerging Opportunities".

Dr. Freedman has helped Wake Forest amass one of the world's largest single-center collections of DNA samples from African- Americans with kidney disease and diabetes. He and his colleagues at Beth Israel Deaconess Medical Center and NIDDK reported the role of the APOL 1 gene as a major risk factor for kidney failure in African-Americans. Variants in APOL 1 contribute to approximately 40 percent of all ESRD in this population. Dr. Freedman's research challenged long-held beliefs about hypertension as a cause of kidney disease in African-Americans. His work proved that hypertension often results from primary APOL1- related kidney disease and that hypertension is not the inciting cause of kidney disease.

Thank you for your consideration of this request. Please feel free to contact ASN Senior Policy and Government Affairs Associate Grant Olan at (202) 640-4657 or <u>golan@asn-online.org</u> with questions or for more information. We look forward to hearing back.

Sincerely,

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John R. Sedor, MD, FASN Secretary-Treasurer and Public Policy Board Chair