H.R. 7506, New Era of Preventing End-Stage Kidney Disease Act

Section-by-Section

Sec. 1. Short Title.
States that the title of this Act is the “New Era of Preventing End-Stage Kidney Disease Act.”

Sec. 2. Table of Contents.
Provides the table of contents for the bill.

Sec. 3. Findings.
Details Congress’ findings on the prevalence, treatment, and outcomes of end-stage kidney disease and rare kidney disease, as well as federal spending related to end-stage kidney disease and rare kidney disease.

Sec. 4. Definitions.
Defines the National Institutes of Health, the Director of the National Institutes of Health, and the Secretary of Health and Human Services.

Title I – Centers of Excellence and Rare Kidney Disease Research

Sec. 101. NIDDK Centers of Rare Kidney Disease Research.
Creates regional centers of excellence for rare kidney disease, including primary glomerular disease, under the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) to increase awareness of rare kidney disease and develop resources for clinical research, provider training, diagnosis, prevention, and treatment of rare kidney disease. NIDDK currently funds centers of excellence that focus on pediatric nephrology and polycystic kidney disease, but none that focus on rare kidney disease. Authorizes $4 million for each of fiscal years (FYs) 2023 through 2027.

Sec. 102. Rare Kidney Disease Progression Research.
Authorizes NIH research grants for public and nonprofit entities to conduct research on the causes, etiology, symptoms, diagnosis, progression, and treatment of rare kidney diseases, including glomerular diseases. Requires that research funded by these NIH grants include people of color in study populations, include study of the genotype-phenotype relation to disease progression, and not include consideration of Quality-Adjusted Life Years or Disability-Adjusted Life Years, or other similar mechanisms that discriminate against people with disabilities in value and cost-effectiveness assessments. Investing in rare kidney disease research, particularly disease progression, will help to accelerate diagnosis and improve treatment of rare kidney disease. Authorizes $1 million for each of FYs 2023 through 2027.
Title II – Diagnostics

Sec. 201. Conference on Diagnostic Issues Relating to Rare Kidney Disease.
Directs the Secretary of HHS to convene a conference within 12 months of enactment related to diagnostic methods for rare kidney disease, including the use of urinalysis and kidney biopsies. Also includes a study on whether genetic and genomic testing can improve preventative care, health outcomes, and health disparities with respect to rare kidney disease, and whether the federal government can reduce barriers to genetic and genomic testing for rare kidney disease, including by changing coverage provisions. Requires consultation with stakeholders and a report to Congress within 18 months of enactment. Convening a conference on these diagnostic issues will lead to earlier identification and treatment of people living with rare kidney disease, ultimately extending kidney health and likely delaying and/or reducing ESKD costs while increasing quality of life. Authorizes $5 million for the period of FYs 2023 through 2027.

Title III – Communities of Color

Sec. 301. Understanding and Slowing the Progression of Rare Kidney Disease and Treatment in Certain Populations.
Directs the Secretary of HHS to conduct a study on the social, behavioral, and biological factors leading to rare kidney disease; treatment patterns associated with providing care to populations that are disproportionately affected by such disease; access to nephrologists among populations that are disproportionately affected by such disease; ongoing efforts and recommendations to slow the progression of end-stage kidney disease in populations that are disproportionately affected by rare kidney disease; and patient trust of treating providers among populations that are disproportionately affected by such disease. The Secretary must report on the study to Congress within 12 months of enactment. This study will help stakeholders to better understand how to slow disease progression and improve treatment of rare kidney disease in communities of color. Authorizes $1 million for each of FYs 2023 through 2027.

Sec. 302. Communities of Color Service Program.
Creates the “Communities of Color Service Program” within the existing HRSA health workforce program for postgraduate training in the field of nephrology, including knowledge of issues related to the APOL1 gene. The Communities of Color Service Program will help to educate providers about rare kidney disease, strengthen the nephrology workforce, and improve renal care for people of color.

Sec. 303. NIH Report on Research Programs.
Directs the Director of the NIH to report on the diversity of recipients of NIH research grants and the extent to which NIH kidney disease research grants focus on communities of color. The report must be published on the public website of the agency. Because kidney diseases, including rare kidney diseases, disproportionately affect people of color, it is crucial that kidney disease research funded by NIH include research for and by people of color. Authorizes $200,000 for each of FYs 2023 through 2027.

Sec. 304. Partnerships with Organizations and Agencies.
Provides for grants through existing or new authority for nonprofit and community-based organizations, including community health centers, and State and local governmental agencies to provide education and referrals for patients in communities of color regarding kidney disease, including rare kidney disease. This grant program will help to accelerate diagnosis and improve care of rare kidney disease by increasing public awareness in communities of color. Authorizes $2 million for each of FYs 2023 through 2027.

Title IV – Provider Education

Sec. 401. Primary Care Provider Training Grant Program.
Establishes a grant program for hospitals, medical schools, academic training programs, public entities, nonprofits, and consortia of such entities to plan, develop, and operate a nephrology training program for primary care providers. This grant program will help to educate providers about rare kidney disease, accelerate diagnosis of rare kidney disease, improve treatment of rare kidney disease, and strengthen the primary care workforce. Authorizes $800,000 for each of FYs 2023 through 2027.

Sec. 402. Grant Program for Development and Implementation of Curricula for Continuing Education on Kidney Disease.
Establishes a grant program for public and nonprofit entities to provide continuing education and training to health care professionals on identifying, referring, and treating individuals with kidney disease. This grant program will help to educate providers about rare kidney disease, accelerate diagnosis of rare kidney disease, improve treatment of rare kidney disease, and strengthen the primary care workforce. Authorizes $1.6 million for each of FYs 2023 through 2027.

Title V – Coverage and Experiments to Reduce Dialysis and Transplant Costs

Sec. 501. Medical Expertise in Pharmacy and Therapeutic Committees.
Requires that pharmacy and therapeutic (P&T) committees determining Medicare Part D coverage for orphan drugs include at least two independent experts with expertise in the field of medicine related to that drug. Requiring orphan drug expertise on P&T committees will help to ensure that coverage determinations of novel therapies for rare diseases, including rare kidney diseases, are well informed.

Sec. 502. Reducing Dialysis and Transplant Costs Related to Rare Kidney Disease.
Directs the Secretary of HHS to conduct experiments to evaluate methods for treating rare kidney disease, focusing in particular on treatments that would delay or eliminate the need for dialysis and transplant, and to conduct a comprehensive review of methods to increase public awareness of rare kidney disease, including in communities of color. The Secretary must submit a report on such experiments and study within 24 months of enactment. The experiments required under this section will help to mitigate the need for dialysis and transplant and reduce federal government spending on end-stage kidney disease.