

The New Era for Preventing End-Stage Kidney Disease Act (H.R 7506)

There are at least 150 different disorders that are considered rare kidney diseases, which in many cases rapidly progress to kidney failure and contribute to the \$120B Medicare spends each year on chronic kidney disease and end-stage kidney disease. However, thanks to the 21st Century Cures Act, a bipartisan legislative achievement, we are on the cusp of a new era of innovation and care that holds the promise of hope for thousands of families suffering from these long-overlooked diseases.

The New Era for Preventing End-Stage Kidney Disease Act would help transform the diagnosis and delivery of care to rare kidney disease patients by increasing community and Health Care Provider awareness and education, addressing kidney health disparities in communities of color which are disproportionately affected by many of these conditions, advancing rare kidney disease research, and directing the Department of Health and Human Services (HHS) to begin exploring how this new era could improve and save lives, as well as reduce federal health care expenditures. More specifically, the legislation would:

Establish Rare Kidney Disease Research Centers at the National Institutes of Health (NIH):

- Develop resources for clinical research, provider training, diagnosis, prevention, and treatment of rare kidney diseases.
- Direct NIH to conduct a signature genotype-phenotype study to inform rare disease diagnosis.

Help rare kidney disease patients get diagnosed and receive care faster

- Direct HHS to convene a conference on diagnostic methods for rare kidney disease to address existing barriers and help accelerate the diagnosis of rare kidney disease.
- Direct the HHS to conduct a study on early intervention of genetic screening and whether it can improve rare kidney disease health outcomes and preventative care.

Address kidney health disparities in communities of color:

- Create a “Communities of Color Service Program” of nephrology fellowships in underserved areas.
- Direct the National Institutes of Health (NIH) to report on diversity in research programs.
- Provide patient education and referral programs for nonprofits, local agencies, and community-based organizations.
- Conduct a study on social, behavioral, and biological factors for rare kidney disease progression in populations of color.

Promote provider education & patient access to specialty care:

- Establish a primary care provider training grant program and a grant program for kidney disease continuing education for Healthcare Professionals.

Direct HHS to study how this “new era” of treating rare kidney disease could reduce dialysis and transplant costs, and ensure medical expertise in coverage decisions:

- Ensure rare kidney disease experts have a seat at the table in helping to determine Medicare Part D coverage.
- Direct HHS to test and evaluate treatments that delay or eliminate the need for dialysis or a transplant.

The New Era of Preventing End-Stage Kidney Disease Act is led by Rep. G.K. Butterfield (D-NC) and Rep. Gus Bilirakis (R-FL), co-chairs of the Congressional Rare Disease Caucus. To cosponsor or learn more about this legislation, contact Caitlin Van Sant (Caitlin.VanSant@mail.house.gov) or Chris Jones (cjones@mail.house.gov).