

Congress of the United States
Washington, DC 20515

March 24, 2016

The Honorable Tom Cole
Chairman
Labor, Health and Human Services,
Education and Related Agencies Subcommittee
Committee on Appropriations
U.S. House of Representatives
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Labor, Health and Human Services,
Education and Related Agencies Subcommittee
Committee on Appropriations
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Cole and Ranking Member DeLauro:

Thank you for your leadership of the Labor, Health and Human Services, Education and Related Agencies (LHHS) Appropriations Subcommittee. As you work to develop the fiscal year (FY) 2017 LHHS Appropriations Bill, please include the language below regarding recent research advancements and emerging opportunities in glomerular diseases, such as Nephrotic syndrome and Focal Segmental Glomerulosclerosis (FSGS), within the Committee Report accompanying the bill.

FSGS is a rare disease that attacks the kidney's filtering units (glomeruli) causing serious scarring which leads to permanent kidney damage and even failure. FSGS is a leading cause of end-stage renal disease, kidney dialysis and transplantation. FSGS is disabling, potentially fatal, and treatment options remain limited for affected individuals. In recent years, research coordinated by the National Institutes of Health (NIH) has improved our scientific understanding of glomerular diseases, including discovering the role that the APOL1 gene plays in the onset of FSGS in African Americans. More should be done though to advance research activities and improve the lives of families impacted by glomerular diseases.

The language below builds upon glomerular diseases recommendations that the Subcommittee has made in the past, including through the Committee Report accompanying the FY 2016 House LHHS Appropriations Bill.

1) National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at NIH:

Glomerular Diseases.—The Committee is pleased by the ongoing success of the Nephrotic Syndrome Study Network [NEPTUNE] and encourages support for the emerging Cure Glomeruloneuropathy [CureGN] initiative.

2) National Institute on Minority Health and Health Disparities (NIMHD) at NIH:

Focal Segmental Glomerulosclerosis [FSGS].—The Committee understands the crucial role that the APOL1 gene plays in the onset of FSGS and subsequent end stage renal disease in African Americans, and encourages NIMHD to pursue research collaboration with NIDDK.

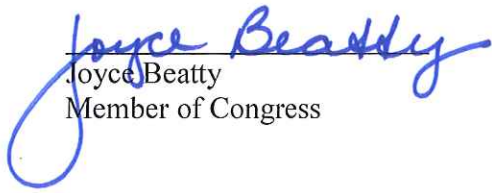
Thank you for your consideration of this request.

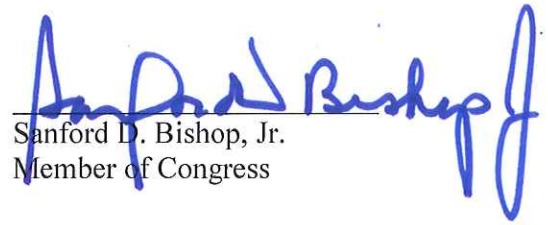
Sincerely,


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Member of Congress


Ted Deutch
Member of Congress



Alcee Hastings
Member of Congress


Joyce Beatty
Member of Congress


Sanford D. Bishop, Jr.
Member of Congress


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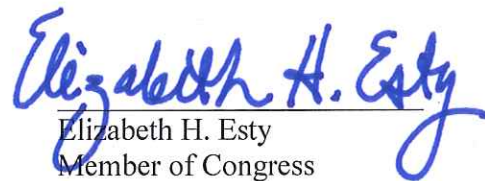

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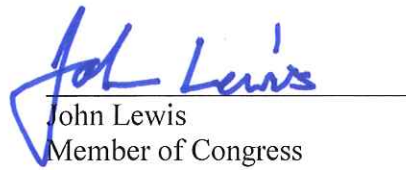

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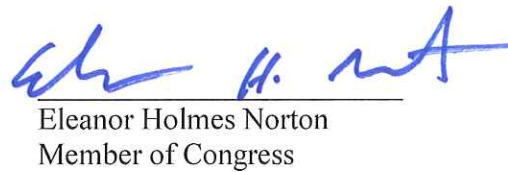

Alan Grayson
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Sheila Jackson Lee
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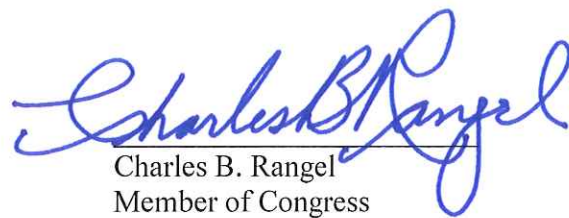

Mike Kelly
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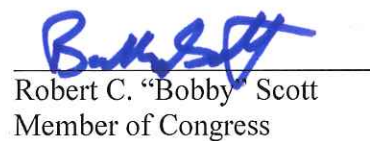

Patrick Meehan
Member of Congress


Eleanor Holmes Norton
Member of Congress

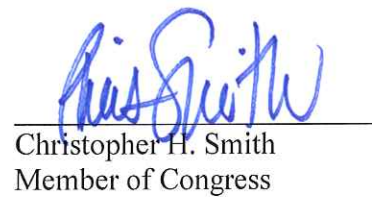

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